

LEVELS OF FAMILY FUNCTIONING
AMONG FAMILIES WITH A CHRONICALLY ILL CHILD

BY

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A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF NURSING

Department of Nursing
University of Manitoba
Winnipeg, Manitoba

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This thesis
is dedicated to
my parents, Harold and Evelyn Eccles,
who have always shown me
the true essence of
family love and caring
which is often immeasurable

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Life is not a matter of
 holding good cards -
But of playing a
 poor hand well -

Robert Louis Stevenson

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ABSTRACT

Two samples, consisting of 25 parents with a chronically ill child each (index group) and 25 parents with healthy children only (control group), were used in this study in order to answer three questions:

- (a) would the adaptation level among families with healthy children only be more balanced than the adaptation level among families with a chronically ill child?;
- (b) would the variables: past experiences with crises, coping strategies used by the family and resources available and used by the family predict both families' level of functioning?; and
- (c) would the extreme functioning index families differ from the mid-range and balanced functioning index families on the above variables?

In order to answer these questions, each of the 50 families filled out five questionnaires:

- (a) Basic Demographic Information Sheet;
- (b) Family Adaptability and Cohesion Education Scale;
- (c) Family Inventory of Resources for Management;
- (d) Family Inventory of Life Events; and
- (e) Coping Health Inventory for Parents.

Index and control group families were similar with respect to number of children, ages of parents and level of income, but control group parents tended to have higher education levels and to be

employed in white collar occupations. Index and control families had similar means on both dimensions of family functioning, and were very close to national norms.

For the index families, the variable of total resources for management was found to have predictive power on their level of family functioning. For the control families, the variable involving the coping strategy of maintaining social support, self-esteem, and psychological stability had no predictive power on their level of family functioning. The scale measuring the coping strategy of understanding the medical situation through communication with other parents and consultation with medical staff was able to differentiate between extreme, mid-range, and balanced index families.

This study did not provide conclusive support for the hypothesis that families with a chronically ill child will have more extreme family functioning scores than families with healthy children only. However it did provide minimal support for the important role social support, past stressors, coping mechanisms and other resources play on the functioning of the family unit. More empirical research needs to be undertaken in order to identify other variables that may affect family functioning. Education for families, health professionals and the public should stress the recognition of families in distress and ways to enhance their family functioning.

LEVELS OF FAMILY FUNCTIONING
AMONG FAMILIES WITH A CHRONICALLY ILL CHILD

CHAPTER 1

1. INTRODUCTION

1.0 Statement of the Problem

One of the greatest crises any family can experience is that of having a child diagnosed with a chronic illness. This experience with a chronic illness tears into the family's life as a functioning unit and confronts each member with a crisis. For the parents, this involves coming to terms with anxieties and uncertainties of the illness, including the fear that the child's condition may deteriorate. They must also attempt to preserve family functioning while at the same time incorporating the regimens, treatments, and other needs of the ill child into everyday life. For the child, there is an increased dependency on others, possible changes in body appearance, limitations on activities, and a possible decline in self-esteem. The healthy siblings within the family may also find themselves in a less than advantageous position. Jealousy and guilt are frequent feelings experienced by the siblings of an ill child. Miller (1980) stated that while any diagnosis of illness within the family is overwhelming, the diagnosis of a chronic illness in a child has the potential to disrupt completely the family functioning.

Medical advances have given children with chronic illnesses a chance to live longer and to experience higher quality in their lives. Research and clinical practice must be directed at maximizing the functioning of the family unit, thereby providing a quality life for the whole family. With the prolongation of life, however, the illness has a long-term impact on the physical, emotional, and social resources of both the child and the family. Throughout the course of the illness, there are different trajectories that necessitate repeated adaptation of family members, such as the diagnosis, possible surgery, relapses, medical complications, and, for some, the terminal stages. Whatever course the illness takes, health services are often required to minimize trauma and to maximize the ability of the family to develop and maintain positive and healthy coping patterns.

1.1 Concept of Chronicity

A chronic illness is defined as:

All impairments or deviations from normal which endanger the existence of or threaten to terminate the physical, mental, and spiritual experiences that constitute a person's being. Chronic diseases may also have one or more of the following characteristics: are longstanding, leave residual disability, are caused by non-reversible pathological alterations, require special training, and may be expected to require a long period of supervision, observation, and care. (Mayo, 1956, p. 65)

Hobbs, Perrin, & Ireys (1985) stated chronic illness is a health condition that lasts more than three months in a year or that leads to continuous hospitalization for at least one month in a year. This concept is further expanded by introducing the issue of severity. A

chronic illness is defined as severe if it: (a) places a financial burden on the family, (b) presents psychological and/or emotional problems for the child, and (c) disrupts family functioning (Hobbs, Perrin, & Ireys, 1985).

Past literature reflects the practice of a single-disease focus in research of chronic illness entities. Special characteristics, causes, treatments, and effects of one specific disease were often emphasized in the research process. That is, research developed from a disease-by-disease approach. This approach has provided many complications when attempting to generalize results to children with other chronic illnesses.

Currently, researchers have attempted to direct efforts towards a homogenous approach; that is, studying varied illnesses as a group because of their chronicity factor, rather than focusing on individual diseases. Partly responsible for this is the low prevalence rate of specific and rare diseases in children, creating difficulty when attempting to generate an adequate sample size. Thus this homogenous approach to research with children with varied chronic illnesses is being utilized more frequently. This shift has aided in understanding the effect of chronic disease on the family rather than specificities of certain disease entities and related medical matters. Pless & Pinkerton (1975), Stein & Jessop (1983), Pless & Perrin (1985), and Hobbs, Perrin, & Ireys (1985) have documented the need for a homogenous approach in research in relation to chronic illnesses. Strauss & Glaser (1975) cited two major advantages of

studying the general problems of chronic illness rather than specific diseases. They maintained that strict medical knowledge should be supplemented with a general skill in assisting families to cope with common problems associated with the illness. That chronically ill persons and their families share common problems such as social isolation, immobility, family disruption, and social stigmatization is also a point in favor of a homogenous or uniform approach to research.

1.2 The Chronically Ill in Society

The chronically ill are, by and large, a neglected group in our society. Often society's awareness of the chronically ill is briefly heightened by the annual plea for funds by volunteer and self-help groups.

However, society cannot possibly be entirely cognizant of the intense suffering and stress the ill individual and his/her family must endure. Nor is it fully aware of the enormous drain on the health care system by the chronically ill. VanDam, Anderson & Bauwens (1981) maintained that the western culture may not wish to be informed of the burden of the chronically ill on society. Few people tend to want to be involved with the chronically ill for any prolonged period of time. They further maintained that western culture is very health-oriented and more concerned with high technology cures than care. With the exciting aspects of advanced

technological methods of health care, the interest in the day-to-day functioning of the chronically ill is minimal at best. Ness & Huchala (1987) concurred by suggesting that the presence of the chronically ill in society, particularly those whose conditions are visually evident, represents a deviation from normal, thereby creating a threat to society. Hobbs, Perrin, & Ireys (1985) stated this attitude is so prevalent in western culture that ambivalence about providing assistance to those labelled as "defective," "inferior," or "unfit" frequently occurs.

1.3 Purpose of the Study

This study was designed to measure the adaptation level among families with a chronically ill child (index families) using families with a healthy child (control families) as a control group. The study also examined whether variables such as past experiences with crises, coping strategies used by the family, and available resources predicted both sets of family levels of functioning. The third question examined was whether or not the extreme functioning index families (those families who demonstrated too much or too little cohesion or adaptability in their day-to-day functioning) differed from the well functioning index families (those who demonstrated the ability to balance the dimensions of cohesion and adaptability) on these variables.

CHAPTER 2

2. CONCEPTUAL FRAMEWORK

2.0 The ABCX-Double ABCX Model of Family Adaptation

Reuben Hill's work in 1949 on family stress caused by war-induced separation and reunion can be linked to the development of the ABCX model of family stress (Hill, 1958). The ABCX model of family stress has been tested repeatedly throughout the past 30 years and essentially remains unchanged (McCubbin & Patterson, 1980).

The theoretical construct for the basic ABCX model is as follows: "A (the stressor event)--interacting with B (the family's crisis meeting resources)--interacting with C (the definition the family makes of the event)--produce X (the crisis)" (Hill, 1958).

The basic ABCX Model developed by Hill focuses primarily on pre-crisis variables that can determine the outcome of a particular stressor for the family. However, researchers such as Burr (1973) and Hansen & Johnson (1979) found that family stress research requires a model which takes into account family efforts over time to recover from a crisis situation. The Double ABCX Model of Family Adaptation (see Appendix A) was developed by McCubbin & Patterson in 1981 and takes into account post-crisis variables; such as: (a) additional life-stressors (normative and non-normative) making family adaptation more difficult, (b) the psychological and

social resources which families use in managing crises, (c) the process by which the family achieves adaptation, and (d) the final outcome (McCubbin & Patterson, 1980). The Double ABCX Model arose from family war-induced crises studies by McCubbin, Boss, Wilson, & Lester (1980) and was further tested with families with a chronically ill child (McCubbin, Nevin, Larsen, Comeau, & Patterson, 1982).

Although the concept of stress has been used frequently throughout research and theory development, an explicit and consistent definition tends to remain elusive. A stressor, however, or the A factor is well defined as those life events or occurrences of sufficient intensity to bring about change in the family system (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981). These changes may be in various areas of family life; such as, family boundaries, goals, patterns of interaction, quality of relationships, roles, or values (McCubbin & Patterson, 1981). Although stressors usually imply an impending negative outcome, many stressors may bring forth a positive change. Because changes, whether positive or negative, are a threat to any balanced system, they remain stressful (Berdie & Selig, 1981). Family stress, on the other hand, is not seen as inherent in the stressor itself, but rather is viewed as an outcome of the response of the distressed family to the stressor and refers to the residue tensions generated by the stressor which remains unmanaged (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980).

Two factors, the B and C factors, determine the potential for crisis within a family. The B factor is the family's capacity to hinder events or change in the family system from creating a crisis or disruptiveness in the system (McCubbin & Patterson, 1981). McCubbin, Joy, Cauble, Comeau, Patterson, & Needle (1980) outlined three components within a family's resource reservoir: (a) personal resources, (b) internal resources, and (c) social support. Personal resources refer to qualities and aids individual family members use in times of stress (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981). They include financial well-being, education, health, and psychological attributes (George, 1980; Pearlin & Schooler, 1978). Family internal resources refer to ability to manage personal resources (Paolucci, Hall, & Axinn, 1977; Deacon & Firebaugh, 1975); ability to identify resources (Paolucci, Hall, & Axinn, 1977); and problem solving ability (Aldous, Condon, Hill, Straus, & Tallman, 1971; Reiss, 1971). Cobb (1976) defined social support as information exchanged between individuals which provides: (a) emotional support, (b) esteem support, and (c) network support. These supports provide individuals with the belief that they are cared for, valued, and that they belong to a network of communication (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981).

Hill's C factor is the definition the family makes of the event. This is a subjective perception of the stressor and how it will affect his/her particular family. This subjective meaning can reflect a

family's values and previous challenges in meeting crises. A family's perception of a stressor can range from positive--that is, having a positive effect on the family--to negative--that is, having a detrimental effect on the functioning of the family (McCubbin & Patterson, 1981).

These three factors--the stressor, the family's resources, and the family's perception of the situation--all influence the family's ability to prevent a crisis. Burr (1982) defined a crisis or the X factor as the amount of incapacitatedness or disorganization in the family where resources are inadequate. This term signifies the variation in the amount of disruptiveness, incapacitiveness, or disorganization of the family ranging from no crisis to a high amount of crisis. If no crisis results, this does not mean that stressors are not present; rather, that they are of a routine nature (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981).

McCubbin & Patterson's (1981) Double ABCX Model attempts to explore family's adaptation post-crisis or the family's efforts over time to recover from a crisis situation. Because these family crises evolve over a period of time, families seldom deal with a single stressor at a time; instead they face a pile-up of stressors, both normative and non-normative. Thus, they may face a non-normative (situational) crisis, such as a life-threatening illness in the family; simultaneously with normative (maturational) stressors, such as launching other children; and other non-normative stressors, such as death of a parent, unemployment, etc. Coping mechanisms

utilized, such as substance abuse, can also add to the pile-up. This pile-up is referred to as the aA factor in the double ABCX model (McCubbin & Patterson, 1981). The bB factor consists of both existing resources (those used pre-crises) and new resources strengthened or developed in response to the new or additional demands arising out of the crisis situation or as a result of the pile-up (McCubbin & Patterson, 1981). The cC factor, or system perception, is oriented toward a post-crisis perspective of the total situation. This factor includes perception of added stressors, old and new resources, and coping strategies utilized to bring the family into balance (McCubbin & Patterson, 1981). In addition to the aA, bB, and cC factors, an additional factor, called family coping, determines the adaptation of a family. McCubbin & Patterson (1981) stated that coping includes behavioral responses of family members in order to eliminate stressors, to attempt to relieve the intra-family conflicts and tensions, as well as to achieve further social, psychological, and material resources needed to reach family adaptation.

2.1 Adaptation

The core concept of family adaptation is that of balance. Family adaptation is achieved when the demands of either a family member, the family system, or community meet the capabilities of another (McCubbin & Patterson, 1981; McCubbin, Cauble, & Patterson, 1982). In crisis situations, the family attempts to achieve a balance at both the individual-family level and at the family-

community level. Family adaptation can range on a continuum from maladaptation to bonadaptation. Maladaptation is characterized by continued imbalance at one or both levels or achievement of balance at cost; i.e., deterioration of personal development of family members or decline or loss of family independence (McCubbin & Patterson, 1981). Bonadaptation is characterized by a balance of both levels of functioning resulting in strengthening of family integrity, promotion of personal development of family members, and maintenance of family independence (McCubbin & Patterson, 1981).

Since family adaptation involves balancing aspects of family life, such as independence of individual members and family togetherness, compromise is necessary. The families that demonstrate bonadaptation have compromised family integrity and cohesion as well as allowing the family members to develop independently and to pursue their own goals (McCubbin & Patterson, 1981). The model utilized in this study to assess families' adaptation which takes into account the balance needed in bonadaptation is that of Olson & McCubbin's (1982) Circumplex Model of Family/Marital Systems.

2.2 Circumplex Model of Family/Marital Systems

The Circumplex Model of Family/Marital Systems attempts to supply a workable framework for bringing together three dimensions of family behavior: cohesion, adaptability, and

communication (see Appendix B). Family theory and family therapy literature recognizes these three dimensions as critical in order to provide comprehensive models for researchers, theorists, and clinicians to utilize when working with families/couples under stress (Burr, 1973; Olson, Russell, & Sprenkle, 1979; Reiss, 1971; Russell, 1979; Hill, 1958; and Bowen, 1966). Olson, Russell, & Sprenkle (1979) organized these three concepts such that the identification of sixteen types of marital and family systems is facilitated.

Family cohesion is defined as the amount of emotional bonding that family members have toward one another while at the same time experiencing individual autonomy (Olson & McCubbin, 1982). There are eight concepts that together encompass the cohesion dimension--emotional bonding, boundaries, coalitions, time, space, friends, decision making, and interests and recreation.

See Table 2:1 page 13

There are four levels of cohesion ranging from extremely low (disengaged) to moderately low (separated), and moderately high (connected) to extremely high (enmeshed). When cohesion levels are found to be very low, such that all members

TABLE 2:1

Family Cohesion Dimension: Clinical and Research Indicators

	DISENGAGED (Very Low)	SEPARATED (Low to Moderate)	CONNECTED (Moderate to High)	ENMESHED (Very High)
Emotional Bonding	Very Low	Low to Moderate	Moderate to High	Very High
Independence	High independence of family members.	Moderate independence of family members.	Moderate dependence of family members.	High dependence of family members.
Family 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.
Time	Time apart from family maximized (physically and/or emotionally).	Time alone and together is important.	Time together is important. Time alone permitted for approved reasons.	Time together maximized. Little time alone permitted.
Space	Separate space both physically and emotionally is maximized.	Private space maintained; some family space.	Family space maximized. Private space minimized.	Little or no private space at home.
Friends	Mainly individual friends seen alone. Few family friends.	Some individual friends. Some family friends.	Some individual friends. Scheduled activities with couple and family friends.	Limited individual friends. Mainly couple or family friends seen together.
Decision Making	Primarily individual decisions.	Most decisions are individually based, able to make joint decisions on family issues.	Individual decisions are shared. Most decisions made with family in mind.	All decisions, both personal and relationship, must be made by family.
Interests and Recreation	Primarily individual activities done without family. Family not involved.	Some spontaneous family activities. Individual activities supported.	Some scheduled family activities. Family involved in individual interests.	Most or all activities and interests must be shared with family.

