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UNIVERSITY OF ALBERTA

PARENTAL ADAPTATION TO THERAPEUTIC INTERVENTION ON CHILDREN WITH CONGENITAL HEART DEFECTS

BY

BARBARA ROSEN-HARRIS

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN

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THE UNDERSIGNED CERTIFY THEY HAVE READ, AND RECOMMEND TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH FOR ACCEPTANCE, A THESIS ENTITLED PARENTAL ADAPTATION TO THERAPEUTIC INTERVENTION ON CHILDREN WITH CONGENITAL HEART DEFECTS. SUBMITTED BY BARBARA ROSEN-HARRIS IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN COUNSELLING PSYCHOLOGY

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Marvin Westwood

DATE:

DEDICATION

This Dissertation is dedicated to my father,
Dr. Harold Rosen,
from whom I learned the true meaning of
persistence and determination

Abstract

The purpose of this study was to examine adaptation in parents of children with a congenital heart defect (CHD) and to compare these parents with parents of children investigated for CHD and diagnosed with a benign heart murmur. The study was based on the theories of family crisis and family adaptation. The study examined five factors derived from the T-Double ABCX Model of Adjustment and Adaptation advanced by McCubbin & McCubbin (1987). It was hypothesized that parents whose children experienced interventions for CHD would report a) more difficulty with adaptation, b) perceive their child's illness to be more severe, c) and perceive their child's illness as more serious than the actual medical classification of seriousness. It was also hypothesized that parents who report more concerns regarding their ill child and who experience more negative feelings will have more difficulty with adaptation; and parents who perceive their family as having a high degree of hardiness, use more coping resources and skills,and report satisfaction with their own coping ability will have less difficulty with family adaptation.

The subjects, fifty-eight primary parents, completed an Information Questionnaire, a Perception of Severity of Illness Rating Scale, Hymovich's Parent Perception Inventory - Concerns, Spouse Concerns, Beliefs and Feelings, Coping, and Spouse Coping Scales, Family Hardiness Index, and Family Crisis Oriented Personal Evaluation Scales. Adaptation was measured by the Family Assessment Measure III.

The findings supported the hypotheses relating to parental perception of severity of illness being greater in the intervention groups and the intervention groups perceiving the seriousness of illness as greater than the medical classification of seriousness. Three medical descriptive variables, number of diagnostic catheterizations, number of interventional catheterizations, and number of parental concerns were found to be predictive of perception of severity of illness. Family adaptation being more difficult for the parents of children with CHD was not supported. Family hardiness was found to be predictive of family adaptation.

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CHAPTER I

Introduction

The Problem and Its Significance

This study is concerned with the impact of congenital heart disease on a family, and in particular the parental ability to adapt to therapeutic medical intervention for their child diagnosed with a congenital heart defect.

The American Heart Association (1981) estimates for incidence of congenital heart defects is six out of every one thousand live births which accounts for 30% of all congenital abnormalities (Jordan & Scott, 1981; Moller, Neal, & Hoffman, 1988). 3,500 infants are born in Canada each year with Congenital Heart disease (Moller, et al, 1988). A defect may range from being so mild that the individual is not ever aware of it, to being extremely severe, requiring immediate postnatal intervention.

The specific etiology of heart defects is undetermined. In fact in 90 percent of cases the cause is unknown. Current opinion indicates that cardiovascular malformations result from a complex interaction among various genetic and environmental factors. Classification is difficult since there are at least one hundred forms or variations. It is also possible for more than one form to exist in the same child, and each type may produce different symptoms. Too often, parents will blame themselves or each other, constantly re-examining family history or specific incidents during the pregnancy. This tends to establish a cycle of guilt and resentment which in turn can interfere with coping abilities.

Serious heart defects in an infant are usually discovered either in utero via ultra-sound examination of the fetus, at birth, or within six weeks of birth. Most heart defects are amenable to intervention, if not soon after birth, then within the first few months or years of life. Although surgery is the primary interventional technique, the continuing development and perfection of therapeutic catheterization procedures is quickly gaining ground (Fellows, 1984; Schlant, 1986). Linde (1982) remarked on the improved clinical methods of diagnosis, advances in catheterization techniques and echocardiography which have served to alter the natural history of heart disease.

Both catheterization and surgical procedures invoke both hope and fear for parents - hope that the procedure will indeed be a successful correction of the defect, and fear of receiving a negative or uncertain prognosis. Today, more than ever before,interventions are performed on patients with congenital heart defects with very promising results. For example, balloon septostomy, a catheterization procedure, has increased the survival of infants with Transposition of the Great Arteries from 20% before 1964 to

85% more recently (Fellows,1984). This increase in the perfection and use of interventional techniques inevitably has an impact on the families of congenital heart patients, an impact which can conceivably leave the family in a state of emotional limbo for an extended period of time. The emotional state can depend on procedural outcome and future prognosis regarding further interventions, as well as the possibility and degree of chronic difficulties.

When the catheterization is utilized for diagnostic information, the procedure is not routine for the young patient or the family. Although necessary, the procedure is invasive, of immediate benefit only to the physicians, and the initial trauma is both physical and emotional, prior to possible further invasive intervention (Kitchen,1978). Whether the child will undergo a catheterization procedure or surgery as an intervention, the traumatic experience is similar with regard to the steps involved once admitted to hospital (or transferred to pediatric cardiology from another unit, eg. postnatal nursery). Previous studies (Glaser, Harrison, & Lynn, 1964; Barnes, 1969; Oestreich, 1969; Garson, Benson, Suler, & Patton, 1978) have documented the extreme stressfulness of cardiac disease and concomitant hospitalization and surgery in children, to the point that it can affect the parent-child relationship. Furgal (1981) interviewed parents of pediatric cardiology patients about to undergo an invasive procedure and found that the stresses which the parents found either overwhelming or threatening included, after the first mention of a possible cardiac defect: the surgery and time spent waiting to hear the outcome, the cardiac catheterization (both diagnostic and interventional), the large number of adjustments to be made in a short period of time, both child and parents being unsure of their role in the hospital setting, parental feelings of inadequacy, and the constant fear that the child will die.

Purpose

The purpose of the study was to investigate parental adapatation ability to a therapeutic intervention for their child with congenital heart disease. A secondary purpose is to determine if and why some families adapt well while others become dysfunctional when faced with such intense stress. The theoretical framework which served as a basis for the study involves family crisis theory and the family adaptation model initiated by Hill (1949,1958) as the ABCX Model of Adjustment, and explored further by others (among them, Burr, 1973; Cohen & Lazarus, 1979; Hansen & Johnson, 1979; Holroyd, 1974; and Lazarus, 1981). This theory was expanded upon by McCubbin and his colleagues (1981, 1982, 1983, 1987) into the Double ABCX Model of Adjustment and Adaptation and subsequently into the T-Double ABCX Model which included the variable of family typology.

The T-Double ABCX Model of Family Adjustment and Adaptation

McCubbin and his associates (see McCubbin & McCubbin, 1987) further expanded their Double ABCX Model of Family Adaptation to include family typology and separated the model into two phases, adjustment and adaptation. "The T-Double ABCX framework focuses on the family's efforts to manage the demands it faces (from stressors and strains) with its capability for meeting demands (resources and coping), mediated by the family's appraisal (situational and schema) so as to achieve a balance in family functioning (called adjustment and adaptation)" (p.68). The two distinct phases are separated by a period of family crisis when the family's equilibrium is at risk. The first stage of the model, adjustment, is the pre-crisis stage and focuses on those family "types, strengths, and capabilities" which explain why some families are better able than others to adjust to minor stresses (changes, demands, or normative or nonnormative transitions) which do not involve major modifications in the manner in which a family operates. When a crisis occurs in the family (i.e. a situation which is a result of a demand-capability imbalance), the theoretical framework of the T-Double ABCX model explains what family "types, strengths, and capabilities" are required to cope with this major transition or change which demands reorganization and adaptation. The adaptation phase "focuses upon family efforts over time to recover from a crisis situation" (p.14) and thereby attempt to attain a " new level of balance and fit...at both the individual-to-family and family-to community levels of functioning" (p.15).

This study utilized the second stage of the T-Double ABCX model of Adjustment and Adaptation, i.e. the adaptation phase, since it best represents the unremitting stress of a chronic illness requiring one or more intervention procedures which may be accompanied by an ambiguous outcome and prognosis. The birth of a child with congenital heart disease, by the nature and implication of the disease, creates a crisis situation compounded by the potential for a chronic demand-capability imbalance. Family members are faced with a constant need for adaptive coping strategies, regardless of how well they may have adjusted to the reality of the child's illness initially.

With respect to looking at the aspect of medical intervention, the T-Double ABCX Model should be effective in assessing families and their needs. If a demand-capability imbalance exists as a result of either the chronicity or critical interventional procedure aspects of the illness, then use of this model should make it possible to identify the imbalance and thereby develop adequate therapeutic interventions. For example, an appropriate family intervention might focus on encouraging both parents to share in the child's medical care, thus changing the family role structure, increasing effective communication, and diminishing the chances that the child's illness will become a pivotal point of conflict in the family. In terms of specific coping strategies which could be beneficial to both the child and parents, anxiety management and relaxation training prior to the therapeutic intervention (e.g. catheterization), with the parents not only involved, but also helping to train their child, could enhance everyone's sense of control.