FROM: McCubbin, H., Cauble, A.E. & Patterson, J.M. (1982). Family stress, coping and social support. Illinois: Charles C. Thomas Publishers, pg.50.

of the family have such high levels of autonomy, the family operates with little or any cohesive effort. When cohesion levels are very high, there is so much togetherness as a family, individual attributes are not recognized. In order to achieve a balance, families must exist in the middle levels. Throughout the literature, cohesion has been emphasized as an important concept in family functioning (Bowen, 1966; Olson & McCubbin, 1982; Reiss, 1971).

The second concept of the Circumplex model is that of adaptability. It is defined as the ability of the family system to change dimensions such as power structure, relationship rules, and role relationship in response to situational and developmental stress (Olson & McCubbin, 1982). There are seven concepts that together encompass adaptability dimension--family power (assertiveness, control, and discipline), negotiation styles, role relationships, relationship rules, and feedback.

See Table 2:2 page 15

There are four levels of adaptability ranging from extremely low (rigid) to moderately low (structured), and moderately high (flexible) to extremely high (chaotic). As with cohesion, the moderate levels of adaptability are desirable for effective family functioning (Olson & McCubbin, 1982).

TABLE 2:2

Family Adaptability Dimensions: Clinical and Research Indicators

	Assertiveness	Control	Discipline	Negotiation	Roles	Rules	System Feedback
CHAOTIC (Very High)	Passive and Aggressive Styles.	Limited leadership.	Laissez faire. Very lenient.	Endless negotiation. Poor problem-solving.	Dramatic role shifts.	Dramatic rule shifts. Many implicit rules. Few explicit rules. Arbitrarily enforced rules.	Primarily positive loops; few negative loops.
FLEXIBLE (High to Moderate)	Generally Assertive.	Egalitarian with fluid changes.	Democratic. Unpredictable Consequences.	Good negotiation; good problem-solving.	Role making and sharing. Fluid change of roles.	Some rule changes. More implicit rules. Rules often enforced.	More positive than negative loops.
STRUCTURED (Moderate to Low)	Generally Assertive.	Democratic with stable leader.	Democratic. Predictable Consequences.	Structured negotiations; good problem-solving	Some role sharing	Few rule changes. More explicit than implicit rules. Rules usually enforced.	More negative than positive loops.
RIGID (Very low)	Passive or Aggressive Styles.	Authoritarian leadership.	Autocratic. Overly strict.	Limited negotiations; Poor problem-solving.	Role rigidity. Stereotyped roles.	Rigid rules. Many explicit rules. Few implicit rules. Strictly enforced rules.	Primarily negative loops; few positive loops.

FROM: McCubbin, H., Cauble, A.E. & Patterson, J.M. (1982). Family stress, coping and social support. Illinois: Charles C. Thomas Publishers, pg. 52.

These two concepts, combined to form a Circumplex model, enable the identification of sixteen types of family and marital systems. As with any circumplex model, the central areas are more common, while the extreme areas are likely to indicate a maladaptive family (Olson & McCubbin, 1982).

The sixteen family types are further categorized into three groups: (a) balanced--the central four areas, (b) mid-range--the groups with one extreme dimension, and (c) extreme--the groups that are extreme on both dimensions (see Appendix B).

Olson & McCubbin (1982) indicated that one of the advantages of a theoretical model is that hypotheses can be formulated and tested in order to expand the model further. A central hypothesis derived from the Circumplex model is that balanced families will function more adequately than extreme families (Olson & McCubbin, 1982). This hypothesis assumes a curvilinear relationship on the dimensions of cohesion and adaptability. A hypothesis derived from this central hypothesis and one that was tested in this study is that couples and families with serious problems will tend to have more extreme scores on one or both of these dimensions (Olson & McCubbin, 1982). Two other hypotheses postulated by Olson, Russell, & Sprenkle (1979), and derived from this model, were: (a) couples and families will change their cohesion and adaptability to deal with situational stress and life changes in the family life cycle, and (b) positive communication skills will facilitate their attempts to balance cohesion and adaptability.

The two concepts of the Circumplex model, cohesion and adaptability, were developed and tested by David Olson, Douglas Sprenkle, and Candyce Russell. Sprenkle & Olson (1978) tested the dimension of adaptability in 25 couples involved in marriage counselling and 25 couples not involved in any form of counselling. Each couple was given a simulated crisis to deal with. They found that during the crisis, the non-counselled families tended to have more balanced levels of adaptability than those of the counselled families. Russell (1979) tested both dimensions of cohesion and adaptability. Using simulated crises, she tested 31 non-clinical families with adolescent girls. As hypothesized, she found that all of the low functioning families fell into the extreme types while high functioning families fell into the balanced types. Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson (1983) conducted a national survey with 1,000 families across various life cycles. They found that higher levels of cohesion and adaptability were found in higher functioning families. Thus, for non-problem families, a linear relationship appears to exist between family functioning and the dimensions of cohesion and adaptability. This relationship is in contrast to the curvilinear relationship found in problem families.

2.3 Hypotheses

2.3.0 Hypothesis 1

Families with a healthy child (control group) will tend to have more balanced scores on the dimensions of cohesion and adaptability than those families with a child with a chronic illness (index group).

2.3.1 Hypothesis 2

For families with a healthy child and for those with a chronically ill child, the set of variables (past experiences with crises, coping strategies utilized by the family and resources available and used) will predict their level of functioning.

2.3.2 Hypothesis 3

Extreme functioning families with a chronically ill child will tend to have higher family life change scores, lower family resource scores, and higher parental coping scores than those balanced and mid-range functioning families with a chronically ill child.

CHAPTER 3

3. LITERATURE REVIEW3.0 Historical Approaches Regarding Research on Chronically Ill Children and the Family

To date there has been a paucity of sound methodological research on the functioning of families with a child suffering from a chronic illness. Much of the "research" has been anecdotal in nature (Adams, 1978; Binger, Ablin, Feuerstein, Kushner, Zoger, & Mikkelsen, 1969; Fergusson, 1976; Friedman, Chodoff, Mason, & Hamburg, 1963; Heffron, Brommelaere, & Masters, 1973; Kirkpatrick, Hoffman, & Futterman, 1974; Ross, 1979). In addition, many studies have been retrospective, providing a descriptive picture of the problem, but limiting external validity of the findings. Much of the research generated has not included control groups for baseline comparisons (Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen, 1969; Friedman, Chodoff, Mason, & Hamburg, 1963; Heffron, Brommelaere, & Masters, 1973; Kirkpatrick, Hoffman, & Futterman, 1974; Spinetta, 1981). Another methodological flaw in many studies is that they have included only children with one chronic illness, making generalization to families with children of varying chronic diseases difficult (Apley, Barbour, & Westmacott, 1967; Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen, 1969; Spinetta, 1981; Turk, 1964). Levels of family functioning have been examined in

some of the research; however, the effect of variables such as the amount of past stress in the family, resources available to the family, and coping strategies on family functioning has been "not specified" in many studies. These variables can moderate family functioning and need to be examined in an empirical manner.

3.1 The Family with a Chronically Ill Child

3.1.0 Emotional Needs of Parents

The fact that family functioning is disrupted in families with a chronically ill child is a recurrent theme throughout the literature. Much emphasis in the literature has been placed on the parent's emotional response. During the period following diagnosis, the family may manifest the reaction of shock and disbelief (Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen, 1969; Hymovich & Barnard, 1973; Miller, 1980; Larkin, 1987; and Thomas, 1987). Along with shock and disbelief, most parents experience some guilt. Friedman, Chodoff, Mason, & Hamburg (1963) reported that 46 parents interviewed felt guilty at not discovering the symptoms of their child's illness earlier. Hymovich (1976) indicated that mothers often feel guilty for abandoning the siblings while fathers may experience guilt because they can only pay the bills and not assist with the direct care of the child.

It is understandable that the family also becomes frustrated, confused, angry, helpless, anxious, and uncertain (Friedman, Chodoff,

Mason, & Hamburg, 1963; Travis, 1976; Mulhern, Crisco, & Camitta, 1981; Rotherberg, 1982; Ross-Alaolmolki, 1985; and Waechter, 1987). Both parents feel helpless at not being able to care for their child during any hospitalization periods (Gyulay, 1976; Martinson, Armstrong, Geis, Anglim, Gronseth, MacInnis, Kersey, & Nesbit, 1978; and Ross-Alaolmolki, 1985). Typically during hospitalization, it is physicians and nurses who are caring for the child, while parents have very little control.

Perhaps one of the hardest and most heartbreaking events for the family to deal with is that of facing a child's approaching death. Schoenberg, Carr, Peretz, & Kutscher (1972) found that even while maintaining hope and mastering activities throughout the course of the child's illness, the parents usually begin disengaging from the child shortly before his/her death. At that time, parents are particularly vulnerable to the guilt that may result from emotional detachment accompanying anticipatory mourning. A number of investigators have observed parental detachment from the dying child, particularly in the later stages of an illness (Adams, 1979; Friedman, Chodoff, Mason, & Hamburg, 1963; Fulton & Fulton, 1972; and Schoenberg et al, 1972). Indications of detachment from a chronically ill child approaching death include direct and overt signs, such as physical withdrawal from the child or visible redirection of energies toward other family members and other areas of interest, such as wishing to get away from the child or wishing it were over

(Friedman, Chodoff, Mason, & Hamburg, 1963; and Schoenberg et al, 1972).

The psychological hazards for both the parents and the child become more pronounced if the child survives longer than expected. In such instances, premature detachment can potentially lead to neglect of the child's emotional and/or physical needs with concomitant parental guilt during the course of the child's illness and following his/her death (Futterman, Hoffman, & Sabshin, 1972). At times hospital personnel have complained about a family's seemingly lack of concern, callous behavior, and disinterest in a child who has been ill for a prolonged period of time or who has had an extended terminal phase of his/her illness. However, detachment prepares parents for the actual loss of a child and permits them to have energy available to deal with other problems and to reconstitute their relationships with other family members when the child dies (Adams, 1978; Cowen, Mok, Corey, MacMillan, Simmons, & Levison, 1986; McCollum & Schwartz, 1972).

3.1.1 Marital Relationship

One of the areas of family functioning shown to be significantly affected in families with a chronically ill child is that of the marital relationship. Turk (1964), in a study of 25 families with a child with cystic fibrosis, found that there were significant problems in communication between spouses, usually correlated with a deprivation of emotional and sexual needs and having less time to

spend alone with the spouse. A very small sample size, lack of a control group, and lack of methodological criteria in which to measure the marital relationship make it difficult, however, to generalize these findings to other parents with chronically ill children. The literature reveals, however, that parents have a variety of complaints such as difficulties in communication (Adams, 1979; Gyulay, 1978; Heffron, Brommelaere, & Masters, 1973; Turk, 1964; and Eisner, 1985); changes in normal family routines due to either hospital visits and other adjustments made for the child (Ross, 1978; Stein & Jessop, 1983); less time to spend together as a couple (Friedman, Chodoff, Mason, & Hamburg, 1963; and Turk, 1964); social isolation from friends (Heffron, Brommelaere, & Masters, 1973); and separation from each other due to the child's hospitalizations (Adams, 1979; Hymovich & Barnard, 1973).

There has been a paucity of literature regarding actual divorce rates between parents of either chronically ill or life-threatened children. Kaplan, Grobstein, & Smith (1976) studied forty couples three months after the death of a child from leukemia and found that 5% of couples had divorced and 18% were separated. Hamovitch (1964) found significant marital discord in 10% of parents studied. He did not give a divorce/separation rate. Begleiter, Burry, & Harris (1976) found a divorce rate of 17% in the 29 families with children with cystic fibrosis studied. Heller & Schneider (1978) found that the stress of having a dying child can have long-term disruptive effects such as divorce, separation, depression, and an

increased incidence of alcoholism. In a recent study, Lansky, Cairns, Hassanein, Wehr, & Lowman (1978) compared the divorce rate between parents of children with cancer to the state divorce rate. They found that there was not a significant difference between the rates. They did find, however, that there was significant marital discord among the parents of the chronically ill children (assessed by the Arnold sign indicator analysis of the Minnesota Multiphasic Personality Inventory). Masters, Cerreto, & Mendlowitz (1983) stated that the divorce rate is higher in couples who have a child with a high occurrence chronic illness such as cystic fibrosis. Thus, it appears that the crisis of a chronically ill child may have various effects on different couples. For some couples, the illness may bring the couples closer together but for other families, the crisis may cause severe marital discord. The literature, however, supports the latter possibility as more prevalent.

3.1.2 Past Experiences with Crises

One variable that may influence the family's adaptation pattern when faced with a chronically ill child is that of past experiences with crises. McCubbin & Patterson (1982) stated that family maladaptation can result from an apparent overload of responsibilities and a pile-up of expected and unexpected events, hardships inherent in the stressor and the trial and error efforts to cope with the stressor. They list three factors that may contribute to the overload: (a) member and system change over time, (b) intra-

family boundary ambiguity, and (c) social ambiguity (McCubbin & Patterson, 1981).. In a study on family coping with a child with cerebral palsy, McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982) found that parents experienced statistically significant levels of pile-up stressors such as work-family transitions and strains, intra-family strains, and total life events and strains. Binger Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen (1969), in a retrospective study of parents of 23 children with a chronic illness, found that a significant number of mothers reported absent fathers who spent excess time at work and in other activities as a stressful factor and one that impeded successful adaptation. McCubbin & Patterson (1981) reported that these multiple changes and demands that occur simultaneously can often be persistent and hard to resolve or may not be resolvable at all. Nevin (1978) also found that these families who had a pile-up of family life changes and strains had more conflict than families with fewer life changes and strains. Cowen, Mok, Corey, MacMillan, Simmons, & Levison (1986), in a study of 299 families with a child with cystic fibrosis, found that the chronic illness itself tended to make the family more vulnerable to the other stresses of life.

The literature cites many other examples of past or simultaneous stressors or crises that may affect the adaptation of a family to a chronically ill child: ill child reaching childhood milestones (Futterman, Hoffman, & Sabshin, 1972; Travis, 1976; Pless & Pinkerton, 1975); sibling rivalry (Adams, 1978; Turk, 1964;

Rothenberg, 1982); financial burdens (Martinson, Armstrong, Geis, Anglim, Gronseth, MacInnis, Kersey, & Nesbit, 1978; Ross-Alaolmolki, 1985; Burr, 1985); transportation and assistance getting to check-ups and treatments (Kagen-Goodheart, 1977; Eiser, 1985); changes in roles, routines, and expectations of family members (Hymovitch, 1976; Ross, 1979; Masters, Cerreto, & Mendlowitz, 1983; Burr, 1985); marital discord (Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978; Turk, 1964; Larkin, 1987); conflict between family members and health practitioners (Kirkpatrick, Hoffman, & Futterman, 1974; Kupst, Blatterbauer, Westman, Schulman, & Paul, 1977); discipline problems (Heffron, Brommelaere, & Masters, 1973); Gayton, Friedman, Tavormina, & Tucker, 1977); death of grandparents and close friends (Adams, 1979); manipulateness of ill child (Heffron, Brommelaere, & Masters, 1973); another ill family member (Heffron, Brommelaere, & Masters, 1973); and social isolation from friends (Friedman, Chodoff, Mason, & Hamburg, 1963; Heffron, Brommelaere, & Masters, 1973; Thomas, 1987; Dunlap & Hollinsworth, 1977).

3.1.3 Resources Available to the Family

Three factors within a family's resource repertoire have been cited throughout the literature as being important in facilitating the family's adaptation to the stress of a child with a chronic illness. McCubbin, Joy, Cauble, Comeau, Patterson, & Needle (1981) have identified these factors as the family members' personal resources,

the family system's internal resources, and the social support system.

Personal resources refer to a broad range of reserves available to individual family members in times of need. These are usually in the form of economic reserves, education (the ability to perceive the situation realistically and to problem solve), health (physical well being), and psychological resources (personality characteristics) (McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981). Lin, Dean, & Ensel (1981) conducted a study which looked at the impact that income or financial reserve had on the depression level of 99 adult subjects. They found that financial reserves had a much greater effect than the number and severity of stressful life events the person experienced. Ross-Alaolmolki (1985) stressed that financial certainty often enables the parents to cope more effectively with a chronically ill child.

Little research has been carried out related to the effect education has on the adaptation of other family members to a chronically ill child. Pearlin & Schooler (1978) identified three psychological resources which can reduce the effects of stress: (a) mastery--i.e., locus of control (whether one perceives he/she has control of his/her life or whether one perceives he/she has no control over his/her future); (b) self-denigration--the extent to which one holds negative view about oneself; and (c) self-esteem--the extent to which one holds positive views about oneself. There has been much work done regarding locus of control or mastery and

the level of stress. Johnson & Sarason (1978) administered the Beck Depression Inventory, the State Trait Anxiety Inventory, a locus of control scale, and life-experiences survey to undergraduates. They found that in those students with an external locus of control, negative life changes correlated with the measures of depression and anxiety. There is a paucity of research available regarding the effect self-esteem and self-denigration have as moderating variables on stress.

A second resource system cited in the literature that affects a family's adaptation to stressors is that of family system resources. Problem solving ability among family members has been recognized as a key family system resource (Aldous, Condon, Hill, Straus, & Tallman, 1971; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981). The ability to problem solve may provide a critical purpose in moderating the effects of stress.

One of the most commonly mentioned and reportedly effective resources was that of social support. Social support has been described in a myriad of ways, but the most widely referred definition has been that of Cobb (1976) who purported that social support is information exchanged at an interpersonal level which provides emotional support, esteem support, and network support. There has been a vast amount of research examining the relationship between social support, life stress events, and physical and psychological adjustment of individuals such as physical health status (Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen, 1969);

emotional adjustment to illness (Adams, 1979; Heffron, Brommelaere, & Masters, 1973; Kirkpatrick, Hoffman, & Futterman, 1974); general mental health (Williams, Ware, & Donald, 1981); natural disasters (Drabeck, Key, Erickson, & Crowe, 1975); during pregnancy (Nuckolls, Cassel, & Kaplan, 1972); minority groups (McAdoo, 1982); aging (Blazer, 1982); various diseases such as asthma (de Araujo, van Arsdel, Holmes, & Dudley, 1973); depression (Lin, Dean, & Ensel, 1981); and myocardial infarctions (Finlayson, 1976).

McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982) conducted a study on families of children with cerebral palsy. They administered the Family Inventory of Resource for Management (FIRM) to both low conflict and high conflict families. They found that low conflict (well functioning) families were characterized by higher levels of esteem and communication, and mastery and health. The low conflict families also shared family esteem (respect from friends, relatives, co-workers, and among family members), mutual assistance (helping each other and relatives), and family mutuality with a sense of interpersonal support, togetherness, and co-operation. It would, therefore, appear that social networks act as a buffer against the hardships of caring for a child with cerebral palsy.

Venters (1981) interviewed families of children with cystic fibrosis. The study suggested that parents would share the burden of the illness among family members. Other research indicates that parents seek social support in the form of friends and family (Binger,

Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen, 1969; Tilden & Weinert, 1987; Rawlin & Horner, 1988); other parents in the same situations (Ross, 1979); and professionals (Kirkpatrick, Hoffman, & Futterman, 1974; Martinson, Armstrong, Geis, Anglim, Gronseth, MacInnis, Kersey, & Nesbit, 1978).

It is strongly apparent that families who are not socially isolated have a greater ability to adapt. Social support facilitates feedback, shares concrete help in dealing with their stress, provides emotional assistance and social contacts, and provides a non-threatening atmosphere in which to vent their concerns.

3.1.4 Coping Strategies Utilized by Family Members

McCollum & Schwartz (1972) have proposed a scheme delineating four adaptational responses or coping strategies parents employ when faced with the stress of caring for a chronically ill child. These include information seeking, invoking emotional support, compartmentalization, and rehearsal of death.

Upon learning the diagnosis of a chronic illness in their child, one of the first things parents may do is to seek information. As well as seeking information about the illness and about their child's status, most parents search for the meaning of their child's illness (Holaday, 1984). In one study by Venters (1981), coping strategies used by parents with a child with cystic fibrosis were examined.. Families assessed to have adequate coping strategies were found to have endowed the illness with meaning. The illness was regarded

positively and was defined in terms of a religious and/or medical-scientific philosophy of life. Although this particular study cannot be generalized to other illnesses, or to certain ethnic and religious cultures which deem the illness as "God's will," the process of information seeking can help the family adjust to any crisis. Heffron, Brommelaere, & Masters (1973); Holaday (1984); and Waechter (1987) concurred with the importance of this coping strategy as an adjunct in reaching bonadaptation.

Invoking emotional support through friends, relatives, professional staff, clergy, and other parents can also reduce feelings of loneliness, temporarily satisfy heightened dependency needs, and afford some gratification experiences (McCollum & Schwartz, 1972). Bozeman (1955); Friedman, Chodoff, Masters, & Hamburg (1963); Burckhardt (1987); Rawlins & Horner (1988); and Tilden & Weinert (1987) found that parents frequently sought out family and other friends as a means of social support. Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen (1969), in a classic study of parents of 23 chronically ill children, reported that most families received much support from the health professionals, clergy, and other parents. The study did not mention relatives as a source of support, however. Heffron, Brommelaere, & Masters (1973) stated that during their group discussions with parents of chronically ill children, 18 parents reported that the best form of support was from other parents with ill children. This paper reports an obvious bias, however, as the parents reporting this as beneficial support were

already involved in a self-help network. The reports from the parents do indicate, however, that parents do seek out emotional support as a means of coping.

The third coping strategy is that of compartmentalization or partialization. Adams (1979) pointed out that, in order to cope, parents learn to take one day at a time. Binger, Ablin, Feuerstein, Kushner, Zogel, & Mikkelsen (1969) stated that all parents suggested that the best way to deal with the illness was to live "day-to-day." Friedman, Chodoff, Mason, & Hamburg (1963) concurred with this as an important coping strategy. Solnit & Green (1959) stressed the necessity of delivering information to parents gradually so they have time to cope with each piece of information. Heffron, Brommelaere, & Masters (1973) observed parents further compartmentalizing their lives into a "sick" world and a "well" world. During each of these periods, the family would act accordingly, thus eliminating the necessity of dealing with the "sick" world continuously.

In order to deal with the child's potential death, parents often fantasize or work through their anxieties about parting with their child, or rehearse the death. Kubler-Ross (1979) saw this as an important part of the beginning of acceptance of the child's imminent death. This can take the form of actually rehearsing the death cognitively or of making plans for funerals, donations, etc. This anticipatory grieving allows the family to prepare more adequately for the child's death.

3.1.5 Summary

That the functioning of the family system is disrupted as a result of the stressor of a chronically ill child is a theme recurrent throughout the literature. However, whether a family achieves "bonadaptation" or "maladaptation" appears to depend upon variables such as their past experiences with crises, the coping strategies used by family members, and resources available and used by family members. This study will attempt to determine whether, indeed, that is true.

CHAPTER 4

4. METHODOLOGY4.0 Design

This study was designed to compare levels of functioning between two sets of families: those with a chronically ill child (index group), and those with only healthy children (control group). It also explored the relationships of variables such as: (a) past experiences with crises, (b) coping strategies used by the family, and (c) resources available to family members, to each family's actual level of functioning.

A non-experimental research design was chosen as subjects were not randomly assigned to groups and no treatment was administered during the study. This study used one form of non-experimental research design, the descriptive survey design. Descriptive approaches to research may consist of two formats. Comparative descriptive design concentrates on examining the differences between two groups. Correlational descriptive design examines the relationships between variables that exist in the research study (Bush, 1985; Burns & Grove, 1987; Wilson, 1985; Roberts & Burke, 1989). Descriptive design cannot be used to infer causal relationships. Both the comparative and correlational approaches were employed in this study.

4.1 Selection of Chronic Illnesses Studied

Three chronic childhood illnesses were identified from which to obtain an index sample. Even though the concept of a homogenous group of chronic illnesses had been incorporated into this study, three separate disease entities were selected. These three disease groupings, however, had similarities that enabled them to be studied together.

The diseases, cystic fibrosis, cerebral palsy, and a category entitled other, were selected for this study. The other category represented spinal abnormalities such as myelomeningocele, spina bifida, and cerebral palsy with complications such as blindness and deafness. McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982) stated that diseases involving non-progressive impairment of neuro-muscular function include cerebral palsy, myelomeningocele, and spina bifida, thus providing a general diagnostic category.

All the illnesses selected were non-surgical, or entirely medically treated conditions. All diseases are life-long and chronic, therefore providing the children and family with no periods of respite or remission. They all have a biologic etiology and occur either prenatally, at birth, or shortly after birth. They all require daily prescribed treatments that must be administered by another person. Social isolation frequently occurs for all children. In cystic fibrosis, infections must be avoided at all costs, therefore limiting the activities in which the children may engage. In the cerebral palsy and other category, severe neuromuscular abnormalities determine

the type and extent of the activity. Financial costs are high for all families. Costly medications, oxygen therapy equipment, wheelchairs, mobility aids, and special transportation services are frequently necessary.

There are two major differences among the illnesses. First, cystic fibrosis is regarded as chronic and possibly life-threatening, whereas cerebral palsy and the other category are considered chronic disabilities. The second difference lies in the visibility of the conditions. Other than a slightly enlarged abdomen and thorax, cystic fibrosis is often not noticeable. Cerebral palsy and the other category are often grossly apparent, creating many self-image problems for these children.

4.2 Identification of Subjects

Both index and control families were identified by the following inclusion criteria:

1. all families must have intact marriages (parents married and living together);
2. all families must reside in the city of Winnipeg (as defined within the boundaries of the perimeter highway); and
3. healthy child and ill child/children must be between the ages of 1 and 16 years.

The criterion of intact marriage controls for the varying effect that different relationship states (i.e., common-law, single parent, divorced or widowed parents) may have on family functioning. The

geographical criterion controls for the variation in family functioning in urban versus rural families. The criterion regarding the age of the chronically ill child and healthy child enables special influences that infancy and late adolescence may have on family functioning to be excluded.

4.3 Selection of Index Families

Potential index families were identified from two agencies: the Society for Manitobans with Disabilities (SMD), and the Home Care Department of the Children's Hospital (CH). A telephone call and subsequent follow-up letters explaining the purpose of the study, the procedure, and a request for a sample were sent to the Executive Director of the Society for Manitobans with Disabilities and the Coordinator of the Home Care Department (see Appendix D).

These contact persons were given a copy of the inclusion criteria and requested to generate a potential sample list accordingly. Once the families had been identified by the agency, they were sent a covering letter by the agency explaining the study; a letter from the researcher (see Appendix E); a participation form (see Appendix F); and a pre-addressed, stamped envelope (the latter three provided by the researcher). The families were requested to return the form if interested in participating in the study. As completed participation forms were sent directly to the researcher, the agencies were not aware of the identity of responders and non-responders.

The Home Care Co-ordinator at the Children's Hospital identified 24 possible families. Of the 11 families responding, 10 families actually participated. One family declined to take part after further consideration. Thirteen families did not respond.

See Table 4:1 page 39

The Co-ordinator at the Society for Manitobans with Disabilities identified 29 families as potential index families. Seventeen families volunteered; however, 15 families participated, as one family changed its mind and one family moved out of province prior to data collection. Twelve families did not respond.

4.4 Selection of Control Families

In order to obtain a random and large enough sample, seven school divisions were contacted and presented with a proposal of the study and request for a sample in one primary and one secondary school within their division. Of the seven divisions contacted, three did not wish to take part in the study. Of the remaining four, two declined at a later date and two actually participated.

See Table 4:2 page 40

Table 4:1

Response Rates from Index Families

	Children's Hospital	Society for Manitobans with Disabilities
Non-responders	13	12
Participants	10	15
Non-interested	1	2
Total sent out	24	29
(met inclusion criteria)		
Response rate	45.8%	58.6%

Table 4:2

Response Rates from School Divisions

Divisions contacted	7
Refusals	3
Respondents	4
Non-interested	2
Participants	2

The superintendents of each division solicited one primary and one secondary school on a volunteer basis. The principal of each school was contacted and a follow-up letter sent describing the study and requesting a sample (see Appendix G). Each of the four principals were requested to identify 50 families meeting the inclusion criteria. Once the families had been identified by the principal, they were sent a covering letter by the school explaining the study; a letter from the researcher (see Appendix H); a participation form; and a pre-addressed, stamped envelope (the latter three provided by the researcher). The control families were requested to return the participation form if interested.

Out of letters sent to 100 families with children in 2 schools in the St. Boniface School Division, 28 responses were received. Two families declined at a later date and 13 were not utilized due to an excess of control families. Thirteen families from the St. Boniface School Division were participants. Of the 100 requests sent to families with children in 2 schools in the Fort Garry School Division, 18 responses were received. Three families changed their minds and 3 were not utilized, also due to an excess of control families. Twelve families were participants from the Fort Garry School Division. Thus, 25 families participated, matching that of the index group .

See Table 4:3 page 42

Table 4:3

Response Rates from Control Families

	St. Boniface School Division		Fort Garry School Division	
	Primary	Secondary	Primary	Secondary
Number of families				
contacted	50	50	50	50
Non-respondents	41	31	42	40
Respondents	9	19	8	10
Non-interested	2	-	1	2
Not utilized	1	12	1	2
Participants	6	7	6	6
Total participants = 25				

4.5 Data Collection

Once the participant forms were received, both index and control families were contacted by telephone in order to explain the study in detail and to set up a convenient time to visit with the survey forms (see Appendices I and J). Each family was visited in its home and requested to fill out five forms taking approximately forty minutes of its time. A basic demographic form provided information that enabled the families to be analyzed regarding certain variables (see Appendices K and L). They were also requested to fill out four measurement tools (see Appendices M, N, O, and P). A copy of the consent form (see Appendix Q) was presented to all families taking part in the study, as well as a thank-you letter, thanking them for participating (see Appendix R for Critical Path).

4.6 Instrumentation

4.6.0 Family Adaptability and Cohesion Evaluation Scale (FACES III)

The primary area of family functioning assessed for both index and control families was that of adaptation. The tool used to measure family adaptation was the Family Adaptability and Cohesion Evaluation Scale (FACES III) developed by Joyce Portner and Richard Bell in 1982 (Olson, Portner, & Bell, 1982). The original FACES was developed in 1978 and subsequently FACES II and FACES III were developed to overcome any shortcomings of FACES I and

FACES II, hence improving its reliability, validity, and clinical utility. The FACES III, a Likert-type scale, was used to measure two aspects of adaptation: cohesion and adaptability (see Appendix M). The 20-item scale contains 10 cohesion items and 10 adaptability items. Each of the five concepts related to cohesion (emotional bonding, supportiveness, family boundaries, time and friends, and interest in recreation) has two related items within the scale. There are also two items for each of the adaptability concepts (leadership, control, and discipline) and four items for the combined concepts of roles and rules. Once both husband and wife have each completed the scale, a mean family score can be obtained. Based on relevant cutting points, the family is placed on a circumplex grid in order to obtain one of 16 family types. The 16 types are further categorized into three groups--balanced, mid-range, and extreme--according to the level of functioning within the family.

The face and content validity of the scale is considered to be very good (McCubbin & Patterson, 1981). Regarding the construct validity of the FACES III tool, the Pearson correlation between the two dimensions of cohesion and adaptability is $r = .03$, indicating the independence of the two dimensions. In FACES III, the correlation between adaptability and social desirability was reduced to .00. However, because high cohesion is valued within our society, the correlation between cohesion and social desirability was not reduced to .00, but left at .35. The reliability, using Chronbach Alpha, ranges from .58 to .77, adequate for both cohesion and adaptability (Olson,

Portner, & Lavee, 1985). An important aspect of FACES III is that it was designed to assess how family members perceive their current level of functioning and how they would like it to be. Thus, two scales are provided, that of an ideal scale and that of a perceived scale. Families fill out both scales in order to provide information regarding the level of family satisfaction within the family system.

Two populations were initially studied to develop the FACES scale. Portner & Bell assessed the empirical validity with 410 young adults and the clinical validity with 35 marriage and family counsellors in 1978. They then proceeded to test the instrument on 210 parent and adolescent triads. At this time, the alpha reliability was .83 for cohesion and .75 for adaptability (Olson, Portner, & Lavee, 1985). In 1981, the FACES scale was used to compare 55 families in family therapy with a matched control group of 117 healthy families. It was found that the healthy families fell into the balanced areas in the Circumplex model and that the clinical families fell into the extreme areas (Olson, Portner, & Lavee, 1985). The same 117 families were compared with 33 families with runaways in 1982. As hypothesized in the study, the clinical families tended to be more chaotic and disengaged (Olson, Portner, & Lavee, 1985). A number of empirical studies have since been undertaken with the FACES scale as the methodological tool to measure the functioning in schizophrenic and neurotic families (Clarke, 1984), alcoholic families (Killoran & Olson, 1984), and delinquent families (Rodick, Henggler, & Hanson, 1985).

4.6.1 The Family Inventory of Life Events (FILE)

In order to assess the pile-up of stressors or the level of past experiences with crises (the aA factor of the Double ABCX Model) in both the index and control families, the Family Inventory of Life Events (FILE) was used. FILE was developed by McCubbin, Patterson, & Wilson in 1981 in an effort to assess family stress (McCubbin & Patterson, 1981). FILE is a 71-item self-report instrument which can be used to assess both normative and non-normative events and life-changes occurring in the family over the past 12 months. FILE also contains 34 items that relate to events occurring prior to the past 12 months, in order to record stressors that may have a long-term and chronic effect on the family (see Appendix N). The development of FILE was guided by both important stressors identified in past literature and from clinical research. The 71 items of FILE are grouped into nine sub-scales: (a) intra-family strains (conflict and parenting strains); (b) marital strains; (c) pregnancy and child-bearing strains; (d) finance and business strains; (e) work-family transitions and strains; (f) illness and family care strains (illness onset and child care, chronic illness strains, dependency strains); (g) losses; (h) transitions 'in' and 'out'; and (i) legal strains. The parents complete the scale together at which time the following data is obtained: (a) nine sub-scale scores; (b) total recent family life change score (total of all sub-scales); and (c) total past life change scores.