Hypotheses

In this study the author will address the following hypotheses which are based on McCubbin & McCubbin's (1987) theoretical model of Adaptation:

1) Subjects whose children have experienced interventional procedures for Congenital Heart Defects (CHD) will report more difficulty with family adaptation than subjects whose children were investigated for congenital heart disease and diagnosed with a benign murmur.

2) Subjects whose children have had interventional procedures for CHD will perceive their child's illness as more severe than parents of children investigated and diagnosed with a benign heart murmur.

3)Subjects whose children have experienced interventional procedures for congenital heart disease will perceive their child's illness as more severe than the actual medical classification of the defect(s).

4) Subjects who report more concerns regarding their child with CHD will have greater difficulty with family adaptation than subjects with less concerns.

5) Subjects who perceive their family as having a high degree of hardiness will have less difficulty with family adaptation than subjects low on family hardiness.

6) Subjects who utilize more coping resources and skills and report satisfaction with their own coping ability will have less difficulty with family adaptation than subjects who report dissatisfaction with their coping skills.

7) Subjects who experience more negative feelings with their experience regarding their child with congenital heart disease will have more difficulty with family adaptation than subjects who report more frequent positive feelings.

Definition of Terms

The definitions of terms which are used in this study are as follows:

Catheterization (Diagnostic): The process of examining the heart by introducing a thin tube (catheter) into a vein or artery and passing it into the heart.

Catheterization (Interventional): The procedure is similar to the diagnostic catheterization, with the exception that the purpose is a therapeutic one rather than diagnostic, and the methodology varies in accordance with the goal of the intervention. As well the risks and complications are higher than for a diagnostic catheterization.

Congenital Heart Defect: Malformation of the heart or of its major blood vessels present at birth. Throughout this study the words defect and disease are used interchangeably.

Cyanosis: a lack of oxygen in the blood as a result of a congenital heart defect.

Echocardiography: A noninvasive process of examining the heart by means of ultra-sound pictures.

Heart-Lung Machine: An apparatus that oxygenates and pumps blood during open-heart surgery.

Intervention: Any invasive treatment involved in correcting a congenital heart defect.

Invasive: Any medical procedure which involves entering the heart for the purposes of diagnosis or correction of a congenital heart defect.

Murmur: An abnormal heart sound heard when listening to the heart - a noise occurring between the normal heart sounds.

Innocent Murmur: A noise that implies that there is no structural or functional abnormality (Collins-Nakai, 1990).

Summary

In this chapter the rationale and theory related to parental adaptation to the impact of medical intervention on their child with a congenital heart defect has been presented. In chapter two the theories of stress, family stress, crisis, coping, and family adaptation as they relate to the basis of this investigation are examined.

Chapter II

Review of the Literature

Theoretical Concerns Regarding Children with CHD

In this chapter a review of the literature that deals with physical, emotional, and developmental difficulties experienced by children with congenital heart disease (CHD) and their families is presented. Also, the underlying theories of stress, family stress, crisis, coping, and adaptation are discussed in detail in terms of their relevancy to the proposed study.

Research has shown that children with congenital heart disease tend to experience developmental, intellectual and emotional lags that accompany their handicap (Linde,1982). In terms of physical growth, the delay is more apparent in weight than height which usually occurs with congenital heart failure or syndromes. Also intellectual delays are more prominent in cyanotic children and more severe in children whose heart defect is part of a chromosonal disorder syndrome (Linde,1982). Children with cardiac disease can have impaired physical capacity which can limit their ability to perform physical activities and the development of gross motor skills, eg. delayed acquisition of walking and talking. In terms of intellectual development, assessment is difficult in the first three years because assessment instruments tend to focus on gross motor skills and language development. Again, children with cyanosis were more intellectually delayed when assessed prior to corrective surgery. It is important to note that most of the studies which indicated lower intellectual function were carried out in the 1970's when surgery was performed with the use of deep hypothermia and cardiac arrest was associated with a high postoperative incidence of brain damage (Linde, 1982). A recent study by Aram, Ekelman, Ben-Shachar and Levinsohn (1985) indicated significantly lower intelligence quotients for cyanotic children (prior to surgery) than for acyanotic children when the variables of neurologic and genetic status, definitive surgery, social class, and age were controlled for. Other researchers hypothesize that lower measured intelligence scores are related to emotional factors inherent in chronic illness which can prevent the child from adequate environmental exposure and stimulation, such as decreased social contacts, numerous hospitalizations and deficits in school attendance (Roberts, 1979; Linde, 1982; Kong, Tay, Yip, and Chay, 1986;).

The emotional difficulties faced by pediatric congenital heart patients have been attributed in the literature primarily to disorganization in the family functioning, interaction between family members, and parental (especially maternal) inability to cope with the reality of giving birth to a defective child. Linde (1967, 1973,1982), among others (Apley, Barbour & Westmacott,1967; D'Antonio,1976; Bruhn,1977; Mattsson,1979; Roberts,1979; Gochman,1985; Kerns & Turk,1985; Leventhal, Levanthal & Nguyen,1985; Melamed & Bush,1985; Kong, Tay, Yip, & Chay,1986) have concluded that poor psychological adjustment and anxiety in the child with heart disease relates more to maternal anxiety and pampering than to the degree of incapacity or severity of the disease. Garson, Benson, Ivler, & Patton (1978) note that between 30-60% of children with congenital heart disease suffer an emotional disability. This is two to three times the rate of physically normal populations. Their study was based on the well documented premise that children with less severe disease have greater psychological problems, hypothesizing that the indirect effects of the disease are the most important determinants of emotional degree of stability. Offord, Cross, Andrews & Aponte (1972) noted that the degree of overprotection and the effect of the child's illness on the family's life were unrelated to the actual severity of the disease, but were related to maternal distortion of the severity of the defect. Also important were length of time the family had lived with the awareness of the defect, i.e. discovery of disease in an older child accounting for more distortion, and the socioeconomic class of the family, lower indicating greater distortion. Their study also pointed out that the child's degree of anxiety was directly related to the mother's, regardless whether the child had an accurate perception of their disease or not.

Of primary relevance to the proposed study is Offord's et al (1972) finding that the presence of surgery on the child affected the family significantly more severely and was also the most powerful factor influencing the child's as well as the mother's scores regarding perception of disruption in family life.

In summary, it has been documented in the literature that congenital heart disease can itself be a primary cause of developmental delays of a cognitive and gross-motor nature. These intellectual delays were more often noted in cyanotic children. Emotional factors have been implicated in developmental delays, and much research has shown that children with congenital heart disease have experienced disturbed family relationships, much of this being related to maternal anxiety and overprotection.

THEORIES OF FAMILY STRESS, CRISIS, AND COPING

One of the theoretical bases of this study involved stress and the manner in which families, in particular, parents of children with a congenital heart defect who experience an interventional procedure, cope with not only this direct stressor, but also the pile-up of stresses and strains which tend to accompany chronic illness. As previously illustrated, the discovery of illness in a child and the long-term nature of that illness affects not only the child, but also the parents of that child. Not only are parents faced with the usual demands of parenting a child, but also with the special responsibilities of acting for and with the child in regulating and adjusting to the illness. Chronic illness is characterized by its permanency, non-reversibility, and protracted and fluctuating course, resulting in some degree of functional impairment and requiring almost constant monitoring and attention (Mattsson, 1972; Strauss, 1975). Acute phases of the illness have the potential to create a crisis in the family which in turn can create a pile-up of stresses and strains. This section will address the theories of family stress, crisis, and coping, which will subsequently be related to the acute phase of congenital heart disease - the invasive medical intervention. First a brief overview of the history of the concept of stress is presented and then integrated with the concepts of family stress, crisis, and coping all of which relate to the purpose of this study.

STRESS

In the literature are abundant references to the term stress and definitions which are summarily based on the work of Canon who, in the 1920's, referred to stress as the 'flight or fight' response, and Selye's work which began in the 1930's and related stress directly to the development of disease (1956). Later Selye (1976) defined stress as "the nonspecific response of the body to any demand." (p.15). Selye's definition, which is based on the physiology of stress, points out that stress is part of our daily human experience and that there are two types of stress, 'eustress' or good stress and 'distress' or bad stress. Either puts a demand on our system but the effects are either desirable or undesirable. The stimuli which make the demands, either endogenously or exogenously, are called stressors. Selye saw the intensity of the demand for adaptation as creating the biologic stress.

Lazarus (1966) proposed a theory of psychological stress in which he described stress as a universal phenomenon which "often results in intense and distressing experiences and (it) appears to be of tremendous influence on behavior" (p.2). Lazarus' definition of stress was a transactional one, taking into account both situational and individual characteristics. Stress was viewed as "transactions between individuals and situations, rather than either one in isolation" (p.5). Coyne and Holroyd (1982) supported Lazarus' concept of stress, and, along with other researchers, expanded this concept to include person-environment transactions that exceed or tax the individual's resources (Lazarus & Launier, 1978, Coyne & Lazarus, 1980; Lazarus, 1980). "Stress is thus neither an environmental stimulus, a characteristic of the person, nor a response but a relationship between demands and the power to deal with them without unreasonable or destructive costs" (Coyne & Holroyd, 1982, p.108).

Hardiness

Holmes and Rahe (1967) developed the Schedule of Recent Life Events and the Social Readjustment Rating Scale in response to the general concensus that life events impinge on an individual with varying degrees of intensity and reaction, depending on the person's sensitivity at a given point in time. A life event is considered stressful if it causes changes in and demands readjustment of an individual's normal routine. What has become apparent from studies using this scale is that what may be stressful for one person may not induce stress (or distress) in another. Kobasa (1979, 1981, 1982, 1985) determined that the personality variable of hardiness is a primary mediator between stressful life events and illness or health. Hardy persons are considered to possess three general characteristics: a) the belief that they can control or influence the events of their experience; b) an ability to feel deeply involved in or committed to the activities of their lives, and c) the anticipation of change as an exciting challenge to future development. Following from Kobasa's work on the individual personality characteristic of hardiness, the concept of family hardiness was developed

(McCubbin, McCubbin & Thompson, 1987; Patterson, 1989). Family hardiness refers to the internal strengths and durability of the family unit that would function as a buffer or mediating factor in mitigating the effects of stressors and demands, and a facilitation of family adjustment and adaptation over time. Family hardiness is characterized by a sense of control over the outcomes of life events and hardships, and parents have an active orientation towards the management of crisis situations.

FAMILY STRESS AND CRISIS

The concept of family stress can be traced to Hill's (1949) ABCX model of family crisis. This model, on which McCubbin and his colleagues later based their Double-ABCX and T-Double ABCX models of family crisis and adaptation (1981, 1987) has been the landmark work for research into family stress. Hill separated the family's reaction to crisis into several phases. There is an initial period of stunned denial. Then a period of confusion, anxiety, and frequently resentment towards the sick member ensues. Finally, recovery and reorganization occur when the reorganized family may function as well as or better than before the crisis. On the other hand the family may become progressively more dysfunctional which can result in emotional and physical difficulties for other family members as well as the sick member being dramatically affected by the way in which the family reorganizes. In the ABCX model, " A (the stressor event) - interacting with B (the family's crisis-meeting resources) - interacting with C (the definition the family makes of the event) - produces X (the crisis)" (Hill, 1958, p.141). Hill defined crisis as " any sharp or decisive change for which old patterns are inadequate" (cited in Burr, 1982, p.6). Other authors as well have examined the family as a social system (Angell,1936; LeMasters,1957; Rodgers, 1964; and Hobbs, 1965,1968) and defined it in terms of a developmental framework. Rodgers states the family is a "semiclosed system...which is composed of interrelated positions and roles defined by the society of which it is a part as unique to that system" (1964, p.264). These authors have viewed family crisis as a disruption in the smooth operation of the family social system and determined that the less disrupted the family system, the less severe the crisis and vice versa. This viewpoint is at odds with later researchers (McCubbin et al.) who have explored the degree of disruption in the family system in terms of the family's vulnerability and regenerative powers. Angell (1936) found family integration and adaptability to be two important factors related to a family being able to recover from a crisis. Hansen and Hill (1964) noted several factors which they deemed as having a strong influence on crisis recovery. These are: severity of the event, the family's definition of he situation, externalization of blame for the stressful event, adaptability, integration, suddenness of the event, individuated versus kinship type of community, affectional relations among family members, marital adjustment, family council type of control in decision making, participation of the wife outside the home, and previous successful experience with similar types of stress. McCubbin and Patterson (1982) point out that these variables are indicative of the family's resources which are related to the family's vulnerability, i.e. "variation in the ability of a family to prevent a stressor event or change in its social system from creating a crisis, <which> is influenced by the definition the family makes of the seriousness of the change " (p.26 & 27). The other concept, regenerativity or regenerative power relates to "variation in the ability of the family to recover from a crisis " (p.27). These two major concepts, according to McCubbin and Patterson, are the basis for explaining why some families are better able to either defend themselves against crises or recover effectively when a stressor event occurs.

To summarize then, family crisis is a concept which has been studied over the past fifty years and is identified as a family's challenge to effectively cope with a sudden stressor. Effective coping has been felt to depend on a variety of factors, including, the family's definition of the event, their resources within and outside the family, and their degree of vulnerability and regenerativity.

The Impact of Chronic Illness on the Family

Considerable research has been done on the stressful nature of chronic illnesses and invasive procedures, in particular congenital heart disease (CHD), and its effects on both the identified patients and their families. The major aspects of this literature are reviewed here, which also can be shared by other populations, such as families with terminally ill or developmentally handicapped children.

Firstly, research into the psychological and social stressors of congenital heart disease is fairly congruent in terms of general effects and parent-child responses. One area of contradiction, however, concerns the degree to which the child's actual maturational lag is dependent upon the severity of the defect. Carr (1976) points out that deficits are a consequence of the actual severity of the defect and physical restrictions on the child. On the other hand, Offord et al (1972) carried out a study which clearly notes that it is the perception of the disease, rather than the actual severity, which is the predictor of child and family discord. If this hypothesis is true, then it follows that, when parents perceive the disease to be more severe, then the effect on the child will be enforcement of physical and emotional restrictions which, in turn, are causal factors of maturational lag (the next section describes Offord's study in more detail). Perry (1982), in a study of 46 sets of parents of children with CHD, found that parents who perceived their child's heart disease to be more severe reported higher degrees of anxiety. She also discovered that the association of surgery with the defect increased the perception of severity with this population, and concluded that "surgery....has an indirect relationship with parental anxiety,....and this anxiety may persist for a time following surgery" (p.91,92).

The literature is replete with reports about the psychological and social effects of CHD and its impact on the family in terms of personality and relationships within the family, as well as the general functioning of the unit. It is noteworthy that the research focuses on the general aspects of the disease process and not a specific aspect such as an interventional procedure related to family functioning. Apley, Barbour, and Westmacott (1967), in a study of 88 children with CHD, noted a high incidence of parental, sibling, social, and marital upset. Family balance in terms of jobs and housing, for example, were upset and the CHD incurred extra expenses which had an impact on the family's lifestyle. Twenty-four percent of the families reported behavioral and/or psychosomatic disorders in the siblings; and sixty-eight percent of the families reported unsatisfactory mother-child relationships. These results were more pronounced when the CHD was incurable, those families at greatest risk being those in which the parents' own personality development was impaired or who were generally immature, i.e. either overprotective or rejecting of the child.

The adjustments that a child and family members are required to make when faced with any invasive intervention involve numerous components both pre- and post-procedure. Various studies have explored the effects of surgery, confinement in an intensive care unit, and separation from parents, all of which can devastate a child. The admission of a child to a pediatric intensive care unit (ICU) is a very stressful event for parents as well, not only because of the intense medical atmosphere, but also because it changes the parental relationship with the child. (Miles & Carter, 1982, 1983a, 1985; Miles, Carter, Spicher, & Hassanein, 1985). It is well noted in the literature that children with a congenital heart defect experience not only the stress of living with a chronic illness but also the stressors related to the acute crises of hospitalization for invasive procedures (Campbell, Clark, and Kirkpatrick, 1986). Toker (1971) reviews the psychiatric aspects of cardiac surgery in a child, regarding the inherent trauma involved in pediatric surgery. Quoting Bergmann (1965, cited in Toker,p.158), Toker states that "surgery in a child, major or minor,....is likely to arouse his fantasies and fears with regard to being attacked, mutilated, deprived of a valuable part of his own self." Heart surgery, due to the inherent meaning, both symbolically and in reality, of the heart for life, is a disruption which is a significant stressor and involves the elements of fear of death, mutilation and separation. At the same time parents tend to experience considerable strain in their relationship with their child due to the history of caring for a chronically ill child who did not thrive from birth, and who was frequently irritable and negative. A significant body of research has presented mothers as over-protective, insecure in their parenting role, ascribing responsibility for their child's defect to themselves, and generally feeling intense anxiety and guilt (Glaser et al, 1964).

In summary, it is generally agreed that chronic illness represents a significant, ongoing agent of stress for most people. As described above, the consequences are not only in terms of the physical effects for the affected individual, but also the psychological and social adjustments of the child and other family members. Although there has been a fair amount of research which explores the reciprocal relationship between the family and the child in the face of pediatric chronic illness, most of this research has focused on mother-child interactions and the resultant effects in relation to one another.

Congenital Heart Disease, Surgery, and Impact on the Family

In order that data regarding the impact of a congenital defect and resulting interventions be meaningful in the context of the family - for realistically the child with the defect is but one member of this interacting system - the effects on the family system must be evaluated.

With respect to the specific chronic illness of congenital heart disease, research has primarily been descriptive, based on interview data, open-ended questionnaires, personality and behavioral measures regarding both parent and child viewpoints, anxiety scales, attitude surveys and theoretical treatises (Apley, et al, 1967; Offord, et al, 1972; D'Antonio, 1976; Boll, Dimino, & Mattsson, 1977; Bruhn, 1977; Garson et al, 1978; Roberts, 1979; Linde, 1982; Perry, 1982; Sargent III, 1982; Gochman, 1985; Leventhal et al, 1985; Melamed & Bush, 1985; Kong, et al, 1986).