The internal reliability, using Chronbach's alpha for FILE is .72 (McCubbin & Patterson, 1981). Validity assessments were made by correlating the nine sub-scale scores and the total recent life changes score of FILE with the Family Environment Scale developed by Moos in 1976. McCubbin & Patterson (1981) hypothesized that a high FILE score would correlate positively with poor functioning families and correlate negatively with well-functioning families. This hypothesis was supported. Negative correlation occurred between the FILE score and traits indicative of positive family functioning. Positive correlation occurred between the FILE score and traits indicative of negative family functioning. They also found a negative correlation between the FILE score and the pulmonary functioning of a child with cystic fibrosis (McCubbin & Patterson, 1981).

4.6.2 Family Inventory of Resources for Management (FIRM)

The Family Inventory of Resources for Management (FIRM) developed by McCubbin, Comeau, & Harkins in 1981 was used in order to assess the family's repertoire of resources (factor bB in the Double-ABCX model) in both index and control families. Three major areas in the literature influenced the development of this tool: (a) personal resources (resources that individual family members make available to any family member in need--i.e., financial well-being, education, health, and psychological attributes); (b) family system resources (ability of family to manage the resources); and (c) social support (information exchanged between people providing them

with emotional support, esteem support, and network support) (McCubbin & Patterson, 1981).

FIRM is a 69-item self-reporting instrument designed specifically for use with families experiencing chronic illness (see Appendix O). Four sub-scales within FIRM are identified: (a) family strengths I--esteem and communication; (b) family strengths II--mastery and health; (c) extended family social support; and (d) financial well being. The FIRM scales give the following data on completion: (a) total of above four sub-scales; (b) sources of financial support; and (c) social desirability factor (McCubbin & Patterson, 1981).

The internal reliability for the four scales, using Chronbach's alpha is .89, and for the separate scales: (a) .85; (b) .85; (c) .62; and (d) .85 respectively (McCubbin & Patterson, 1981). In order to assess validity, the inter-correlation matrix of the FIRM scales was examined. The scales were found to correlate moderately (McCubbin & Patterson, 1981). Additional validity checks were performed by comparing the FIRM scales with the Family Environment Scale developed by Moos in 1976. Significant positive correlation occurred between the FIRM scales and the Family Environment dimensions of cohesion, expressiveness, organization, and negative correlations between family conflict and four FIRM scales (McCubbin & Patterson, 1981).

4.6.3 Coping Health Inventory for Parents (CHIP)

In order to measure the coping strategies (the coping factor in the Double ABCX model) used by families, the Coping Health Inventory for Parents (CHIP) was administered to both the control and index groups. CHIP was developed in 1979 by McCubbin, McCubbin, Nevin, & Cauble in order to assess the parents' perception of their coping strategies when they have a child who is chronically or seriously ill. CHIP consists of 45 self-report items grouped into three abstract categories: (a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and (c) understanding the medical situation through communication with other parents and consultation with medical staff. Scores are then obtained in these three categories (see Appendix P). Currently, the scale is designed to be completed by parents individually in order to get a more complete view of the family's overall coping strategies.

The internal reliability, using Chronbach's alpha for each of the three abstract categories are respectively: (a) .79; (b) .79; and (c) .71 (McCubbin & Patterson, 1981). As in FILE, validity checks for CHIP were made using the FES (Moos, 1976) and the height/weight index and pulmonary functioning index of children with cystic fibrosis. When the mothers used all three groups of coping patterns, cohesiveness and expressiveness were identified. When fathers used two of the groups of coping patterns, cohesiveness, conflict, organization, and control were identified. As well, when parents

used these groups of coping patterns, associated improvements in the child's health status occurred (McCubbin & Patterson, 1981). Additional validity checks were done by performing discriminant analysis between low conflict and high conflict families with children with cerebral palsy. Parents in high conflict families tended to use more of the coping patterns than did parents in the low conflict families (McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson, 1982).

4.7 Ethical Considerations

The research proposal was submitted to the University of Manitoba School of Nursing Ethical Review Committee for approval prior to initiating the project. Written consent was obtained from each family participating in the study. As both husband and wife were asked to complete separately FACES III and CHIP, they were each asked to sign the consent form, indicating individual consent. Each family was assured that its participation was strictly voluntary and it could withdraw at any time or refuse to answer any or part of questions without penalty. The method of family selection and the procedures were explained to all families via the letter and telephone call. They were also informed of the time needed to complete the forms. The families were told that there were no risks involved and that there was no direct benefit to them. The consent form stated that the families could in no way be individually identified and that all results would be reported as group data. All

information was strictly confidential, with no names being listed anywhere on the survey sheets. The control and index families' forms were coded in separate colors in order for the investigator to distinguish between groups. The answers were coded, with the access to coded data limited only to the investigator and the advisor. The families were also assured that any publication arising out of this study would in no way identify their family. A copy of the consent was left with each family. Any family who wished to receive a copy of the results indicated so at the time of the visit.

4.8 Summary

This chapter has discussed the methodology used in conducting a non-experimental, descriptive study that explored relationships among the variables: (a) past experiences with crises; (b) resources available to family members; and (c) the coping strategies used in families with a chronically ill child and in those with healthy children only. The procedures used in the selection of the sample and collection of data have been outlined. Ethical considerations have also been addressed.

CHAPTER 5

5. RESULTS

Data for this study were collected over a seven-month period from November, 1988 to May, 1989. All five instruments were hand scored and coded by the investigator and then transferred into a computer file. The Statistical Analysis System (SAS) was used for the actual statistical analysis. The characteristics of the final sample of index and control families and summaries of raw data from the instruments were summarized using descriptive statistics.

In order to test Hypothesis 1, a non-parametric test, chi-square was used. Due to the curvilinear nature of the Circumplex model, traditional parametric statistics that rely on mean scores were not suitable. Chi-square enabled comparisons to be made between the frequencies of the balanced, mid-range and extreme groups within the index and control families, rather than between the means obtained from all families.

Stepwise Discriminant Analysis was employed to test Hypothesis 2. This procedure provided information on whether certain characteristics or variables can predict the group to which each subject belonged (Volicer, 1984). Multivariate analysis of variance was used to test Hypothesis 3, which involved the statistical examination of the effect of three factors on the dependent variable.

This chapter describes the characteristics of the final sample of index and control families, provides a summary of raw data obtained

from each instrument and finally addresses the results regarding each hypothesis.

5.0 Characteristics of Final Sample of Index and Control Families

The final sample was composed of 25 two-parent index families and 25 two-parent control families. Both the index and control families lived within the perimeter of the city of Winnipeg. The control families had an average of 2.56 children, all of whom were healthy and illness-free. The index families had an average of 2.28 children. One child from each index family fit into one of three illness categories: (a) cystic fibrosis; (b) cerebral palsy; and (c) other. The ages of the children ranged between 1 and 16.

Both the index and control families were similar in respect to socio-economic status. Eighty-four percent of the index families and 72% of the control families had annual incomes in the \$30,001 - \$60,000 range.

See Table 5:1 page 54

Forty-eight percent of the index husbands had blue-collar occupations as compared to 16% of the control husbands. Fifty-two

Table 5.1

Annual Income by Group

Annual Income	Group		
	Control	Index	Total
Frequency			
Percent			
Row percent			
Col percent			
\$15,001-\$30,000	3	5	7
	6.00	8.00	14.00
	42.86	57.14	
	12.00	16.00	
\$30,001-\$60,000	18	21	39
	36.00	42.00	78.00
	46.15	53.85	
	72.00	84.00	
> \$60,000	4	0	4
	8.00	0.00	8.00
	100.00	0.00	
	16.00	0.00	
Total	25	25	50
	50.00	50.00	100.00

percent of the index husbands had white-collar occupations as compared to 84% of the control husbands.

See Table 5:2 page 56

Twelve percent of the index wives had blue-collar occupations as compared to 0% of the control wives. Forty percent of the index wives had white-collar occupations as compared to 44% of the control wives.

See Table 5:3 page 57

The education pattern in both the index and control group tended to follow the same pattern as the occupation category. Forty-four percent of the control husbands had University preparation as compared to 16% of the index husbands. Forty-eight percent of index husbands had Grade 9-12 preparation in contrast to 24% of the control husbands.

See Table 5:4 page 58

Twenty percent of the control wives had University preparation as compared to 8% of the index wives. Sixty-eight

Table 5.2

Husbands' Occupation by Group

Husbands' occupation	Group		
Frequency			
Percent			
Row percent			
Col percent	Control	Index	Total
Blue collar	4	12	16
	8.00	24.00	32.00
	25.00	75.00	
	16.00	48.00	
White collar	21	13	34
	42.00	26.00	
	61.76	38.24	
	84.00	52.00	
Total	25	25	50
	50.00	50.00	100.00

Table 5.3

Wives' Occupation by Group

Wives' occupation	Group		
	Control	Index	Total
Frequency			
Percent			
Row percent			
Col percent			
Blue collar	0	3	3
	0.00	6.00	6.00
	0.00	100.00	
	0.00	12.00	
White collar	11	10	21
	22.00	20.00	42.00
	52.38	47.62	
	44.00	40.00	
Other	14	12	26
	28.00	24.00	52.00
	53.85	46.15	
	56.00	48.00	
Total	25	25	50
	50.00	50.00	100.00

Table 5.4

Husbands' Education by Group

Husbands' Education	Group		
	Control	Index	Total
Frequency			
Percent			
Row percent			
Col percent			
Grade 9-12	6	12	18
	12.00	24.00	36.00
	33.33	66.67	
	24.00	48.00	
College Certificate	7	6	13
	14.00	12.00	26.00
	53.85	46.15	
	28.00	24.00	
University	11	4	15
	22.00	8.00	30.00
	73.33	26.67	
	44.00	16.00	
Other	1	3	4
	2.00	6.00	8.00
	25.00	75.00	
	4.00	12.00	
Total	25	25	50
	50.00	50.00	100.00

percent of the index wives had Grade 9-12 preparation in contrast to 52% of the control wives.

See Table 5:5 page 60

The mean ages for the husbands and wives of both groups tended to fall into the sociological pattern of the husband being older than the wife. The mean age of the husband in both groups was approximately three years older than the wife in their respective group.

See Table 5:6 page 61

Cumulative information of index group characteristics, control group characteristics, and comparisons between the two groups has been displayed in table format.

See Table 5:7 page 62

See Table 5:8 page 63

Table 5.5

Wives' Education by Group

Wives' Education	Group		
	Control	Index	Total
Grade 9-12	13	17	30
Percent	26.00	34.00	60.00
Row percent	43.33	56.67	
Col percent	52.00	68.00	
College Certificate	5	4	9
Percent	10.00	8.00	18.00
Row percent	55.56	44.44	
Col percent	20.00	16.00	
University	5	2	7
Percent	10.00	4.00	14.00
Row percent	71.43	28.57	
Col percent	20.00	8.00	
Other	2	2	4
Percent	4.00	4.00	8.00
Row percent	50.00	50.00	
Col percent	8.00	8.00	
Total	25	25	50
Percent	50.00	50.00	100.00

Table 5:6
Age by Group

	Index		Control	
	x	SD	x	SD
Husband	36.96	6.57	36.76	3.67
Wife	33.04	4.50	33.88	3.41

Table 5.7
 Characteristics of Index Families

Characteristics	Total Sample		Cerebral					
	N=25	Cystic fibrosis	Palsy	Other				
Husbands	25	10	10	5				
Wives	25	10	10	5				
Income:								
> 60,000	0	0	0	0				
30,001-60,000	21	8	9	4				
15,001-30,000	4	2	1	1				
<hr/>								
Number of children (Mean)	2.28	1.9	2.2	3.2				
<hr/>								
Education	<u>H</u>	<u>W</u>	<u>H</u>	<u>W</u>	<u>H</u>	<u>W</u>	<u>H</u>	<u>W</u>
Grade 9-12	12	17	6	8	5	5	1	4
College	6	4	0	1	3	3	3	0
University	4	2	2	1	2	1	0	0
Other	3	2	2	0	0	1	1	1
Occupation:								
Blue collar	12	3	5	1	3	2	3	1
White collar	13	10	4	4	7	3	2	2
Other	0	12	0	5	0	5	0	2
Age (Mean)	36.96	33.04	35.5	31.3	37.9	34.6	38.0	33.4

Table 5:8

Characteristics of Control Families

Characteristics	Total Families N=25	
Husbands	25	
Wives	25	
Income: >60,000	4	
30,001-60,000	18	
15,001-30,000	3	
Average number of children	2.56	
	Husband	Wife
Education: Grade 9-12	6	13
College	7	5
University	11	5
Other	1	2
Occupations: Blue collar	4	0
White collar	21	11
Other	0	14
Age (average)	36.76	33.88

See Table 5:9 page 65

5.1 Summary of Raw Data in Index and Control Groups

5.1.0 Family Adaptability and Cohesion Evaluation Scale (FACES III)

The means for the index families on cohesion and adaptability were 41.84 and 25.24 respectively. The control families' means were very similar to the index families at 40.34 and 25.5 for the cohesion and adaptability dimensions. The mean adaptability scores for both the index and control groups closely resembled norms established for parents across all family life stages. The norms for cohesion and adaptability are 39.8 and 24.1 respectively. These means were derived from a study involving a national survey of 1,100 couples and families (McCubbin & Patterson, 1981).

See Table 5:10 page 66

Discrepancy scores, which were derived from differences between the wife's and husband's scores were consistent between the two groups at 5.86 and 5.93 for the index and control groups respectively. The administration of an "ideal FACES" scale or a scale which allowed the families to indicate how satisfied they were with

Table 5:9

Comparison of Characteristics Between Groups

Characteristics		Index	N=25	Control	N=25
Income:	>60,000		0		4
	30,001-60,000		21		18
	15,001-30,000		4		3
Number of children (Mean)			2.28		2.56
		Husband	Wife	Husband	Wife
Education:	Grade 9-12	12	17	6	13
	College	6	4	7	5
	University	4	2	11	5
	Other	3	2	1	2
Occupation:	Blue collar	12	3	4	0
	White collar	13	10	21	11
	Other	0	12	0	14
Age (Mean)		36.96	33.04	36.76	33.88

Table 5:10

Comparison of Group Cohesion and Adaptability Means with National Norms

	Index	Control	Norms
Cohesion	41.84	40.34	39.80
Adaptability	25.24	25.50	24.10

the cohesion and adaptability dimensions in their family life provided two satisfaction scores. The results indicated that the control group was more satisfied with the cohesion dimension in its family than the index family. However, the index families were more satisfied with the adaptability dimension in their family functioning than the control group.

See Table 5:11 page 68

Once means for the cohesion and adaptability dimensions were derived from the families, it was possible to classify families into one of 16 family system types, based on relevant cutting points. Each one of the 16 types fits into one of the three family functioning categories: (a) balanced; (b) mid-range; and (c) extreme. Fifteen control families fell into the balanced functioning category in contrast to 11 index families. The mid-range category was comprised of nine control and nine index families. The extreme category consisted of five index families and one control families.

See Table 5:12 page 69

Table 5:11

Mean FACES Scores for Index and Control Groups

	Index	N=25	Control	N=25
Raw cohesion score				
(FACCOSC)	41.84		40.34	
Raw adaptation score				
(FACEADSC)	25.24		25.50	
Ideal cohesion score				
(FACECOID)	45.88		47.02	
Ideal adaptation score				
(FACEADID)	30.46		28.94	
Discrepancy score				
(FACEDIS)	5.86		5.93	
Cohesion satisfaction score				
(CSAT)	4.04		6.68	
Adaptation satisfaction score				
(ASAT)	5.22		3.44	

5.1.1 Family Inventory of Life Events (FILE)

The mean scores on all 11 life event scores were obtained through an actual count of present and past life events in the family's lives. The index families had higher scores on all scores, except on intra-family strains. On the dimensions of marital strains, pregnancy strains, finance-business, work-family strains, illness strains, losses, transitions 'in' and 'out' and legal strains, the index families tended to experience more life events. The index families also encountered higher life event scores in both the past 12 months and prior to that date than did the control families. Illness strains accounted for the majority of the life events experienced by the index families.

See Table 5:13 page 71

5.1.2 Family Inventory of Resource Management (FIRM)

The control families scored higher than the index families on all the scales within the Family Inventory of Resources for Management. Thus, the control families had higher scores on the Family Strengths I--Esteem and Communication, Family Strengths II--Mastery and Health, extended family social support and financial well-being. The control families also had a higher social desirability score and tended to have more sources of financial support (see Table 5:14). According to a normative profile provided by McCubbin

Table 5:13

Mean FILE Scores for Index and Control Groups

	Index	N=25	Control	N=25
Family inventory of life events:				
Intra-family strains	4.32		4.48	
Marital strains	0.04		0.12	
Pregnancy strains	0.16		0.04	
Finance business strains	2.52		1.76	
Work family strains	1.72		1.52	
Illness strains	1.84		0.68	
Losses	0.64		0.24	
Transitions	0.12		0.28	
Legal strains	0.04		0.00	
Total recent family life events	11.40		9.12	
Total past family life events	5.88		3.96	

& Patterson (1981), the control families in this study scored better than average on the scales of Family Strengths I--Esteem and Communication, financial well-being and on the total resource management score. The index group fell into the norms provided.