There has also been considerable research in the area of preparation of the child and/or parent(s), (as well as adult patients), for dealing with invasive procedures (Melamed & Siegel, 1975; Kendall, Williams, Pechacek, Graham, Sisslak, & Herzoff, 1979; Lenhard, 1980; Kendall & Watson, 1981; Anderson, K. & Masur, 1982; Kaplan, Atkins, & Kendall, 1983; Bond Caire & Erickson, 1986; Watkins, Weaver, & Odegaard, 1986; Odegaard, 1986; Anderson, E. 1987). As far as the impact of interventional procedures is concerned however, it has been acknowledged that surgery is the most distressing form of treatment (Calhoun, Selby & King, 1976). In terms of this study, any interventional procedure which separates the child from its family and is invasive would be seen in the same light. Several investigators have documented the reasons for this intense anxiety provoked by the prospect of surgery including, the threat to life itself, loss of important bodily parts, the prospect of chronic or further invalidism, fear of losing control, and fear of not being given all pertinent information (Johnson & Leventhal, 1971; Auerback, 1973; Speilberger, Wadsworth, Auerback, Dunn, & Taulbee, 1973; Wu, 1973). Graham & Conley (1971) reported that women tend to experience greater anxiety than men. Wu (1973) suggested that the degree of distress associated with surgery may be determined by the organ or function to be threatened by the surgery. Most researchers agree that the emotional state of the individual undergoing surgery significantly affects its outcome, both in terms of recovery and postsurgical symptoms.

Despite the considerable amount of research on surgery and anxiety, and effective preparation for surgery, there is little empirical data relating to its impact on children and their families, a conceivably more vulnerable population. Burstein and Meichenbaum (1974) studied 20 children ages 4 to 9 who were about to undergo surgery, their interest being the degree of denial employed by the children as well as their degree of defensiveness. Kitchen (1978) presented a case report by Cline and Rothenberg (1974, cited in Kitchen, 1978) regarding a seven year old child with congenital heart disease who died one month postoperatively for unclear medical reasons. The child's parents however, had been experiencing serious marital problems which did not abate during the critical postoperative period. Previous to the surgery the child, in a play therapy session, had described a septal defect "too big" to repair and announced that the doll "<would> have to die." The conclusion reached by the therapists was that the child gave up his hope for a relaxed home atmosphere and life itself when his parents continued to fight. Gabriel and Danilowitz (1978) determined that the age of the child is significant in terms of successful pre-surgery preparation, the optimal age being between 8 and 11 years. In their study, children in this age range experienced the least serious long-term psychological difficulties after appropriate preparation. These authors note that today surgery is performed in infancy and early childhood, when medical aspects are of primary importance to the life of the child and psychological implications for optimal time of surgery are set aside. This study also found that children's adjustment was interfered with by parents who operated with a regressive, denying attitude.

The emotional effect of cardiac catheterization can be no less disruptive. Aisenberg, Wolff, & Rosenthal (1973) noted that, of the fifty children, ages 4-15, in their study, nearly all the youngest and almost half of the older patients manifested negative behavior and emotional changes such as regression, aggression, emotional lability and increased general and somatic anxiety after catheterization.

Invasive procedures then, have been shown to have negative emotional effects, not only for the identified patients, but also for the family. Research has focused primarily on mothers responses, anxiety experienced by children undergoing invasive procedures as well as effective preparatory methods. There has been very little research examining the longer term impact of medical procedures on the adaptation ability of the family.

This section has examined the concepts of family stress and crisis, especially as they relate to the factors involved in families with children with congenital heart defects. The next section examines coping.

COPING

Research which has dealt with how parents cope with their child's illness has focused primarily on families with terminally ill children, the chronicity aspect of disease processes, preparation of parents and/or their children for invasive procedures, and children with acute illness. There is a dearth of literature, however, examining the impact of an interventional procedure on a child with a congenital heart defect and the family in terms of its ability to cope and continue to function in a healthy cohesive manner.

A review of the literature indicates that the terms 'coping' and 'adaptation' have been used interchangeably. For this study 'coping' is defined in terms of its reference to actively dealing with crises, and 'adaptation' is defined in terms of outcome of coping strategies.

Definitions of Coping

Coping, because of the colloquial nature of the word, has been defined in a variety of ways. Murphy (1962, cited in Lazarus, Averill, & Opton, 1974) has defined it as "any attempt to master a new situation that can be potentially threatening, frustrating, challenging, or gratifying " (p.250). Lazarus' (1966) initial definition described earlier in this chapter was more restricted, applying the concept of stress and coping only to situations involving threat. Later, Lazarus, Averill & Opton (1974) promoted a definition which emphasized the emotional aspect of coping, included both the negative and positive side of emotion, recognized the overlap between problem solving and coping, and emphasized adaptive tasks in which the outcome is uncertain and the individual's limits in terms of adaptive skill may be reached. This definition presents coping as "problem-solving efforts made by an individual when the demands he faces are highly relevant to his welfare...and when these demands tax his adaptive resources" (p.250-251). Lazarus et al emphasized the mediating aspect of the cognitive process of appraisal, a perception which distinguishes the potentially harmful from the potentially beneficial. The first step in the appraisal process is called primary appraisal and an event may be appraised as irrelevant, benign, or stressful. The next step is called secondary appraisal, in which the individual, if the event is perceived as stressful, reviews what resources and coping strategies are available and what the possible outcomes of these strategies might be. The third step, reappraisal, occurs as new information or understanding of the situation is gained, or as the individual cognitively reduces the discomfort experienced. In the latter aspect, such defensive mechanisms as denial, repression, or projection may be involved. Cognitive appraisal of life events has been felt to be the key aspect of coping since this appraisal influences the response. The same event may be perceived by different individuals as irrelevant, benign, and positive, or threatening and harmful (Rutter, 1983).

Another aspect of coping involves the concepts of self-esteem and mastery. The ability to see the positives of a situation and to feel confident that one can master it are based on the level of vulnerability one is experiencing. This tends to be a learned cognitive attribution style which varies on the dimensions of expected outcomes, the perception of outcomes as being within one's control, and the extent to which a person attributes failure to unalterable faults in oneself rather than external factors which may change or can be modified. When people feel hopeless or helpless and unable to do anything about their fate, they are less able to deal with stressful life events.

Coyne and Lazarus (1980) noted that coping may be action-oriented or intrapsychic, that is, focused on problem-solving or on regulation of stressful emotions. Rutter (1983) notes that coping must have the dual function of problem-solving and a regulation of emotional distress. Coping mechanisms may be seen as healthy or they may increase the risk of maladaptation, that is, there is a further dimension of effective and ineffective coping. Another important issue is whether a certain coping strategy will be effective for most situations requiring it. Perlin and Schooler (1978) noted that "having a particular weapon in one's arsenal is less important than having a variety of weapons...The single coping response, regardless of efficacy, may be less effective than bringing to bear a range of responses to life strains" (p.127).

Coping, then, refers to two distinct tasks - responding to the situation as well as one's feelings about the situation. The overall pattern has two phases, a) an acute phase which requires that energy be directed at minimizing the impact of the stress, and b) a reorganization phase which demands that the new reality is faced and accepted (Moos, 1976). The most recent definition of coping is process-oriented as opposed to trait-oriented.It is a reorganization of earlier definitions by Lazarus and is one which clarifies the concept best: coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman,1984, p.141).

Coping and Control

It has been reported throughout the literature that effective coping relies heavily on an individual feeling control over a situation (Lazarus,1966, 1968; Cohen & Lazarus, 1973). Anderson (1987) notes that having information about a situation merely determines the initial responses to an event and sets the stage for the development of coping strategies. An individual will experience stress when there does not appear to be a means of controlling the outcome of a situation. This aspect of control has been studied further in terms of locus of control, i.e. internal vs external, internal referring to the perception of having control over life situations, and external referring to the belief that control is in the hands of others, e.g. medical personnel. Moos and his colleagues have studied the issues of coping with physical illness (Moos & Tsu, 1977; Moos &

Billings, 1982). Moos and Billings (1982) established three broad groups of coping strategies: a) appraisal-focused coping, which involves attempts to define the meaning of a situation through logical analysis, cognitive redefinition, and cognitive avoidance (denial); b) problem-focused coping, which involves attempts to change or eliminate the source of the stress, to change the self, and develop a more tolerant situation; c) Emotion-focused coping, which involves methods of maintaining an effective equilibrium, some of which may lead to maladaptation (e.g. alcohol consumption). Lazarus (1984) also focuses on two functions of coping, these being a) the management or altering of the problem with the situation causing distress (problem-focused coping) and regulation of the emotional response to the problem (emotion-focused coping). Lazarus notes that these two methods of coping can either facilitate or impede one another.

Family Coping

Most of the research on the theory of coping has been carried out with the individual in mind. Little has been written from a group perspective. When we consider children's responses to stressful situations, it has been established that a great deal of their coping strategies are based on the responses to the situation by other family members, in particular, their parents. Family styles or coping strategies as a group may not necessarily be the sum of the behaviors of the individuals in that group (Rutter, 1983). The family or parental strategies are dependent upon many other variables, both from an intrapsychic and interrelational perspective, as well as external variables such as social support, accurate information, and so on.

Coping with Invasive Procedures

Firstly, in examining ability to cope with an invasive procedure, the literature is replete with studies which have focused on reducing anticipatory anxiety in surgical patients, pediatric and adult, as well as family members (Melamed & Siegel, 1975; Kendall, Williams, Pechacek, Graham, Shisslak, & Herzoff, 1979; Kendall & Watson, 1981; Anderson & Masur, 1983; Kendall, 1983; Campbell, Clark, & Kirkpatrick, 1986; Odegaard,1986; Anderson,1987).

These studies have examined coping styles and methods of anxiety reduction in relation to the invasive procedure, but deal only with the intervention and subsequent rate and quality of physical recovery. There has been no study to date which explores the longer term effects of an invasive intervention on family adaptation. A relevant factor to the present study, however, regards the issue of control, which is reported to be the key factor in coping with the anxiety of an invasive procedure both for the child as well as the parents. Campbell, et al (1986) tested a program of stress management training for both parents and their children (ages 6-17) who were to undergo cardiac catheterization. The findings indicated that not only was provision of information to the parents and child beneficial but the group which received information plus stress-management training responded more positively both in hospital and once at home, i.e., with more cooperation and less upset both emotionally and behaviorally, than the control group which received information only. The emphasis in this study was placed on the parent assuming an active role as therapeutic ally, rather than the more passive role as recipient of information only. The focus was to provide parents with new coping stategies, and this may have given them an elevated sense of control. In turn, the children were not overloaded with parental concerns and had an appropriate model to follow when coping with their own fears, while receiving congruent messages from their parents. The goal of anxiety reduction in any medical procedure is successful physical and emotional recuperation, which this study suggests can be achieved more effectively by including parents on the medical team in an active, supportive manner. This study also corroborates previous studies reported earlier which point to parental attitudes as being decisive in how well a child copes with illness and/or invasive procedures and subsequent family functioning as a whole.

The dimension of control was examined by Anderson (1987), whose study evaluated whether preoperative preparations for cardiac surgery, among other stress reducing factors, increased patients' sense of control over recovery. Consistent with Lazarus' theory, belief in control over recovery best predicted preoperative anxiety. It must be noted here that parents of children undergoing invasive interventions do not have a sense of control over the situation, at least during the acute phase of the intervention itself.

Perception of Severity of Illness

In terms of chronic disease processes, it is suggested in the literature that the presence rather than the actual severity of a disease is indicative of coping difficulties for parents (Offord et al, 1972). In this study, which examined twenty children from 9-17 years with suspected or confirmed congenital heart disease, the presence of surgery was the most powerful factor influencing the extent to which the child saw the illness as affecting family life and was significantly related to the degree that the defect affected family life according to the mother. However, the mothers' distortion of the disease was an even more powerful factor in determining the degree of effect on the family than the presence of surgery.

On the whole, chronic physical disorder has been shown to lead to coping difficulties for the child and family. However, a great deal of these reports are not based on empirically based research, but rather on subjective or impressionistic evaluations. Boll, Dimino, & Mattsson (1978) examined the parenting attitudes and personality styles of mothers of children with acyanotic heart disease and developmentally normal children in order to ascertain whether, 1) mothers of children with chronic illness differ on these dimensions from mothers of healthy children; and 2) mothers' personality styles relate to identifiable parenting attitudes, regardless of the child's medical status. The results indicated that the two groups were quite similar on personality and parenting variables. However, those mothers with a significant neuroticism score, regardless of the medical status of their child, were more prone to parenting attitudes associated with parent-child conflict. The assumption here is that when these attitudes are present in a parent of a chronically ill child, the family will tend to have problems coping with the on-going stresses inherent in the illness.

Gottesfeld (1979), discussing the impact of a child born with CHD on the family, points out the stresses and strains prior to and after diagnosis, along with coping mechanisms generally used. She points to three major issues confronting the family prior to diagnosis: a) fear of loss, b) fear of the unknown, and c) guilt. Coping tends to follow a similar pattern to that of a grief reaction: a) denial is dominant initially and is a positive protective defense prior to a completed diagnosis; b) anger and guilt follow - anger at God, the doctors, themselves, and the child. Guilt is associated with the anger, as well as continuing denial to help the family go on; c) depressive feelings are next, and these tend to come and go, depending on a variety of variables affecting the family, such as ability to make the necessary life changes, degree of information and support received, and the child's medical status; d) eventually the goal of all coping, acceptance and a return to normal family functioning, is reached when the family feels a sense of control over the wide variety of stresses and strains which appear to confront it continuously. A few of the variables Gottesfeld points out as affecting the coping process include the severity of the illness and the length of "stress time" (p.103), the child's position in the family relative to siblings, the meaning of the diagnosis to each family member, the overall effect of the diagnosis on life-style and financial status, and availability of functional support systems.

Comparative Groups

Other chronic disease states such as cerebral palsey (CP) and cystic fibrosis (CF) have undergone considerable study with regard to effects on the child and family's coping patterns (McCubbin, Nevin, Cauble, Larsen, Comeau, & Patterson, 1982; Johnson, Muyskens, Bryce, Palmer, & Rodnan, 1985). These patterns can also be synonymous with those utilized by CHD families. In their study of family adaptation to having a child with cystic fibrosis (CF), Johnson et al determined that families who coped well utilized external social support and fostered family coherence as two prime methods of coping. This study also determined that later born children with CF are easier to cope with than first born due to the family having had an opportunity to develop normally as a family prior to the birth of the CF child.

McCubbin et al (1982) focused on a number of variables in their study of cerebral palsy (CP) families, parental coping among them. In this study, coping patterns of mothers included keeping the family together and stable, maintaining medical care for the CP child, as well as other family members, and attending to their own personal and emotional needs, such as exercise, personal resources, and independence. External social support from friends was also rated as being very important to the mothers. Fathers coping resources included the maintenance of family stability, obtaining support from their spouses, and investing in themselves as individuals. Most important to fathers however, was attending to job needs, socializing on a regular basis with their wives, and supporting the need for medical treatments being carried out at home.

Another major coping strategy which has been reported in the literature is from a religious or positive belief perspective. Venters (1982) in a study of families of CF children,found a variety of these resources being utlized. Having a religious philosophy helped in finding a satisfactory meaning for the illness; other parents gained strength in comparing their situation with similar families with ill or handicapped children; living day to day was helpful to others as opposed to long term planning; and focusing on the child's strengths rather than weaknesses was another useful coping strategy.

Families of terminally ill children present another comparative population to the proposed study population. These families, like families of chronically ill children, require a mourning period at the time of diagnosis, and the grief persists throughout the course of treatments. For the former population, when the child does not survive, the <u>active</u> grief and mourning tend to be finite once the family is able to reach a level of acceptance and resume their lives. Chronic illness never goes away - the child always remains less than a normal healthy child, even in the face of successful corrective (yet not necessarily curative) procedures. This situation can produce recurrent grief for parents as the child passes through the various developmental stages at a restricted or different pace, or faces an interventional procedure which may or may not improve the child's prognosis. Coping resources are determined, to a substantial degree, by the actual impact of the child's limitations on the whole family in terms of where they live, finances, amount of free time, interpersonal relationships, parental careers, and so on (Leventhal et al, 1985). As well, each time the child requires an interventional procedure, the family has to reorganize its roles and face an unknown, or at best tentative diagnosis and /or prognosis. Coping strategies in families of terminally ill children are reported to focus primarily, at least, in the diagnostic and treatment stages, on the preservation of life (Leventhal, et al, 1985). Among other coping resources, as referred to above with other families with special medical needs, social support and medical networks are the most utilized resources for these families, since gathering and sharing of information helps to ameliorate the constant stress of the often ambiguous aspects of both terminal and chronic illness.

SUMMARY

The above review of studies regarding the emotional effects of congenital heart defects for both the child and family illustrates the extreme stress inherent in both confronting the disease process from a chronic perspective and coping with the sometimes numerous acute phases of hospitalization and/or interventional procedures. It is evident that many of the difficulties faced by parents in terms of their own coping with their child's illness relates directly to how they coped initially after the child was born. Most parents require a mourning period, i.e. learning to accept the loss of an expected normal child. During this period many parents,and mothers in particular, are reported to manifest feelings of guilt, excessive anxiety, anger,and rejecting feelings which tend to be expressed through either overprotection and pampering, withdrawal, or negligent handling of the infant or child. Based primarily on how the child is viewed within the family, many children may manifest a negative self-image and significant levels of anxiety, which are generally expressed via physical or verbal aggressive behavior, emotional withdrawal, depression, and unrealistic fears.

It has also been pointed out that acute phases of the disease, such as hospitalization and invasive interventions, diagnostic or corrective, create intense stress for the child and family. These acute phases are akin to crises which will impinge on the family's coping process. The child's coping success depends almost entirely on parental support. Therefore, the parents are required to learn how to effectively handle their own anxiety and present an optimistic and calm point of view to their child.

When we examine stress and crisis theory in relation to its effect on families, it is important to remember that stress per se cannot be directly related to maladaptation because of the variety of coping processes which it generates. Lazarus (1980) notes that poor adaptation is as much a result of inept coping as it is of environmental demands, or stressors.

The above review of both the theoretical and empirical aspects of family stress, crisis and coping in families of children with chronic illness, and more specifically families of children with CHD who require an interventional procedure, discusses a multitude of potential responses to demands faced by these families which have the potential to produce a pile-up of stresses and strains. Some families adapt successfully, utilizing various productive coping strategies, while other families find the acute stress and meaning of the procedure(s) overwhelming and become or continue to be dysfunctional. It is noted that much of the research has focused on one parent, usually the mother, in exploring coping patterns. This appears to be related to the fact that in a higher percentage of families, the mother is the primary caregiver to the ill child.

The major focus of this study is to clarify just what this adaptational process involves.

Theory of Family Adjustment and Adaptation

The multitude of demands, conceptualized as pile-up of stresses and strains by McCubbin and Patterson (1981, 1982), which families of children with congenital heart defects tend to experience, can easily disrupt the family unit if the family's resources are already overtaxed, thereby leaving the family less able to make further adjustments when faced with more demands. An example of this would be a family experiencing a normative transition, i.e. the birth of a baby, only to find out that the child requires immediate diagnostic and interventional procedures for a congenital heart defect. This situation can create a state of crisis for the family, as the family is required to "evolve and adapt to changes within and outside the family unit" (McCubbin & McCubbin, 1987, pp.14). The numerous potential stresses and strains which can create a pile-up for this family include mourning the loss of an expected normal child; constant worry about the child's present and future well-being, internal family tensions between spouses and with other children in the home; financial concerns; the constant need for information from medical sources; immediate lifestyle changes beyond what had been anticipated with the birth of a child; and personal health concerns.