See Table 5:14 page 73

5.1.3 Coping Health Inventory for Parents (CHIP)

The index families scored considerably higher than the control families on the scale of maintaining family integration, co-operation, and an optimistic definition of the situation (CHIPFAM). The scores for both groups were similar on the scales of maintaining social support, self-esteem, and psychological stability and understanding the medical situation through communication with other parents and consultation with medical staff (CHIPSUP and CHIPMED respectively).

See Table 5:15 page 74

Separate scores were also obtained for the husbands and wives. Wives in the control group consistently used more coping strategies than the husbands on all the scales. The wives in both the control and index group had scores which fell into the norms set by

Table 5:14

Comparison of FIRM Scores in Index and Control Groups with
National Norms

Scale	Index	Control	Norms
Family strengths I	38.52	40.44	29-40
Family strengths II	39.48	47.44	30-48
Financial well-being	37.76	41.80	19-37
Extended family social support	9.4	9.6	7-11
Social desirability	13.56	15.04	9-15
Sources of financial support	4.84	5.20	4-6
Total management score	125.16	139.48	93-129

Table 5:15

Mean Scores on CHIP in Index and Control Groups

Scale	Index N=25		Control N=25	
	x	SD	x	SD
Maintaining family integration, co-operation, and an optimistic definition of situation (CHIPFAM)	59.94	8.94	40.82	6.15
Maintaining social support, self-esteem, and psychological stability (CHIPSUP)	26.42	7.45	27.74	5.06
Understanding the medical situation through communication with other parents and consultation with medical staff (CHIPMED)	13.72	4.57	13.26	4.77

McCubbin & Patterson (1981). Scores obtained by the husbands in both index and control groups also fell within the normative areas.

See Table 5:16 page 76

5.2 Hypothesis 1

According to Hypotheses 1, families with a healthy child (control group) would tend to have more balanced scores on the dimensions of cohesion and adaptability than those families with a child with a chronic illness (index group). Contrary to this prediction, there was no significant difference between groups on the dimensions of cohesion and adaptability. Utilizing a chi-square analysis in order to observe any differences in frequencies, the control group did not appear to have more balanced family functioning scores ($\chi^2=3.282$, $df=2$, $p>.05$).

See Table 5:17 page 77

5.3 Hypothesis 2

Hypothesis 2 stated that for families with a healthy child (control group) and for those with a chronically ill child (index

Table 5:16

Comparison of Husband and Wife CHIP Scores for Index and Control
Groups with National Norms

Score	Index	N=25	Control	N=25	Norms	
	H	W	H	W	H	W
Maintaining family integration, co-operation, and an optimistic definition of the situation (CHIPFAM)	36.28	43.6	37.76	43.88	16-56	25-55
Maintaining social support, self-esteem, and psychological stability (CHIPSUP)	23.88	28.96	25.32	30.16	15-41	16-40
Understanding the medical situation through communication with other parents and consultation with medical staff (CHIPMED)	11.36	16.08	10.04	16.48	4-19	8-22

Table 5:17

Table of FaceCode by Group

Facecode	Group		
	Control	Index	Total
Frequency			
Percent			
Row percent			
Col percent			
Extreme	1	5	6
	2.00	10.00	12.00
	16.67	83.33	
	4.00	20.00	
Mid-range	9	9	18
	18.00	18.00	36.00
	50.00	50.00	
	36.00	36.00	
Balanced	15	11	26
	30.00	22.00	52.00
	57.69	42.31	
	60.00	44.00	
Total	25	25	50
	50.00	50.00	100.00

group), the following set of variables would predict the family's level of functioning:

- (a) total past 12-month life experience and events score;
- (b) the total resources available to the family for management of crises;
- (c) the coping strategy score involving maintenance of family integration, co-operation, and an optimistic definition of the situation;
- (d) the coping strategy involving the maintenance of social support, self-esteem, and psychological stability; and
- (e) the coping strategy involving the understanding of the medical situation through communication with other parents and consultations with medical staff.

To test this hypothesis, stepwise discriminant analysis was used in order to test whether the above set of variables would predict the level of family functioning.

5.3.0 Index Group

Stepwise discriminant analysis within the index group revealed that only the total resources available to the family were found to have an effect on the level of family functioning ($r^2=.2254$). The other variables did not have any predictive power.

5.3.1 Control Group

Stepwise discriminant analysis within the control group revealed that the only variable found to have any predictive power was that of the coping strategy involving the maintenance of social support, self-esteem, and psychological stability ($r^2=.2447$). The other variables did not have any effect on the level of family functioning for the control families.

5.4 Hypothesis 3

Hypothesis 3 stated that extreme functioning families with a chronically ill child would have higher family life change scores, lower family resource scores, and higher parental coping scores than those balanced and mid-range functioning families with a chronically ill child.

5.4.0 Family Life Change Score

Analysis of variance indicated that the results were non-significant; that is, the above hypothesis was rejected and the null hypothesis accepted--there were no differences between the extreme, mid-range, and balanced functioning index families on the family life change score ($F=0.53$, $p>.05$).

5.4.1 Family Inventory of Resources for Management

Analysis of variance indicated non-significant results; that is, the above hypothesis was rejected and the null hypothesis accepted --there were no differences between the extreme, mid-range, and balanced functioning index families on the family inventory of resources for management score ($F=3.20$, $p>.05$).

5.4.2 Parental Coping Scores

Analysis of variance indicated non-significant results for the scales for the coping strategies involving maintenance of family integration, co-operation, and an optimistic definition of the situation and for that involving the maintenance of social support, self-esteem, and psychological stability, thereby rejecting the hypothesis and accepting the null hypothesis; that is, there were no differences between the extreme, mid-range, and balanced index families on these areas of coping. However, significant results were obtained for the coping strategy of understanding the medical situation through communication with other parents and consultations with medical staff, thus enabling the acceptance of the hypothesis that there were significant differences between the extreme, mid-range, and balanced families on this dimension.

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Table 5:18

Analysis of Variance Results for the CHIP Scales

	Index families		
	Extreme Families	Mid-range Families	Balanced Families
Maintaining family integration, co-operation, and an optimistic definition of situation (CHIPFAM)	44.70	40.39	37.41
F=1.50 p>.05			
Maintaining social support, self-esteem, and psychological stability (CHIPSUP)	27.10	28.23	24.64
F=1.50 p>.05			
Understanding the medical situation through communication with other parents and consultation with medical staff (CHIPMED)	15.60	14.39	12.32
F=4.12 p<.05			

5.5 Summary

With respect to demographic data, the results from this study indicated that the index and control groups were similar with respect to number of children, ages of parents, and level of income. Control group parents tended to have slightly higher education levels and to be employed in white-collar positions more often than the index group parents.

Descriptive analysis revealed that both index and control groups had similar means on both dimensions of family functioning and that they were very close to national norms. The control group was more satisfied with the cohesion dimension in their family whereas the index group was more satisfied with the adaptability dimension. On the Family Inventory of Life Events scale, the index families had experienced slightly more life events in the past 12 months than the control families. Control families demonstrated a higher number of resources for management of stress than the index families. With regard to coping strategies used by both families, index families scored higher on the coping strategy of maintaining family integration, co-operation, and an optimistic definition of the situation than did the control families. Both groups of families obtained similar scores on the other CHIP scores and fell within national norms provided.

The results of this study did not support Hypothesis 1. No difference was demonstrated between the index and control families on the scores of cohesion and adaptability. Hypothesis 2 was only

partially supported. For the index group, the variable of the total resources for management was found to have predictive power on family functioning. For the control group, only the coping strategy involving maintenance of social support, self-esteem, and psychological stability had an effect on the level of family functioning. Hypothesis 3 received only very minimal support. Extreme functioning index families did not differ from mid-range and balanced families on the variables of the total life event score in the past 12 months, etc. However, as predicted, the results provided significant support for extreme functioning index families had higher parental coping scores, involving communication with other parents in the same situation and consultation with medical staff.

CHAPTER 6

6 DISCUSSION

A sample of 25 index families (those with a child with a chronic illness) and 25 control families (those with healthy children only) was studied in order to answer three questions:

- (a) Did the families with only healthy children tend to function better than those families with a chronically ill child?;
- (b) Were there factors (i.e., past experiences with crises, coping strategies used by family members, and resources available, and used by the family) that would predict both groups' level of functioning?; and
- (c) For the index group, would the extreme functioning families have a higher family life change score, a lower family resource score, and a higher parental coping score?

The results of this study did lend support to certain aspects within each question. This chapter will discuss the findings under each hypothesis with possible explanations and literature support provided. Limitations of this study will be explored as well as implications for future research, education, and clinical practice for nurses and other health practitioners.

6.0 Hypothesis 1

As addressed in Chapter 5, Hypothesis 1 was not supported. The difference between the index and control group in family functioning was non-significant. That is, no difference was found on the dimensions of cohesion and adaptability between the index and control groups.

The notion that families without a chronically ill child may present more balanced family functioning scores than those with a chronically ill child has been shown to be a plausible hypothesis from past literature on family stress theory. The fact that this study did not support this hypothesis can be partially explained by both methodological and theoretical issues. In their discussion of the Family Adaptability and Evaluation Cohesion Scale (FACES) and the Circumplex Model of Marital and Family Systems, Olson, Portner, & Lavee (1985) have used FACES to compare the functioning of "normal families" with that of "problem families." These "problem families" included couples undergoing marital therapy, families with runaways, schizophrenic families, alcoholic families, sex offenders, delinquent families, and families with chronically ill children (Olson, Portner, & Lavee, 1985). That families with a chronically ill child may differ significantly from families undergoing therapy and other families with problems is supported by this study, making them an inappropriate group to compare with control or "normal families." In fact, they may be more closely related to the control or "normal" families than those of the "problem" families. Thus, the wide

variation in the use of "problem" or index families used by Olson, Portner, & Lavee in 1985 may account for the non-significant results of this study due to an erroneous hypothesis derived from the Circumplex Model of Marital and Family Systems.

Another reason for the non-significant findings may be related to the homogenous conceptualization of the medical illnesses included in the study. Even though evidence is emerging for studying these chronic illnesses as one, differences nonetheless do exist between them. It may have been that one of the diseases may not have been stressful enough to induce changes (negative) in family functioning.

The cross-sectional sample may also have accounted for non-significant findings. Because the Double ABCX Model implies that a "pile-up" of life events and changes is necessary to influence family functioning, perhaps a longitudinal study is necessary to obtain a true picture of family functioning (McCubbin & Patterson, 1982).

Singer and Irvin (1989) stated that often families with an illness in their family, particularly a chronic illness, are strengthened by the many challenges and function much better than families without this experience. McCubbin, Sussman, & Patterson (1983) stated that many parents seemed to thrive on the challenge of caring for the chronically ill. Families with a chronically ill child may periodically have difficulty adapting but they do pass through various stages of family functioning (Singer & Irvin, 1989). Due to the volunteer nature of the study, the families (both index and

control) may, in fact, have been in an intermittent period of adjustment, thus not presenting a general overall or typical picture of the families.

Hawkins & Singer (1989), in a study exploring the effect of a program designed for assisting parents to cope with stress, stated that families tending to be more chaotic (extreme functioning) were often from a lower income bracket. The demographic data revealed that the majority of the sample in this study fell within the mid-income bracket.

Any interventions undertaken by the agencies providing the samples for the study were not directly assessed in this study. These interventions may have assisted the index families with "unhealthy" or "extreme" areas of family functioning. This may have introduced another variable, therefore threatening the internal validity of the study and producing non-significant results.

Another possibility exists, however; that is, that in fact there actually may not be any difference in family functioning between families with a chronically ill child and those with healthy children only. Recent literature has begun to cite evidence supporting the null hypothesis of this study--that no difference is present between families with and those without a chronically ill child; therefore, the presence of a chronically ill child may not have a direct influence on family functioning levels. Literature, particularly that aimed at health care professionals, tends to portray families with members with a disability as "problem families" (McCubbin & Patterson,

1981); or as distressed families (Summers, Behr, & Turnbull, 1989). There are other empirical studies that have demonstrated "bonadaptation" among families with a chronically ill child (Abbott & Meredith, 1986; McCubbin & Patterson, 1981; Pallner & McDonald-Wekler, 1985). That these families with a chronically ill child may be very similar to other families in terms of family functioning certainly appears to be a valid postulation, and one that deserves further examination.

Although not part of Hypothesis 1, the results from the FACES scale demonstrated that index families were less satisfied with their level of family cohesion than the control families; that is, they were not as cohesive as they would have liked to have been. Although the index families fell within norms established for the cohesion dimension, their satisfaction score on this dimension indicated that they desired more cohesiveness in their family system. That cohesion is threatened in families with a chronically ill member is a theme recurrent throughout literature due to such factors as: (a) absence of compatible activities among family members (Diamond, 1974); (b) negative reactions to the ill child (Schwietzer & Deely, 1982); and (c) fear of the loss of the ill member (Miller, 1980). The fact, however, that the index families fell within national norms, does provide some support for the efforts of families with a chronically ill member to maintain their level of cohesiveness.

The study also indicated that the index families had more satisfaction regarding their adaptability levels than the control

families; that is, they were more easily able to change and adapt their family system as the situation warranted. Given the many different and unexpected circumstances that may arise for a family with a chronically ill child, roles, rules, and control, may need to change. Other family members may need to take charge, reverse, or expand their roles within the family or plans may have to be altered due to a sudden setback in the ill child's condition. In a study with families of children with cerebral palsy, McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982) found that low conflict families or those families that functioned well, tended to be more adaptable and have less struggles with the ever-changing situations.

6.1 Hypothesis 2

Hypothesis 2 stated that for both the index and control families, the variables--(a) past experiences with crises; (b) coping strategies used; and (c) resources available and used--will predict their level of functioning. The results indicated that only one variable had any predictive power in each of the groups.

6.1.0 Index Group

For the index group, results revealed that the only variable found to have any predictive power on its level of family functioning was the total resources available to the family for management of stress. The fact that the index families did not differ significantly

from the control families in terms of family functioning may be related to their high resource score.

The finding that total resources may predict the level of family functioning in a family with a chronically ill child is supported by current literature regarding the necessity and importance of resources on adaptation and functioning. Peters (1984) found that the size of the social network and the helpfulness of that network were variables that positively influenced family functioning in families with a chronically ill member. According to Hobbs, Perrin, & Ireys (1985), family resources can be a most important context for promoting healthy family functioning. Many other researchers have postulated that social support and resources available to family members with handicapped, chronically ill, or disabled children have a major impact on family functioning (McCubbin, Cauble, & Patterson, 1982; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983). Social support has been noted to be a "buffering" agent from stressors that families may face (Gottlieb, 1981). In a study with families of handicapped children, intimate social support was found to be one of the best predictors of family adjustment (Friedrich, Wiltner, & Cohen, 1985).

As well as social and community supports, the family's personal and internal resources (i.e., financial and psychological abilities) are noted to have a positive influence on family functioning (McCubbin & Patterson, 1981). The index families in this study fell within the established norms for family strengths I and II [(esteem

and communication) and (mastery and health)] and closely resembled low conflict families with a chronically ill child in a study of family resources in low versus high conflict families undertaken by McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982). This does provide tentative support that family internal and personal resources do influence family functioning.

The results, indicating that the variables:

- (a) past experiences with crises;
- (b) coping strategy of maintaining social support, self-esteem, and psychological stability;
- (c) coping strategy of maintaining family integration, co-operation, and an optimistic definition of the situation; and
- (d) understanding the medical situation through communication with other parents and consultations with medical staff

did not predict the family functioning level of the index families, remain somewhat of a paradox with current literature. Much empirical research with families has demonstrated that these variables do, in fact, have an effect or are predictive of family functioning levels (Nevin, 1978; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1981; Holaday, 1972; and Waechter, 1987). The partial lack of support for Hypothesis 2 may be related to methodological issues, however. As discussed in the results and in the upcoming limitations section, the confidence placed in the small

sample size employed in this study is less than in a study using a much larger sample size. A possibility exists, that, contrary to available literature, these variables do not influence family functioning. This will be explored in the Implications for Future Research section. The most likely explanation, however, rests with the former possibility regarding methodological inadequacies of the study.

6.1.1 Control Group

Results revealed that only the variable (maintaining social support, self-esteem, and psychological stability) had predictive power on the control group's level of family functioning.