What is required to adequately assess family functioning when faced with the impact of an interventional procedure on a child with congenital heart disease is a model of family adaptation which incorporates the psychological, intrafamilial, and social variables. As presented earlier in this chapter, Hill (1949) developed a model of family crisis which was directed towards the study of war separation and reunion in order to determine how families were able to make positive adaptations to stressful situations. McCubbin and his associates have advanced Hill's (ABCX) model to include both normative and extraordinary stress situations (Figley and McCubbin, 1983; McCubbin & Figley, 1983). Whereas Hill's model focused on pre-crisis variables, McCubbin et al developed the Double ABCX Model of Adjustment and Adaptation to include post-crisis variables (McCubbin & Patterson, 1981) in order to describe: " a) the additional life stressors and changes which may make family adaptation more difficult to achieve, b) the critical psychological and social factors families call upon and use in managing crisis situations, c) the processes families engage in to achieve satisfactory resolution, and d) the outcome of these family efforts" (p.9).

The Double ABCX Model then, was developed to predict both the degree of disruption in family functioning in the face of a crisis event or change in the family system, and its ability to adapt and attain a new balance in functioning. McCubbin and his associates have applied this model to the study of chronic disease states and their effects on families, eg. cerebral palsy (McCubbin et al., 1982), and myelomeningocele (Comeau, McCubbin, & Nevin, 1980). It is a model which has enabled researchers to comprehensively examine concurrent stressors, family resources, family perceptions, and its behavioral coping repertoires (see McCubbin & Patterson, 1981). The T-Double ABCX Model of Family Adjustment and Adaptation is a further advancement of the Double ABCX Model. The following is a description of the adaptation phase of the T-Double ABCX Model, as well as the factors within the model which are examined in this study.

The Family Adaptation Phase

The adaptation phase (see of Figure 1) of the T-Double ABCX Model establishes that the level of family adaptation (XX) in response to a crisis situation (X) is a function of the family's level of regenerativity (R) which is determined by the pile-up of stressors, transitions and strains (AA), interacting with the typology of the family (T), interacting with the family's adaptive strengths, capabilities, and resources (BB),and social support systems (BBB), interacting with the family's appraisal of the situation (CC) and the family's schema or world view (CCC), interacting with the family's problem solving and coping responses (PSC) (McCubbin & McCubbin, 1987). The current study examined pile-up of stresses, family resources, the family's appraisal of their child's illness, the family's schema or

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world view, and coping responses in relation to the outcome variable of adaptation. An overview of each aspect as it relates to the sample population follows.

(AA) Pile-up of Family Demands

Pile-up is defined as the accumulation of demands which a family faces at a given point in time as a result of specific changes, transitions, stressors, or strains. These demands may evolve from within the family, eg. marital or parent/child conflicts, and child or adult development, or from outside the family in the community, eg. work commitments, and societal role changes. McCubbin & McCubbin (1987) have established five major types of demands which result in a pile-up in the family system: a) The crisis and its hardships: Inherent in the crisis situation are inevitable hardships which add to the demands facing the family. With respect to a child with congenital heart disease, the hardships of dealing with an interventional procedure can be numerous, including the possibility of having to travel away from home for the procedure, finding care for children left at home, being separated from family members (support), helping the child to accept and understand the need for the procedure(s), obtaining answers to the many ambiguous aspects of the medical situation, finding a solid source of information and support from amongst the medical personnel, and finding extra financial support if necessary. This list is by no means exhaustive, since each family faces its own set of hardships depending on their developmental stage, socioeconomic and educational baseline, and so on.

b) Normative transitions: Family developmental transitions occur simultaneously to the crisis, and serve to increase the demands upon the family unit, as they also require family adjustment and adaptation.

c) Prior strains: These are defined as unresolved earlier stressors or transitions which tend to exacerbate in the face of the current crisis situation and add to the pile-up of demands. In a family with a child with CHD undergoing an interventional procedure for example, ongoing parental conflict will increase the tension and anxiety for both the child and parents, running the risk of interfering with the outcome of the procedure or the longer term prognosis for the child.

d) Consequences of family efforts to cope: Coping efforts by family members may serve to add to the pile-up of demands, especially if these coping efforts produce more burdens for the family. For example, financial strain and/or role strain may result if previously both parents were working, and the medical, emotional, and developmental needs of the child require one parent to be at home full time, or if an extended family member, such as a grandparent, moves into the home to aid in the child's care.

e) Intra-family and social ambiguity: This refers to the ambiguity which appears to be inherent in every crisis situation, since change and the necessity for adaptation create uncertainty about the future. "The family may experience ambiguity about its structure,...family roles, rules, responsibilities, and durability " (p.17). For many crises, the family requires societal support in the form of programs or formal networks. If these are absent or unclear, the burden on the family increases since its ability to manage stress may depend upon adequate community-based solutions. In terms of the present study population there are numerous ambiguities which the family faces. The etiology of the congenital heart defect is usually unknown, leaving the family to speculate and look for a source to blame. Depending on the severity of the defect, the child's developmental and medical status or prognosis may be unpredictable for a long time. Treatment issues may be ambiguous, even after diagnostic procedures are completed, and the family may have to wait weeks or even months before a therapeutic decision can be reached. During this time medical care may be at best palliative and the child's condition runs the risk of deteriorating due to infections or a general weakening in physical condition. These are just some of the possible sources of ambiguity which add to the pile-up of demands of CHD families.

(BB) Family Strengths, Resources, and Capabilities and (BBB) Community Resources and Supports

In the T-Double ABCX model McCubbin & McCubbin (1987) focus on two sets of capabilities: what the family has, i.e. resources and strengths, and what the family does both as a unit and as individual family members, i.e. their coping mechanisms. The three potential sources of resources include individual family members, the family unit, and the community, one of which [illegible] the source for an adaptive resource. These resources [illegible] be tangible (e.g. money) or intangible (e.g. self-esteem). There are both individual or personal resources as well as family system resources which were discussed in detail previously in this chapter. McCubbin & McCubbin (1987) specify resources in each of these categories including innate intelligence, knowledge and skills obtained from education, training or experience, dynamic personality traits (e.g. extroversion), physical and emotional well-being, a sense of mastery which heightens one's feeling of control in one's life, and positive self-esteem. The latter two resources are the most important yet most fragile when the pile-up of demands becomes overwhelming. In terms of family system resources, cohesion or family unity involves mutual trust, appreciation, support, and respect for individuality; adaptability is the ability of the family to be flexible in the face of obstacles; and organization involves the family's ability to achieve a fluidity with respect to family roles and rules, parental leadership, and clear generational boundaries. One of the most critical family resources highlighted by McCubbin & McCubbin is that of communication. "Quality communication is of particular importance to stress management in families because it enables the group to coordinate their efforts to manage demands and because it helps to reduce ambiguity, which is part of what makes change so stressful" (p.18).

Community resources (BBB factor) are acknowledged as being important to family coping by McCubbin & McCubbin. These resources refer to any source outside the family which it may utilize to help meet its demands. Social support has been viewed as one of the most effective mediators between stress and the breakdown of health. Cobb (1976, cited in McCubbin & McCubbin, 1987) defines social support as " information exchanged at the interpersonal level which provides emotional support, leading the individual to believe that he or she is cared for; esteem support, leading the individual to believe that he or she is esteemed or valued; and network support, leading the individual to believe that he or she belongs to a network of communication involving mutual obligation and understanding" (p.19). McCubbin & McCubbin (1987) have added "appraisal support" or feedback which enables the individual to assess one's functioning, and "altruistic support" or feedback from others which indicates that one has given of oneself. Social support is emphasized as involving a "qualitative exchange of communication in an atmosphere of trust" (p.19). McCubbin & McCubbin point out that social support is most often reciprocal, thereby relegating formal networks such as health care providers to a separate arena, instrumental in providing esteem and appraisal support, and needing to be careful not to negate one's sense of control in life.

(CC) and (CCC) Family Appraisals

McCubbin and McCubbin (1987) describe three levels of appraisal. In the adjustment phase, or first level, is the family's "appraisal of the specific stressor event, strain or transition (C factor)" (p.20). The second level comprises the family's situational appraisal, which involves the definition the family makes of the relationship between the demands and their capabilities to handle them (CC factor). As discussed previously in this chapter, parental perceptions have a great deal to do with how the child's illness impacts on the family as a whole and individually. McCubbin & McCubbin note that there are instances when demands, resources and coping behaviors exist or are evaluated through one's perception. When one's resources are perceived as being inadequate compared to the demand(s), an imbalance occurs which in turn produces tension and stress. An example of this type of situation is the perception of severity of illness. If parental perception of severity is greater than is realistic, implications exist for both child and family in terms of limitations placed on activity, social contacts, and the family's lifestyle. The more realistic the perception, the greater the chance of the parents feeling of competence in coping with the medical aspects of the disease as well.