Certainly, literature supports the notion that the coping mechanism of maintaining social support, self-esteem, and psychological stability is one variable that positively influences family functioning. Pearlin & Schooler (1982) stated that it is what a person "is" that determines his/her ability to cope with day-to-day stressors. This included the person's psychological stability and personality (i.e., self-esteem). McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982) found in a study of families with children with cerebral palsy that the control group families had developed their psychological competence in order to deal with most hardships or stressors.

The evidence from the study that the two coping mechanisms-- (a) maintaining family integration, co-operation, and an optimistic

definition of the situation; and (b) understanding the medical situation through communication with other parents and consultation with medical staff--did not influence the control family's level of functioning may be explained by the fact that these two coping variables primarily influence families with an ill child. The former strategy is centered on behaviors directed at maintaining a positive outlook when a family member has an ill child. The latter strategy involves measurement of behaviors directed at understanding medical information needed to care for the chronically ill child. Burke (1987), in a study examining parental coping and competence in disabled and non-disabled children, indicated that the link between the coping mechanisms involving communication and consultation with medical professionals is present primarily in situations where there is a chronically ill child. She also indicated that there is some ambiguity whether this coping mechanism is beneficial to parents of children who are not ill (Burke, 1987). The questions in the survey were modified slightly for the control families (i.e., instead of a question about the illness involved, the question would be relevant to "when your child is ill"). This reworking of the questions, albeit necessary, may have influenced the answers received by the control families, as some children in the control families had never been ill at all.

Analysis of data indicated that the variable of past experiences with crises did not have any predictive power as to the control family's level of functioning. As the control families tended to have

scores on this dimension that fell within national norms, perhaps the variable was not significant enough to provide evidence of a relationship between the level of family functioning and the experiences with crises. This finding also presents a contradiction to the literature stating that a pile-up of stressors could influence family functioning (McCubbin, Sussman, & Patterson, 1983). Methodological issues may also explain this. Control families volunteering for this study may have had less change and stressful events in their lives than other families without a chronically ill child. More rigorous measurement techniques and a larger sample size is needed to confirm this.

The total resources for management of stress score also did not have any predictive power on the control group's level of functioning. This also contradicts current family stress theory. One of the scores within the Family Inventory of Resources for Management Scale involves that of social desirability. The control group tended to have a higher social desirability score, indicating the need to supply "socially appropriate" answers. The control families did exceed the mean obtained from McCubbin & Patterson (1981)-- ($\bar{x}=12$, $SD=1$). Correlational studies indicated a very slight positive correlation between the total resource management score and the social desirability score (Pearson $r=.37842$) (McCubbin & Patterson, 1981). Thus, the control families may not have given a totally accurate picture of their available resources.

One might also predict that because the education/occupation levels of the control group differed significantly from (were higher than) the index group, this would correlate positively with the total resource score, in turn influencing the family functioning level. The fact that the control group was in an advantageous situation over the index group would suggest that, if any confounding effect was to be observed, it should have been in the direction in favour of the control group. We should have expected to see the disadvantaged index group even more discrepant in its family functioning scores from the control group. The fact that there was no significant difference between the two groups is evidence that this confounding effect was negligible at best.

6.2 Hypothesis 3

Hypothesis 3 involved the exploration of the different family functioning levels of the index group only. The extreme functioning index families were hypothesized as having higher family life change scores, lower family resource scores, and higher parental coping scores than the mid-range and balanced functioning index families. Again, the results provided only partial support for this hypothesis.

6.2.0 Family Inventory of Life Events

Analysis of variance indicated a non-significant result, thereby providing support for the null hypothesis, that there was no difference between the extreme versus mid-range and balanced

groups in their family life event score. Although literature, such as McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson (1982), stated that extreme or high conflict families had higher family life event scores than low conflict families (mid-range and balanced), this study did not lend support to this postulation. There may be two plausible reasons for this. Firstly, the utilization of only the events occurring within the past 12 months as representative of family life changes may have underscored some families on this dimension. Research has supported that a pile-up of stressors does indeed affect how a family copes and adapts to stressors (McCubbin & Patterson, 1981; and Singer & Irvin, 1989). Therefore, all life event scores (those within the past 12 months and those past 12 months) should have been combined in order to furnish a more accurate picture of life changes in all categories of the index family.

Literature that cites evidence for the effect of past life events on family-functioning primarily has used one level of index or "problem" families (Nevin, 1978; and Cowen, Mok, Corey, MacMillan, Simmons, & Levison, 1986). Fragmenting the families (index) down into categories, as this study has done, may provide alternative information and theories.

6.2.1 Family Inventory of Resources for Management

The hypothesis, that extreme functioning index families would have lower family resource scores than the mid-range and balanced

index families, was not supported by the data obtained from this study.

Past research exploring the relationship between resources and family functioning demonstrated results contrary to this (George, 1980; Lin, Dean, & Ensel, 1981; Ross-Alaolmolki, 1985; and Aldous, Condon, Hill, Strauss, & Tallman, 1971). Methodological flaws in this study may have accounted for the non-significant findings. The volunteer aspect of this study may have attracted only the index families with a strong support system, therefore not providing a representative index group. Failure to support this hypothesis may have also been due to the small sample size. The extreme functioning index group consisted of five families, or 20% of the sample, while the mid-range and balanced groups contained the remaining 80% of the entire index sample. The number in the extreme functioning group, therefore, may simply be too small to obtain valid results.

Contrary to the literature, however, there is a very remote possibility that this null hypothesis is true; that is, there are no differences between the extreme, mid-range, and balanced functioning index families in terms of resources available and used for adaptation. This may be due to the fact that because all index families face the stress of coping with a chronically ill child, they constantly draw on the resources available to them. They might also have all been provided with some interventions designed to increase their resources by the Agencies that supplied the samples. This was

not directly assessed in this study. However, the former possibility seems more likely.

6.2.2 Parental Coping Scores

Hypothesis 3 was minimally supported in that extreme functioning index families had significantly higher scores than the mid-range and index families on the scale measuring the coping strategies of communicating with parents in the same situation and consulting with medical personnel. McCubbin & Patterson (1981) found that parents in high conflict families tended to use more coping patterns than did parents in low conflict families. While this may appear incongruent with some past research on stress and coping, this finding supports the theoretical framework of this study. As coping behaviors are developed in response to stressful situations, families in the extreme functioning category would be expected to record greater numbers of the coping behaviors as assessed by the Coping Health Inventory for Parents, since this indicates an active effort to deal with the increased amounts of perceived stress.

It is noted with significance, the coping behavior found to be higher in the extreme functioning family was that of communicating with other families in the same situation and consultation with medical personnel. As this score centered primarily around issues surrounding the ill child, the stress of the ill child was obviously of some importance to these families. These families had recorded a

higher number of behaviors involving the development of relationships with other parents with a chronically ill child, as well as the medical staff.

In a study with parents with a chronically ill child, Heffron, Brommelaere, & Masters (1973) reported that communication with other parents in the same situation appeared to be a prevalent form of coping. Other research indicated that consultation with medical staff and other professionals was frequently sought by parents with a chronically ill child (Rawlins & Horner, 2988; Tilden & Weinert, 1987; and Burckhardt, 1987).

6.3 Limitations of Study

There were several limitations to this study. Due to the descriptive nature of the study, no causal relationships could be inferred. Because medical treatments had already been in place by varied health professionals, it was impossible to attempt to measure whether these treatments had any effect on the level of family functioning. Wilson (1985) stated that these "ex post facto" designs study events or experiences after the fact (p. 243). Even though this design was able to provide meaningful information about the relationships between variables, it could not lend conclusive evidence for "non-spurious" relationships as experimental controls were lacking (Roberts & Burke, 1989). In spite of the obvious shortcomings of this design, it is often used in nursing research, due to the unethical and impractical manipulation of subjects.

A second limitation of this study pertained to the study sample. The size of the sample was considered to be small ($n=25$). This small sample size may have decreased the validity of the study. As this study employed non-probability purposive sampling, selection of a random sample from the total target population could have strengthened external validity. The number of chronically ill children in Manitoba was small, thus providing a very small target population from which to draw a volunteer sample. Manitoba currently has 105 children from 0-25 with cystic fibrosis (Cystic Fibrosis Association, 1989) and 125 people from 0-35 with cerebral palsy (Cerebral Palsy Association, 1989).

The index sample for this study represented approximately 11% of the total target group. It was difficult to assess how representative this sample was, as the statistics available for the individuals in Manitoba with these diseases are not available. Unless a family chose to belong to one of the associations, it was excluded from the target population. Currently no agency keeps track of the exact number of individuals in each illness category. One might question whether the families registering with the associations are better informed, and thus have higher family functioning levels. However, the results were only representative of this target population and could not be generalized to a larger population (i.e., chronically ill children in Canada). Although the sample size was small, the results did provide initial underpinnings with which to conduct further research.

An α of .05 was set for all tests within this thesis, inherently setting a Type II error probability, especially given the sample size of 25. Because many of the hypothesis were not supported, the question arises that perhaps the results were due to small sample size, therefore leading us to falsely failing to reject the null hypothesis. To have any sort of power, approximately five subjects were needed per cell for the chi-square analysis and between 10-25 subjects per group per variable for discriminant analysis. For the chi-square analysis, one cell had only one subject, therefore decreasing the power of that test. For discriminant analysis, five variables were used; thus, 50 subjects per group were needed for minimal generalizability.

The volunteer aspect of this study may have attracted only the families who demonstrated balanced family functioning. Volunteers tend to be better educated and better adjusted emotionally and socially than non-volunteers (Rosenthal & Rosnow, 1969). Therefore, the index families who volunteered may have been better adjusted than other families with a chronically ill child. Kovacs (1985) also noted that volunteer subjects could often be motivated by external or internal factors that could influence the overall findings.

The clarity and scope of the instruments used to measure selected variables may also have been a limitation. Many families were unsure of exactly how to fill out some of the questionnaires (especially CHIP). Although the researcher was present at the time in order to explain the exact process, this may have introduced a

social desirability factor into the results. Although affecting the return rate, using a mail-out questionnaire method may have modified the social desirability element.

The Family Adaptability and Cohesion Evaluation Scale (FACES III) was designed to measure exactly that; namely, adaptability and cohesion. One drawback to this scale was the lack of provision for measuring communication between family members. Although the authors purport that it is a third dimension within the scale that facilitates movement on the other two dimensions, direct empirical measurement of this dimension on the scale is lacking. Peters (1984) stated that communication may have a direct influence on family organization and functioning.

Due to the curvilinear nature of the Circumplex model, it was difficult to analyze the results of the FACES scores. The means obtained provided an approximate location on each dimension, but could not distinguish between extreme scores.

A further limitation may have been the lack of an interview to supplement the quantitative data. Although the presence of the interviewer can often introduce a risk to the internal validity, that risk may not have been exacerbated in this study as the researcher was already present during data collection. As well as supplementing data, an interview would have allowed exploration of feelings and perceptions regarding the child's illness, further collection of data from families with literacy problems, and clarification or elaboration on responses given (Wilson, 1985).

6.4 Summary

6.4.0 Future Implications for Research

That the presence of a chronically ill child places stress on the entire family was not entirely supported by this study. This study did, however, identify important directions for future research. Much more rigorous and empirical research needs to be undertaken in order to evaluate variables such as social support, stressors, coping, and family problem solving. Research needs to go beyond simply identifying and defining these variables to look at ways to buffer the negative effect of stressors on family life in order to enhance overall family functioning.

This study provided minimal support for the important role that social support, past stressors, coping mechanisms, and other resources play on the functioning of the family unit. Because of the multiple variables that can affect family functioning, stronger research paradigms need to be developed in order to obtain a clear picture of the influence of these variables. Longitudinal and qualitative studies may provide more information on the effects of these variables on the family over time.

Although this study measured the levels of family functioning on the dimensions of cohesion and adaptability, research needs to be undertaken on ways families can become more cohesive and adaptable. Interventions that may enhance family functioning

should be studied in empirical and perhaps experimental designs to assess the effects of those programs.

Research should also be focused on families that are not intact, such as single, divorced, or widowed families. High risk families such as teen-age parents or alcoholic families also need to be studied. Ways to mobilize and increase the strength of the family's social supports should be a further research goal.

As this study indicated, larger sample sizes are necessary in order to increase the confidence in the results. Employing an open-ended interview as well as standardized measurement tools may lead to the development of additional insights into the functioning of the family unit.

6.4.1 Future Implications for Education

Research on families with chronically ill children has indicated that education should be directed towards families, health professionals, school teachers, and the public itself.

Parents need to be educated about ways to enhance their family functioning. This may include the potential effects of stress and how it affects their family. It is essential to provide them with information regarding coping strategies for preventing adverse effects and fostering bonadaptation. They also need to be aware of resources available to their family in times of crises.

Part of the curriculum of school teachers and all multi-disciplinary health professionals should include components of

family stress theory. This includes ways to recognize families in distress and the means for assisting them to adapt with the varied stressors they may be facing.

A much more challenging task is to educate the public regarding the chronically ill. Attempts have been made in this direction (i.e., Muscular Dystrophy Telethon), but continued efforts are necessary in order for a change of attitude to take place.

6.4.2 Future Implications for Practice

All members of the health team need to be able to use tools such as those used in this study to obtain a baseline measurement of family's level of functioning prior to any interventions. The identification of parental coping behaviors, community resources, and social supports that might enhance family functioning can present health care services with an opportunity to provide more effective health care. Nurses, social workers, psychologists, and other professionals should utilize routine assessments as part of their interventions with families. This implies a more broadly based approach to family interventions than the traditional medical approach.

Although this study did not look at variables surrounding the functioning and coping efforts used by siblings in families with a chronically ill child, this certainly presents the health care practitioner with an added and most important dimension to consider when planning interventions.

At present, no programs exist to assess an individual's need for assistance in developing coping strategies. A logical step would be to develop and implement some form of intervention tool so that health care resources are made available to those who need them. Thus, the delivery of care would be structured to meet the needs of individuals who would benefit most.

The findings of this study indicated that communicating with other parents in the same situation and consultation with professionals played an important role in the functioning of families with disabled children. Self-help groups, now evolving for many situations, should be encouraged for families. As well, parental-professional ties should be nurtured and developed in order to provide on-going support. That the family will benefit from this relationship offers the most important advantage of all.

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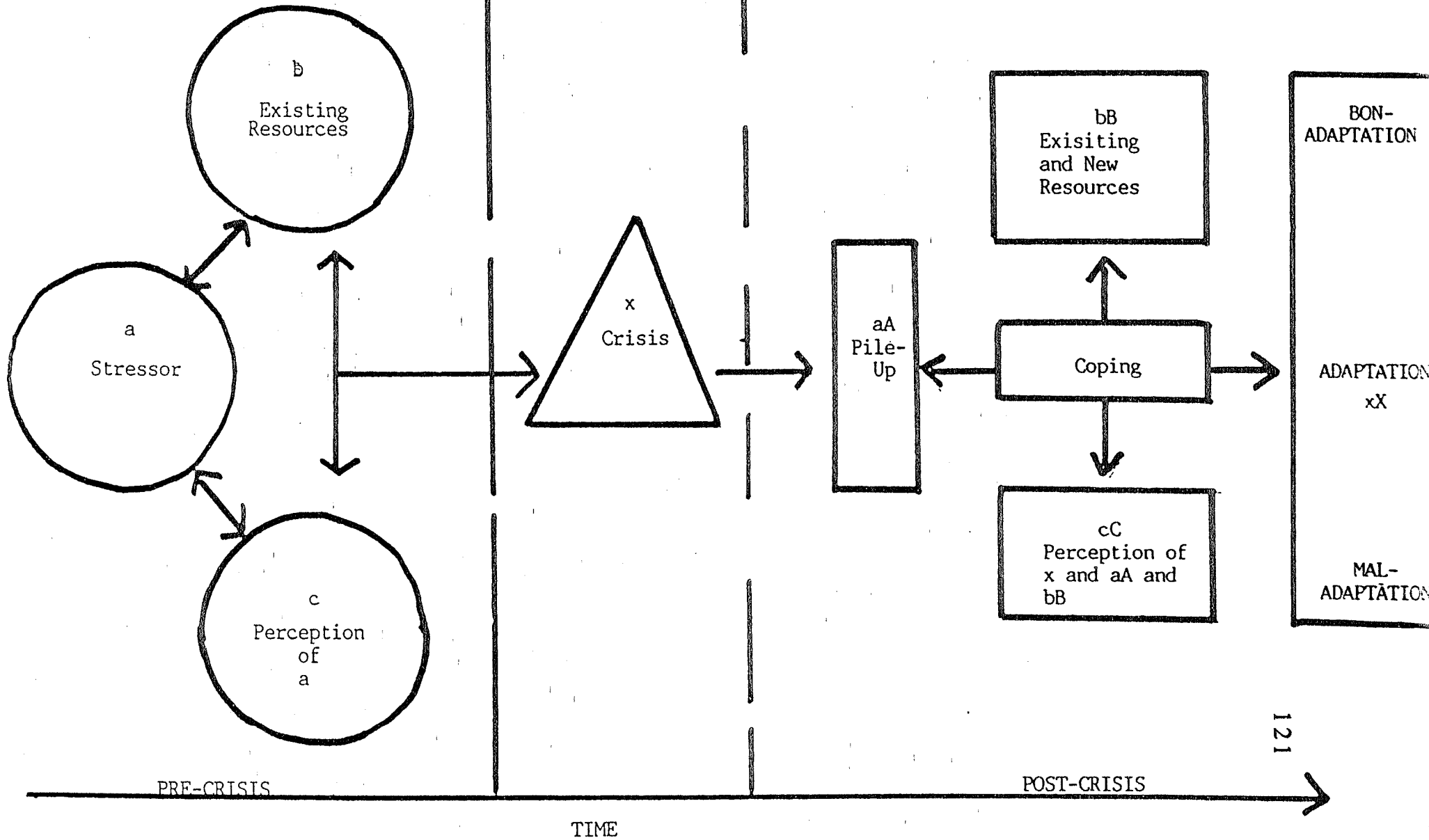
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Appendix A

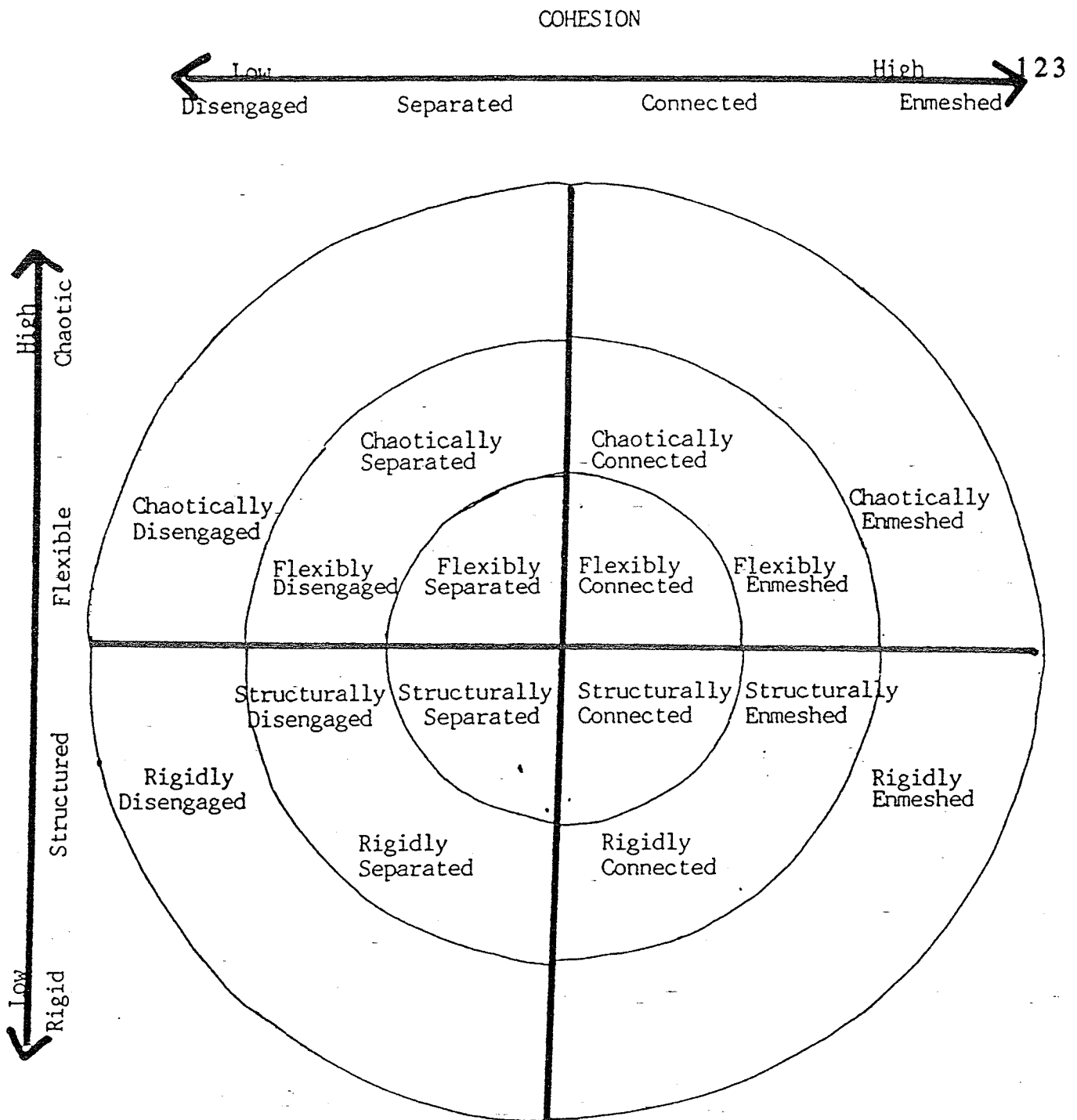
Double ABCX Model of Adaptation

Adapted from: McCubbin, H., Cauble, A.E. & Patterson, J.M. (1982). Family stress, coping and social support. Illinois: Charles C. Thomas Publishers pg. 46.



Appendix B

Circumplex Model of
Marital/Family Systems



Appendix B: Circumplex Model of Marital/Family Systems

Inner Circle - Balanced

Middle Circle - Mid-Range

Outer Circle - Extreme

Adapted From: McCubbin, H., Cauble, A.E. & Patterson, J.M. (1982). Family stress, coping and social support, Illinois: Charles C. Thomas Publishers, pg. 54.

Appendix C

Chronic Childhood Diseases

Appendix C
Cystic Fibrosis

Cystic Fibrosis causes almost all cases of pancreatic deficiency in infancy and a major portion of chronic, non-tuberculous, non-allergic pulmonary disease in childhood (ALS, 1975). The disease occurs in approximately 1:1600 to 1:2500 live births per year and is most common in Caucasians, rare in blacks, and essentially absent in Asiatics (ALS, 1975; Scipien, Barnard, Chard, Howe, & Phillips, 1979). Cystic Fibrosis is hereditary, being transmitted as a recessive trait (O'Neill, 1981). The onset of the disease can occur weeks, months, or years following birth. The disease is characterized by excessive production of a viscid substance by glands producing mucus. This substance, in turn, plugs up pancreatic ducts, liver ducts, and bronchioles in the lungs. When the pancreatic and liver ducts are obstructed, food cannot be metabolized properly as the enzymes produced by the liver and the pancreas are blocked. When the bronchioles within the lungs become obstructed, infections occur repeatedly causing scarring and fibrosis. The sweat glands also produce large amounts of salt, non-disease producing in itself (Pinney & Erickson, 1981; Travis, 1976).

The disease is diagnosed by chest x-ray, sputum analyses, sweat tests, analyses of stool, and examinations of duodenal contents (Lewiston, 1985). Methods of treatment are aimed at ameliorating the symptoms of cystic fibrosis and keeping the child as productive as possible. The treatment regime, involving massive enzyme

administration in order to digest food, antibiotics to prevent respiratory infections, diet modifications, and physical therapy for chest drainage, all require total commitment from the child, family, and health care practitioners. Approximately 50% of children with cystic fibrosis will survive to the age of 10 years, 30% may reach the age of 20 years, and 20% may live to be 30 years old (Scipien et al, 1979).

Cerebral Palsy

Cerebral Palsy, a disease of the neuromuscular system, primarily influences the child's ability to control voluntary muscle movement. Generally this condition is due to damage to some portion of the brain during the pre-natal period, the birth process, or from an infection during the post-natal period (Scipien et al, 1979). Scipien et al (1979) indicates that 1:1000 live births are afflicted with this condition yearly. Of the six out of seven children who survive this disease, retardation of varying degrees is usually the end result. The disease is also characterized by other abnormalities, such as inco-ordination of voluntary movements, paralysis, and weakness. Seizures, visual and auditory deficiencies, emotional disorders, and speech problems can also affect these children (Marlow, 1977).

No cure is currently available for children with cerebral palsy. Therefore, treatment is aimed at maximizing the child's potential for development. Speech therapy, motor skill training, and activities of

daily living training are the major rehabilitation efforts in order to maximize the child's independence and to prevent deterioration. As these children often have a less than adequate self-image, all treatment efforts by both parents and all health care practitioners should incorporate attempts to enhance the child's self-image.

Appendix D

Letter to Agencies

Dear Sir or Madam:

Allow me to introduce myself. My name is Connie Eccles. I am currently conducting a research study for my Masters' Degree in Nursing at the University of Manitoba. As a Nurse, I am very concerned and interested in the adaptation patterns of families with children with disabilities such as Cystic Fibrosis and Cerebral Palsey. Therefore, I am conducting a study in order to look at these patterns more closely.

To complete the study, families with children with either Cystic Fibrosis or Cerebral Palsey are needed. These families would be requested to fill out questionnaires which would then be compared to the results obtained from families with a healthy child. The questionnaires would take approximately 40 minutes to complete. The families would in no way be specifically identifiable, as all results will be reported as group data.

As I would like to obtain the sample of families with children with the above mentioned disabilities through Health Agencies, I would appreciate the opportunity to speak with you regarding a sample from your Agency. I will telephone you in the next few weeks to set up an appointment and would be very pleased to discuss the study in detail with you at that time.

Thank you very much for your time and consideration. I look forward to speaking with you.

Sincerely,

Connie M. Eccles, R.N., B.N.
M.N. Candidate

Appendix E

Letter to Index Families

Dear Sir or Madam:

Allow me to introduce myself. My name is Connie Eccles. As a Nurse, I have frequently been involved with families in which one of the members has been diagnosed with a disability such as Cystic Fibrosis. I am very concerned and interested in factors which may influence these families' adaptation to the disability.

With the support of the School System, several Health Agencies within the city and the University of Manitoba, I am currently conducting a research study for my Masters' Degree in Nursing. The study is being supervised by Dr. Theresa George, School of Nursing, University of Manitoba. The study will examine the adaptation patterns of families with a child with a disability and families with a healthy child. As one of either group, you can provide valuable information for Health Care Practitioners to utilize when working with families with a child with a disability.

I will telephone you within the next few weeks to determine your eligibility and willingness to participate and also to provide you with more information regarding the study. If you decide to participate, you will simply be asked to fill out 5 forms, which will take approximately 40 minutes of your time. There are no risks or inconveniences if you participate, other than the 40 minutes of time spent. All information will be strictly confidential, with no names being listed anywhere on the survey answer sheets. The answers will be coded, with the access to coded information limited only to the investigator and the advisor. Your family will in no way be specifically identifiable, as all data are reported as group results. Please consider this matter, as the more families that participate, the more accurate the results will be. Thank-you for your time and consideration.

Sincerely,

Connie M. Eccles, R.N., B.N.
M.N. Candidate

Appendix F
Participation Form

Yes, I agree to participate in your study. Please contact me with further details.

Name _____

Phone Number _____

Best Time to Phone _____

Yes, I agree to participate in your study. Please contact me with further details.

Name _____

Phone Number _____

Best Time to Phone _____

Appendix G

Letter to Superintendent/Principal

Dear Superintendent/Principal;

Allow me to introduce myself. My name is Connie Eccles. I am currently completing a research study for my Masters' Degree in Nursing at the University of Manitoba. As a Nurse, I am very concerned and interested in the adaptation patterns of families with children with disabilities such as Cystic Fibrosis and Cerebral Palsey. Therefore, I am conducting a study in order to look at these patterns more closely.

To complete this study, families with healthy children are needed with which to compare the families with children with disabilities to. The families with healthy children would be requested to fill out five forms, which would take approximately 40 minutes and then return them by mail. As I would like to obtain these families through the Public School System, I would appreciate the opportunity to speak with you regarding a sample from one High School and one Elementary School within your division. The study proposal has been approved by the Ethical Review Committee at the University of Manitoba. I have enclosed a copy of that approval. I will telephone you within the next week and will be very pleased to discuss the study in detail with you at that time.

Thank you very much for your time and consideration. I look forward to speaking with you.

Sincerely,

Connie M. Eccles, R.N.B.N.
M.N. Candidate

Appendix H

Letter to Control Families

Dear Sir or Madam:

Allow me to introduce myself. My name is Connie Eccles. As a Nurse, I have frequently been involved with families in which one of the members has been diagnosed with a disability such as Cystic Fibrosis. I am very concerned and interested in factors which may influence these families' adaptation to the disability.

With the support of the School System, several Health Agencies within the city and the University of Manitoba, I am currently conducting a research study for my Masters' Degree in Nursing. The study is being supervised by Dr. Theresa George, School of Nursing, University of Manitoba. The study will examine the adaptation patterns of families with a child with a disability and families with a healthy child. As one of either group, you can provide valuable information for Health Care Practitioners to utilize when working with families with a child with a disability.

I will telephone you within the next few weeks to determine your eligibility and willingness to participate and also to provide you with more information regarding the study. If you decide to participate, you will simply be asked to fill out 5 forms, which will take approximately 40 minutes of your time. There are no risks or inconveniences if you participate, other than the 40 minutes of time spent. All information will be strictly confidential, with no names being listed anywhere on the survey answer sheets. The answers will be coded, with the access to coded information limited only to the investigator and the advisor. Your family will in no way be specifically identifiable, as all data are reported as group results. Please consider this matter, as the more families that participate, the more accurate the results will be. Thank-you for your time and consideration.

Sincerely,

Connie M. Eccles, R.N., B.N.
M.N. Candidate

Appendix I

Follow-up Telephone Call to Index Families

Appendix IOutline of Telephone Call to Index Group

May I please speak to Mr. or Mrs. _____?

_____, my name is Connie Eccles. I mailed you a letter a few weeks ago in order to enlist your participation in a research study I am conducting. Do you remember? Good. I received your participation form and am calling to confirm your willingness to participate and also to provide you with further information about the study.

I am interested in studying the adaptation patterns of families with children with disabilities, such as cystic fibrosis and cerebral palsy. I would like to compare these families to families without a child with a disability. Your part in the study would consist of filling out questionnaires which would take approximately 40 minutes of your time. The questionnaires will more accurately represent the family if they are filled out by both you and your spouse. All of the information will be kept strictly confidential. Your family will in no way be specifically identifiable, as all the results are reported as group data.

In order to complete these forms, I would like to visit you at your convenience in order to answer any questions you may have while filling out the questionnaires. Before we set up a time for the visit, I would just like to ensure that you fit into the criteria from which I am selecting my sample. If you are married, reside in Winnipeg, and have a child with a disability, such as cystic fibrosis,

or cerebral palsy, between the ages of 1 and 16, you are eligible to participate. Do you fit these criteria? Good. What time would be convenient for you and your spouse? Thank you very much for your time. I will give you my telephone number in case you have any questions. Please feel free to contact me at any time.

Appendix J

Follow-up Telephone Call to Control Families

Appendix J

Outline of Telephone Call to Control Families

May I please speak to Mr. or Mrs. _____?

_____, my name is Connie Eccles. I mailed you a letter a few weeks ago in order to enlist your participation in a research study I am conducting. Do you remember? Good. I am calling to see if you are willing to participate and also to provide you with further information about the study.

I am interested in studying the adaptation patterns of families with children with a disability, such as cystic fibrosis or cerebral palsy. I would like to compare these families to families with a child without a disability. Your part in the study would consist of filling out questionnaires which would take approximately 40 minutes of your time. The questionnaires will more accurately represent the family if they are filled out by both you and your spouse. All of the information will be kept strictly confidential. Your family will in no way be specifically identifiable, as all the results are reported as group data. Would you and _____ be interested in participating in the study?

In order to complete these forms, I would like to visit you at your convenience in order to answer any questions you may have while filling out the questionnaires. Before we set up a time for the visit, I would just like to ensure you fit into the criteria from which I am selecting my sample. If you are married, reside in Winnipeg, and have children without any disabilities, one of which is being between

the ages of 1 and 16, you are eligible to participate. Do you fit these criteria? Good. What time would be convenient for you and your spouse? Thank you very much for your time. I will give you my telephone number in case you have any questions. Please feel free to contact me at any time.