The third level of appraisal, according to McCubbin and McCubbin, involves the family schema or the families' "set of beliefs....about themselves in relationship to each other and about their family in relationship to the community and systems beyond their boundaries" (p.20). This third level of appraisal is the CCC factor. McCubbin and McCubbin note that family schema, similar to the other T-Double ABCX factors, is not static over time, but is more stable than situational appraisals. Families with a strong family schema indicate that they have a strong investment in themselves as a family, their values and goals, as well as " a sense of shared control and trust in others,.... an optimistic view of life situations complemented by a relativistic view of life circumstances and willingness to accept less than perfect solutions to all their demands" (p.21).

(PSC) Adaptive Coping

The important aspects of family coping were discussed in more detail previously in this chapter. McCubbin &

McCubbin (1987) view coping, or "the process of acquiring and allocating resources for meeting demands" (p.21) as critical to successful adjustment and adaptation. In terms of the T-Double ABCX Model, coping is defined as "a specific effort (covert or overt) by which an individual (or group of individuals such as a family) attempt to reduce or manage a demand on the family system" (p.22). Family coping can either be composed of group problem-solving or individual family member efforts on the part of the family as a whole. McCubbin & McCubbin (1987) note that the goal of coping for the family system is the restoration of a demand-capability balance which can be achieved through the use of the following five general methods: a) direct action to reduce the number and/or intensity of demands, e.g. encouraging the child's independence post-surgery to as great a degree as possible; b) direct action aimed at the acquisition of additional resources not already available to the family, e.g. arranging for home help post-surgery in order that parental emotional and physical energy be maintained; c) the maintenance of existing resources in order that these can be allocated and re-allocated to meet changing demands, e.g. maintaining family unity and social and network support; d) management of tension associated with the persistent strains, e.g. recreational activities, use of humour, exercise, and having an appropriate manner to express pent-up emotions; e) changing the meaning or perception of the situation in order to make it more acceptable, e.g. perceiving oneself and the family as able to cope with the situation, even when one feels overwhelmed. Religious faith can be extremely helpful with respect to appraisal of one's coping strategies.

When dealing with the various demands of a chronically ill child, McCubbin & McCubbin (1987, p.22) point out that coping strategies tend to be grouped together into patterns as opposed to separate behaviors, such as the goal of maintaining family cohesion and unity. When there are multiple family demands, it appears to be more effective to measure coping in terms of a general response rather than situation specific responses.

The Meaning of Adaptation

This complex multivariate model then, attempts to integrate the individual family member, the family system, and the family's community in determining the outcome of the family's responses to stressful situations. In examining each unit it is evident that there are both demands and capabilities. Family adaptation occurs when there is a demand-capability balance, i.e. when the demands of one unit are met by the capabilities of another. Family stress can occur when there is an imbalance at either of two levels, i.e., between family member and family system, eg. when the demands of of an individual family member exceed the family's capability of meeting these demands. The second level of interaction involves balance between the family unit and its community. The family is required to achieve a balance at both the individual-family and family-community levels. McCubbin et al (1981) use the term 'bonadaptation' to describe balance at both levels of functioning which results in a strengthening of the family in terms of its integrity, development, and sense of control over the environment. 'Maladaptation' refers to continued imbalance at either the individual-family or family-community levels or the achievement of a balance at both levels but at the expense of family integrity, personal or family development, or family autonomy. Most often families must reach a compromise and tolerate a less than optimal situation in order to preserve family unity. Compromise is used most often when families are faced with chronic, intractable, stressful situations.

Adaptation or bonadaptation in families with a child with congenital heart disease is indicative of effective functioning at home, in school, and with peers with the child experiencing only those limitations realistically imposed by the defect and any consequences of an interventional procedure. These children are not overly dependent on their families and do not attempt to secure secondary gains from their illness (Mattsson, 1979). The parents of these children tend to enforce only necessary and realistic restrictions, encourage self-care, regular school attendance, and reasonable physical activities with peers.The most common coping strategy used by adaptive parents, as reported by Mattsson (1979, p.260-261), is isolation and denial of anxious and helpless emotions, especially during a medical crisis, which helps them to remain calm and be effective in terms of giving medical care. Very often, feelings of depression and irritability are experienced later when it is "safer to experience them" (p.261). Another coping strategy reportedly used by these families is mastering a feeling of control by learning as much as possible about the disease in terms of its medical, physiological, and psychological aspects. On the other hand, Sargent (1983) describes how in maladaptive families a behavioral spiral develops in which the ill child can be perceived as being highly vulnerable and an overly close relationship with one parent can develop (usually the parent with full responsibilty for medical management); if there were marital difficulties, the parents may become polarized, one becoming overprotective and the other becoming distanced and critical; with increased marital strain the family becomes more rigid, the child's self-esteem suffers, and the child's illness becomes more difficult to control; the family becomes increasingly dysfunctional - the spouses are unable to support one another, maintain clear expectations of their child(ren), and siblings are unable to cooperate and compete with the "symptomatic, vulnerable, overvalued child" (p.983); finally the ill child finds he or she has limited control over his or her body and feels at the centre of significant family stress.

Summary

The foregoing description of the Adaptation Phase of the T-Double ABCX Model denotes the importance of having a model which can incorporate the child, family, and community in assessing the impact of a chronic illness and its acute critical phases. This model lends itself well to the study of families faced with the potential crisis of an interventional procedure on their child with a chronic illness since it explores both the demands facing the family as well as the family's capabilities for meeting these demands. The literature to date has not looked at this particular aspect of congenital heart defects, and studies have yet to determine how and why some families cope so effectively with these potentially overwhelming stressors while other families become considerably dysfunctional.

In the next chapter the methodology for the study which applied several of the significant aspects of the Adaptation phase of the T-Double ABCX Model of Adjustment and Adaptation is presented.

CHAPTER III

METHODOLOGY

In this chapter the subjects involved in this study, the characteristics of the independent and dependent variables studied, the procedure for collecting data, and the method of data analysis are described.

There are specific theoretical factors described in the literature which have been implicated in parental ability to adapt to life crises, in particular, health crises in children. These are: degree of disruption in family life, or pile-up of stresses and strains; parental perception of severity of illness, or parental appraisal of their familial situation; intra-family resources; global beliefs; and coping strategies used by parents.

Research Questions and Hypotheses

The research questions and hypotheses asked in this study explore the ability of parents to adapt to the impact of medical intervention(s) on their child with a congenital heart defect(s) (CHD). Three groups of parents whose children were registered as patients in the Department of Cardiology at a large children's hospital were the targeted subjects. The three groups included parents whose child received interventional surgery or catheterization, and a control group of parents whose child was examined for CHD and diagnosed with a benign heart murmur. The hypotheses and research questions were as follows:

Hypothesis One stated that subjects whose children have experienced interventional procedures for Congenital Heart Defects (CHD) will report more difficulty with family adaptation than subjects whose children were investigated for CHD and diagnosed with a benign murmur.

Research question 1: Is there a significant difference between the groups of parents with respect to family adaptation as measured by the Family Assessment Measure III (FAM) General Scale?

Hypoythesis Two stated that subjects whose children have had interventional procedures for CHD will perceive their children's illness as more severe than parents of children investigated for a heart murmur.

Research question 2: Is there a significant difference between groups of parents whose children experienced medical intervention for CHD and a group of parents whose children were investigated for CHD and were diagnosed with a benign heart murmur in the degree to which they: a) perceive the severity of their child's illness, b) report concerns about their ill child, c) report and utilize coping resources and skills, d) report degree of family hardiness, and e) report beliefs about their role as a parent and feelings/emotions experienced.

Research question 2a: Is there a significant difference between two groups of parents of children with CHD who experience either surgery or an interventional catheterization with respect to the same variables listed in question 2?

Hypothsis Three stated that subjects whose children have experienced interventional procedures for CHD will perceive their child's illness as more severe than the actual medical classification of the defect(s).

Research question 3: Is there a significant difference between parental perception of seriousness of illness and medical classification of seriousness of CHD in their child?

Research question 3a: Is there a significant difference between the Surgery and Catheterization groups regarding medical classification of seriousness of illness?

Hypothesis Four stated that subjects who report more concerns will have greater difficulty with family adaptation than subjects with less concerns.

Hypothesis Five stated that subjects who perceive their family as having a high degree of hardiness will have less difficulty with family adaptation than subjects low on family hardiness.

Hypothesis Six stated that subjects who utilize more coping resources and skills and report satisfaction with their own coping ability will have less difficulty with family adaptation than subjects who report dissatisfaction with their coping skills.

Hypothesis Seven stated that subjects who experience more negative feelings with their experience regarding their child with CHD will have more difficulty with family adaptation than subjects who report more frequent positive feelings.

Research question 4: What is the relationship among the groups between the dependent variable of family adaptation and the independent variables of concerns, family hardiness, coping resources and skills, beliefs and feelings, and perception of severity of illness?

Research question 4a: Is there a relationship between specific empirical data, i.e. descriptive and medical variables such as age of the child, age at diagnosis, time since intervention, number of interventions, number of hospital admissions, parental marital status, and degree of relationship satisfaction, and the degree of family adaptation?

Research question 5: What is the relationship among the groups between parental perception of severity of illness and the other independent variables, i.e. concerns, family hardiness, coping resources and skills, beliefs and feelings, as well as the dependent variable, family adaptation?

Research question 5a: What is the relationship between parental perception of severity of illness and the descriptive demographic and medical variables listed in question 4a?