Appendix K

Demographic Information Sheet for Index Families

DEMOGRAPHIC DATA (I)

Area of City residing in: _____

Highest Level of Education Obtained (Mother)	Grade 8 or less	_____
	Grade 9-12	_____
	University Degree	_____
	College Certificate	_____
	Other	_____

Highest Level of Education Obtained (Father)	Grade 8 or less	_____
	Grade 9-12	_____
	University Degree	_____
	College Certificate	_____
	Other	_____

Occupation of Mother _____

Occupation of Father _____

Combined Annual Salary of Both Parents	Under \$15,000	_____
	\$15,001-\$30,000	_____
	\$30,001-\$60,000	_____
	Over \$60,000	_____

Age of Ill Child _____

Type of Illness Child Has _____

Number of Other Children in family _____

Number of Children residing at home _____

Ages of other children in family residing at home _____

Appendix L

Demographic Information Sheet for Control Families

DEMOGRAPHIC DATA (C)

Area of City Residing In: _____

Highest Level of Education Obtained (Mother) Grade 8 or less _____
Grade 9-12 _____
University Degree _____
College Certificate _____
Other _____

Highest Level of Education Obtained (Father) Grade 8 or less _____
Grade 9-12 _____
University Degree _____
College Certificate _____
Other _____

Occupation of Mother _____

Occupation of Father _____

Combined Annual Salary of Both Parents Under \$15,000 _____
\$15,001-\$30,000 _____
\$30,001-\$60,000 _____
Over \$60,000 _____

Number of Children in family _____

Number of Children residing at home _____

Ages of Children at home _____

Appendix M

FACES III

FACES III

David H. Olson, Joyce Portner, and Yoav Lavee 149

1	2	3	4	5
ALMOST NEVER	ONCE IN AWHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR FAMILY NOW:

- ___ 1. Family members ask each other for help.
- ___ 2. In solving problems, the children's suggestions are followed.
- ___ 3. We approve of each other's friends.
- ___ 4. Children have a say in their discipline.
- ___ 5. We like to do things with just our immediate family.
- ___ 6. Different persons act as leaders in our family.
- ___ 7. Family members feel closer to other family members than to people outside the family.
- ___ 8. Our family changes its way of handling tasks.
- ___ 9. Family members like to spend free time with each other.
- ___ 10. Parent(s) and children discuss punishment together.
- ___ 11. Family members feel very close to each other.
- ___ 12. The children make the decisions in our family.
- ___ 13. When our family gets together for activities, everybody is present.
- ___ 14. Rules change in our family.
- ___ 15. We can easily think of things to do together as a family.
- ___ 16. We shift household responsibilities from person to person.
- ___ 17. Family members consult other family members on their decisions.
- ___ 18. It is hard to identify the leader(s) in our family.
- ___ 19. Family togetherness is very important.
- ___ 20. It is hard to tell who does which household chores.



FACES III: Ideal Version
David H. Olson, Joyce Portner, and Yoav Lavee 150

1	2	3	4	5
ALMOST NEVER	ONCE IN AWHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

IDEALLY, how would you like YOUR FAMILY TO BE:

- ___ 21. Family members would ask each other for help.
- ___ 22. In solving problems, the children's suggestions would be followed.
- ___ 23. We would approve of each other's friends.
- ___ 24. The children would have a say in their discipline.
- ___ 25. We would like to do things with just our immediate family.
- ___ 26. Different persons would act as leaders in our family.
- ___ 27. Family members would feel closer to each other than to people outside the family.
- ___ 28. Our family would change its way of handling tasks.
- ___ 29. Family members would like to spend free time with each other.
- ___ 30. Parent(s) and children would discuss punishment together.
- ___ 31. Family members would feel very close to each other.
- ___ 32. Children would make the decisions in our family.
- ___ 33. When our family got together, everybody would be present.
- ___ 34. Rules would change in our family.
- ___ 35. We could easily think of things to do together as a family.
- ___ 36. We would shift household responsibilities from person to person.
- ___ 37. Family members would consult each other on their decisions.
- ___ 38. We would know who the leader(s) was in our family.
- ___ 39. Family togetherness would be very important.
- ___ 40. We could tell who does which household chores.



Appendix N

FILE



FILE

Family Inventory of Life Events and Changes

IID	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GID	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FID	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hamilton I. McCubbin

Joan M. Patterson

Lance R. Wilson

PURPOSE

Over their life cycle, all families experience many changes as a result of normal growth and development of members and due to external circumstances. The following list of family life changes can happen in a family at any time. Because family members are connected to each other in some way, a life change for any one member affects all the other persons in the family to some degree.

"FAMILY" means a group of two or more persons living together who are related by blood, marriage or adoption. This includes persons who live with you *and* to whom you have a long term commitment.

DIRECTIONS

"DID THE CHANGE HAPPEN IN YOUR FAMILY?"

Please read each family life change and decide whether it happened to any member of your family—including you.

- DURING THE LAST YEAR

First, decide if it happened any time during the last 12 months and check YES or NO.

During Last 12 Months	
Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

- BEFORE LAST YEAR

Second, for *some family changes* decide if it happened any time before the last 12 months and check YES or NO. It is okay to check YES twice if it happened both times—before last year and during the past year.

Before Last 12 Months	
Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

FAMILY LIFE CHANGES	DID THE CHANGE HAPPEN IN YOUR FAMILY?				FAMILY LIFE CHANGES	DID THE CHANGE HAPPEN IN YOUR FAMILY?			
	During Last 12 Months		Before Last 12 Months			During Last 12 Months		Before Last 12 Months	
	Yes	No	Yes	No		Yes	No	Yes	No
EXTRA-FAMILY STRAINS					12. Increased difficulty in managing infant(s) (0-1 yr.)	<input type="checkbox"/>	<input type="checkbox"/>		
Increase of husband/father's time away from family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Increase in the amount of "outside activities" which the child(ren) are involved in	<input type="checkbox"/>	<input type="checkbox"/>		
Increase of wife/mother's time away from family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. Increased disagreement about a member's friends or activities	<input type="checkbox"/>	<input type="checkbox"/>		
A member appears to have emotional problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. Increase in the number of problems or issues which don't get resolved	<input type="checkbox"/>	<input type="checkbox"/>		
A member appears to depend on alcohol or drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	16. Increase in the number of tasks or chores which don't get done	<input type="checkbox"/>	<input type="checkbox"/>		
Increase in conflict between husband and wife	<input type="checkbox"/>	<input type="checkbox"/>			17. Increased conflict with in-laws or relatives	<input type="checkbox"/>	<input type="checkbox"/>		
Increase in arguments between parent(s) and child(ren)	<input type="checkbox"/>	<input type="checkbox"/>			II. MARITAL STRAINS				
Increase in conflict among children in the family	<input type="checkbox"/>	<input type="checkbox"/>			18. Spouse/parent was separated or divorced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased difficulty in managing teenage child(ren)	<input type="checkbox"/>	<input type="checkbox"/>			19. Spouse/parent has an "affair"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased difficulty in managing school age child(ren) (6-12 yrs.)	<input type="checkbox"/>	<input type="checkbox"/>			20. Increased difficulty in resolving issues with a "former" or separated spouse	<input type="checkbox"/>	<input type="checkbox"/>		
Increased difficulty in managing preschool age child(ren) (2½-6 yrs.)	<input type="checkbox"/>	<input type="checkbox"/>			21. Increased difficulty with sexual relationship between husband and wife	<input type="checkbox"/>	<input type="checkbox"/>		
Increased difficulty in managing toddler(s) (1-2½ yrs.)	<input type="checkbox"/>	<input type="checkbox"/>							

FAMILY LIFE CHANGES	DID THE CHANGE HAPPEN IN YOUR FAMILY?				FAMILY LIFE CHANGES	DID THE CHANGE HAPPEN IN YOUR FAMILY?			
	During Last 12 Months		Before Last 12 Months			During Last 12 Months		Before Last 12 Months	
	Yes	No	Yes	No		Yes	No	Yes	No
III. PREGNANCY AND CHILDBEARING STRAINS					VI. ILLNESS AND FAMILY "CARE" STRAINS				
22. Spouse had unwanted or difficult pregnancy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	48. Parent/spouse became seriously ill or injured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. An unmarried member became pregnant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	49. Child became seriously ill or injured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. A member had an abortion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	50. Close relative or friend of the family became seriously ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. A member gave birth to or adopted a child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	51. A member became physically disabled or chronically ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IV. FINANCE AND BUSINESS STRAINS					52. Increased difficulty in managing a chronically ill or disabled member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Took out a loan or refinanced a loan to cover increased expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	53. Member or close relative was committed to an institution or nursing home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Went on welfare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	54. Increased responsibility to provide direct care or financial help to husband's and/or wife's parent(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Change in conditions (economic, political, weather) which hurts the family business	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	55. Experienced difficulty in arranging for satisfactory child care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Change in Agriculture Market, Stock Market, or Land Values which hurts family investments and/or income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	VII. LOSSES				
30. A member started a new business	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	56. A parent/spouse died	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Purchased or built a home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	57. A child member died	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. A member purchased a car or other major item	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	58. Death of husband's or wife's parent or close relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Increasing financial debts due to over-use of credit cards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	59. Close friend of the family died	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Increased strain on family "money" for medical/dental expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	60. Married son or daughter was separated or divorced	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Increased strain on family "money" for food, clothing, energy, home care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	61. A member "broke up" a relationship with a close friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Increased strain on family "money" for child(ren)'s education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	VIII. TRANSITIONS "IN AND OUT"				
37. Delay in receiving child support or alimony payments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	62. A member was married	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V. WORK-FAMILY TRANSITIONS AND STRAINS					63. Young adult member left home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. A member changed to a new job/career	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	64. A young adult member began college (or post high school training)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. A member lost or quit a job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	65. A member moved back home or a new person moved into the household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. A member retired from work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	66. A parent/spouse started school (or training program) after being away from school for a long time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. A member started or returned to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	IX. FAMILY LEGAL VIOLATIONS				
42. A member stopped working for extended period (e.g., laid off, leave of absence, strike)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	67. A member went to jail or juvenile detention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Decrease in satisfaction with job/career	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	68. A member was picked up by police or arrested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. A member had increased difficulty with people at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	69. Physical or sexual abuse or violence in the home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. A member was promoted at work or given more responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	70. A member ran away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Family moved to a new home/apartment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	71. A member dropped out of school or was suspended from school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. A child/adolescent member changed to a new school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>					

Appendix O

FIRM



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:

- ① = *Not At All* — This statement does not describe our family situation. This does not happen in our family.
- ② = *Minimally* — This statement describes our family situation only slightly. Our family may be like this once in a while.
- ③ = *Moderately* — This statement describes our family situation fairly well. Our family is like this some of the time.
- ④ = *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

Describes Our Family:

FAMILY STATEMENTS

Not at all
Minimally
Moderately
Very Well

For Computer Use
SFS RS SD

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

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	15	17
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	27	29

SFS RS SD

FAMILY STATEMENTS

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

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	21	23
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	33	35

Appendix P

CHIP



COPING-HEALTH INVENTORY FOR PARENTS

Family Health Program

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

PURPOSE

CHIP – The Coping-Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which call for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.

HOW HELPFUL was this COPING BEHAVIOR to you and/or your family: Circle ONE number

- 3 = *Extremely* Helpful
- 2 = *Moderately* Helpful
- 1 = *Minimally* Helpful
- 0 = *Not* Helpful

- For each Coping Behavior you did *Not* use please record your "Reason."

Please **RECORD** this by Checking one of the reasons:

Chose not to use it Not Possible

 or

PLEASE BEGIN: Please read and record your decision for EACH and EVERY Coping Behavior listed below.

COMPUTER CODES: IID GID FAMID

COPIING BEHAVIORS

	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I Do Not Cope This Way Because:	Chose Not To	Not Possible
. Trying to maintain family stability.							
Engaging in relationships and friendships which help me to feel important and appreciated.							
. Trusting my spouse (or former spouse) to help support me and my child(ren).							
. Sleeping							
. Talking with the Medical staff (Nurses, Social Worker, etc) when we visit the Medical Centre.							
. Believing that my child(ren) will get better. ×							
. Working, Outside Employment.							
Showing that I am strong.							
Purchasing gifts for myself and/or other family members.							
Talking with other individuals/parents in my same situation.							
Taking good care of all the medical equipment at home.							
Eating							
Getting other members of the family to help with chores and tasks at home.							
Getting away by myself							
Talking with the Doctor about my concerns about my child(ren) with the Medical condition.							
Believing that the Medical Centre/Hospital has my family's best interest in mind.							

COPING BEHAVIORS

	Extremely Helpful	Generally Helpful	Somewhat Helpful	Not Helpful	I Do Not Choose This Way Because:	
					More	Less
17. Building close relationships with people.						
18. Believing in God.						
19. Develop myself as a person.						
20. Talking with other parents in the same type of situation and learning about their experiences.						
21. Doing things together as a family (involving all members of the family).						
22. Investing time and energy in my job.						
23. Believing that my child is getting the best medical care possible.						
24. Entertaining friends in our home.						
25. Reading about how other persons in my situation handle things.						
26. Doing things with family relatives.						
27. Becoming more self reliant and independent.						
28. Telling myself that I have many things I should be thankful for.						
29. Concentrating on hobbies (art, music, jogging, etc).						
30. Explaining our family situation to friends and neighbors so they will understand us.						
31. Encouraging child(ren) with medical condition to be more independent.						
32. Keeping myself in shape and well groomed.						

COPING BEHAVIORS

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	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I Do Not Choose This Way Because:	
					Chose Not To	Not Possible
3. Involvement in social activities.(parties, etc) with friends.						
4. Going out with my spouse on a regular basis.						
5. Being sure prescribed medical treatments for child(ren) are carried out at home on a regular basis.						
6. Building a closer relationship with my spouse.						
7. Allowing myself to get angry.						
8. Investing myself in my child(ren).						
9. Talking to someone (not professional counselor/doctor) about how I feel.						
0. Reading more about the medical problem which concerns me.						
1. Talking over personal feelings and concerns with spouse.						
2. Being able to get away from the home care tasks and responsibilities for some relief.						
3. Having my child with the medical condition seen at the clinic/hospital on a regular basis.						
4. Believing that things will always work out.						
5. Doing things with my children.						

Appendix Q
Consent Forms

CONSENT (INDEX)

164

I understand that the major purpose of this study is to look at the adaptation patterns in families with a child with a disability and in families with a healthy child. I was informed by Connie Eccles, a graduate student of the School of Nursing, University of Manitoba that she is conducting the study and, that Dr. Theresa George, School of Nursing, University of Manitoba is her supervisor.

I understand that my family's name was recommended by either the Children's Centre of Winnipeg or the Society for Manitobans with Disabilities. I have agreed to fill out 5 forms, taking approximately 40 minutes of my time. I understand that there are no risks or inconveniences other than giving up 40 minutes of my time. We, as a family will not derive any direct benefits from the study, but can provide valuable information for Health Care Practitioners to utilize when assisting families with a child with a disability to cope.

I understand that my signature on this consent indicates my voluntary participation. I also realize there is no obligation to participate and that I may withdraw at any time or refuse to answer any or part of questions without penalty. All individual results will be seen by the investigator and her advisor only and any information reported will in no way identify my family specifically, as all results will be reported as group data. I understand my family's name will not appear anywhere on the answer sheet and that the answer sheet will be coded with access limited to the investigator and her advisor only. I have been assured that any publications arising out of this study will in no way identify my family. I will be provided with a copy

of this consent and I understand if I would like a copy of the results, I may do so. I also may contact the investigator at any time if I have any questions or concerns.

Signature of Wife _____

Signature of Husband _____

Date _____

Signature of Investigator _____

Home 269-4616

Office 667-0795

Date _____

CONSENT (CONTROL)

I understand that the major purpose of this study is to look at the adaptation patterns in families with a child with a disability and in families with a healthy child. I was informed by Connie Eccles, a graduate student of the School of Nursing, University of Manitoba that she is conducting the study and, that Dr. Theresa George, School of Nursing, University of Manitoba is her advisor.

I understand that my family's name was chosen randomly from the student rosters within the Public School System. I have agreed to fill out five forms, taking approximately 40 minutes of my time. We, as a family will not derive any direct benefits from the study, but can provide valuable information for Health Care Practitioners to utilize when assisting families with a child with a disability to cope.

I understand that my signature on this consent indicates my voluntary participation. I also realize there is no obligation to participate and that I may withdraw at any time or refuse to answer any or part of questions without penalty. All individual results will be seen by the investigator and her advisor only and any information reported will in no way identify my family specifically, as all results will be reported as group data. I understand my family's name will not appear anywhere on the answer sheet and that the answer sheet will be coded with access limited to the investigator and her advisor only. I have been assured that any publications arising out of this study will in no way identify my family. I will be provided with a copy

of this consent and I understand if I would like a copy of the results, I may do so. I also may contact the investigator at any time if I have any questions or concerns.

Signature of Wife _____

Signature of Husband _____

Date _____

Signature of Investigator _____

Home 269-4616

Office 667-0795

Date _____

Appendix R

Critical Path

Appendix RCritical Path for Data Collection

Index Group	Control Group
Letter to Agencies	Letter to Superintendents
Telephone call to Agency	Telephone call to Superintendent
Sent study proposal for Agency perusal	Sent study proposal for School Board perusal
	Contacted Principal of identified schools
Sent packages to Agencies (letter, participation form, and self-addressed envelopes)	Sent packages to Principals (letter, participation form, and self-addressed envelopes)
Agency sent out packages to identified families	Principal sent out packages to identified families
Telephoned families re: appropriate time to visit with forms	Telephoned families re: appropriate time to visit with forms
Visited families with forms	Visited families with forms
Mailed thank-you letters	Mailed thank-you letters
Analyzed data	Analyzed data
Mailed results to Agencies and families	Mailed results to Principals and families