Subjects and Procedure

The subjects were selected from a computerized listing of families whose children were either treated or assessed for a Congenital Heart Defect between April, 1988 and May, 1989 at British Columbia Children's Hospital. Approximately 50 prospective subjects chosen randomly from the groups were telephoned and asked if they would be willing to participate in the study. Subsequently 220 questionnaire packages were mailed out, which included an Information Sheet introducing the research study, Consent Form, and instructions for completing the questionnaires (see Appendices I, II, & III). Stamped and addressed return envelopes were also provided.

The subjects consisted of fifty-eight families who responded to the mailed questionnaires. These families came from the immediate metropolitan area, as well as smaller urban, rural, and island communities throughout the province of British Columbia (B.C.). The study was limited to:

1) Families of children having had a therapeutic intervention, i.e. surgery or catheterization, for diagnosed CHD, or a clinical investigation of a suspected cardiac defect, i.e. murmur, within the previous year of the date

for sending out the questionnaire package. (The clinical investigation for a suspected murmur involves ultra-sound monitoring of the heart on an out-patient basis and is not an invasive procedure.)

2) Natural or adoptive families, with the child having been in the family since birth or immediately thereafter. This group included both single parent and two parent families.

3) The age range of the children with CHD met the criteria for inclusion within the domain of BCCH guidelines, i.e. birth to sixteen years. In a few cases, for the sake of continuity, children up to eighteen years continue to be followed within the Pediatric Cardiology Department.

4) Families whose primary caregiver willingly spent the time required to complete the questionnaires.

5) Families whose first language was English or whose English was at a sufficient proficiency level to understand and complete the questionnaires without undo difficulty.

Design

The study design involved a survey consisting of mailed questionnaires. As well, two families representing maladaptive and adaptive coping, were interviewed and are described as case studies (see Chapter IV).

The independent variables examined in this study included age of the child with CHD, age at diagnosis, time since intervention, number of medical interventions (this variable applies to the Surgery and Catheterization groups only), number of hospital admissions, parental marital status, degree of parental relationship satisfaction, parental perception of severity of child's illness, parental perception of their concerns regarding their ill child, degree of family hardiness, coping resources and strategies, beliefs and feelings, and spouses' concerns and coping resources/strategies. The dependent variable was family adaptation as perceived by the primary caregiver (subject) completing the questionnaires. Details regarding how each variable was measured follows in the next section.

Instruments

Information on the first seven independent descriptive variables was obtained from the Information Questionnaire (Appendix A), parts of which were developed by the researcher to address the current study population and amalgamated with the Parent Perception Inventory, General Information scale (Hymovich, 1988). The other independent variables were measured as follows:

Perception of Severity of Illness. This is an eight item, five point scale developed by Perry (1982) and modeled after Broussard's Neonatal Perception Inventory (Broussard & Hartner, 1971, cited in Perry, 1982). It was developed to determine parental perception of severity of illness. The items comprise symptoms of congenital heart disease which are most common. The parent is asked how much difficulty his/her child has had with each symptom, ranging from "none" to "a great deal". The last item asks how serious the parent thinks the child's illness is. Values range from one to five for each response, "none" having a value of one and "a great deal" a value of five. The item scores are totaled with a range of 8-40, with higher scores indicating more severe illness perception on the part of the parent.

This instrument was used as an independent variable contributing to pile-up of stresses and strains, as well as situational appraisal.

Hymovich's Parent Perception Inventory (Hymovich, 1988): The measures included in this inventory were designed for use with families of children who have long-term disabilities or chronic illnesses. This inventory is a revised version of the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) (Hymovich, 1983; 1984; Hymovich & Baker, 1985). The PPI consists of six scales: Concerns (64 items); Beliefs and Feelings (34 items); Coping (60 items); General Information (30 items); Siblings (25 items); and Spouse Concerns and Coping (66 items).

Internal consistency and test-retest reliability were determined by Hymovich on a pilot population of 22 parents (12 mothers and 10 fathers). Reliability coefficients ranged from .62 to .93. Validity studies are in progress.

Several of the scales were utilized, as measures contributing to various aspects of McCubbin's T-Double ABCX Model (1987). The General Information Scale, along with thirteen additional items generated by the author, was used to ascertain demographic and parent and child descriptive information; The Concerns and Spouse Concerns Scale were included to assess pile-up of stresses and strains; Beliefs and Feelings, Coping, and Spouse Coping Scales were included to assess resources and coping aspects, as independent variables. The scales are organized on a Likert-type scale with values ranging from 0 to 3 or 0 to 4. Some items are reversed for scoring.

<u>Family Hardiness Index</u> (FHI, McCubbin, McCubbin, & Thompson, 1986): The FHI was developed to measure the characteristic of hardiness which is considered to be a stress resistance and adaptation resource in families to mitigate the effects of stressors and facilitate family adjustment. "Hardiness" as a concept originated with Kobasa (1985) who defined it as a personality characteristic consisting of both behavioral and cognitive components acting as stress buffers. Family hardiness refers to the internal strengths of the family unit characterized by a sense of control over the outcome of life events and hardships, a view of change as beneficial, and an active orientation to the management of stressful situations.

Although McCubbin et. al. (1986) have not normed this scale, they carried out studies on 304 non-clinical families as part of their ongoing research. Means and standard deviation information are available for this population. The FHI is a 20 item instrument which includes four subscales: the Co-oriented Commitment subscale measures the family's sense of internal strengths, dependability, and ability to work together; the Confidence subscale measures the family's sense of being able to plan ahead, being appreciated for efforts, ability to endure hardships and experience life with interest and meaningfulness; the Challenge subscale measures the family's efforts to be innovative, active, and to experience new things and to learn; the Control subscale measures the family's sense of being in control of family life rather than being shaped by outside events. The subjects responded to each statement which described their current family situation as false, mostly false, mostly true, true and not applicable. Nine items had their scores reversed. Total scores range from 18 to 60, with subscale total scores ranging from 9 to 24.

The internal reliability for the FHI is .82. Both construct and concurrent validity studies were carried out, with criterion indices of family strengths hypothesized to be associated with hardiness. Positive correlations resulted from comparing criterion indices of family flexibility, family time and routines (i.e. ability to maintain stability and continuity), family satisfaction, marital satisfaction, and community satisfaction in the range of .11 to .23.

This instrument was included as a measure of family resources and global appraisals or family schemas.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES), McCubbin, Olson, & Larson, 1981): The F-COPES was designed to record effective problem-solving attitudes and behavior which families develop to respond to problems and difficulties. The instrument is made up of 30 coping behavior items which focus on the two levels of interaction outlined in the T-Double ABCX Model: a) individual to family system or internal handling of problems between family members, which refers to the way individual family members handle difficulties via the resources residing within the nuclear system; and b) family to social environment or external handling of problems, which refers to the active behaviors the family use to acquire resources outside the nuclear system (McCubbin, Olson, & Larson, 1987). F-COPES integrates family resources and the meaning perception factors which are identified in family stress theory into coping strategies. This instrument is based on two previously developed inventories by McCubbin et al, the Family Coping Inventory (FCI) (1981) and the Coping Health Inventory for Parents (CHIP) (1979).

There are two major scales, Internal Family Coping Patterns, which has three subscales, a) Confidence in

Problem Solving which reflects the family's appraisal of problems and their sense of mastery; b) Reframing Family Problems relates to the family's perceptual orientation toward stressful events, i.e. is change positive, negative, or neutral?; and c) Family Passivity focuses on inactive or passive behaviors which a family may use, e.g. avoidance, when one is unsure of one's ability to change a situation. The second major scale, External Family Coping Patterns comprises five subscales, a) Church/Religious resources; b) Extended Family; c) Friends; d) Neighbours; and e) Community Resources, such as agencies, programs, counselling services, and the medical community.

The overall reliability for the instrument is .77, with a range of .64 to .70 for the subscales within the first category, and .70 to .87 for the five subscales in the second category. Test-retest reliability studies with a four to five week time lapse on a sample of 150 yielded a total scale reliability of .71. The standardization sample was the largest (N=2740) which was split into two groups and factor analyses carried out with correlations ranging from .39 to .85. The factors involving cognitive adjustment indicated lower test-retest scores in comparison with other factors which reflect more concrete behavioral items. There are separate norms available for adults and adolescents (male and female) for each F-COPES subscale and the total scale.

Each subject rated the 30 items on a five-point Likert-type scale indicating the extent to which they agreed or disagreed. The items were scored 1 to 5, with four items being reversed. The total possible score ranges are 30 to 150, with subscale total score ranges of 20 to 40.

This instrument was included as a measure of problem solving and coping as an independent variable.

Family Assessment Measure III (FAM III), (Skinner, Steinhauer, & Santa-Barbara, 1984): The FAM III is a self-report instrument that provides quantitative indices of family strengths and weaknesses. FAM III, based on a process model of family functioning, emphasizes the "dynamic interaction between the major dimensions of family functioning [as well as] the interface between the intrapsychic subsystems and the interpersonal dimensions of the family system" (Steinhauer, Santa-Barbara, & Skinner, 1984, p.77). FAM III, which is the third revision of FAM, consists of three components: 1) a General Scale which focuses on the family as a system, 2) a Dyadic Relationships Scale which measures relationships between specific pairs in the family, and 3) a Self-Rating Scale which taps the individual's perception of his/her functioning in the family. Each scale provides a different perspective on the functioning of the family. There are seven dimensions which relate to the process model and are incorporated into each scale: Task Accomplishment, Role Performance, Communication, Affective Expression, Involvement, Control, Values and

Norms. In addition to the seven subscales listed above, the General Scale also includes two response style subscales of Social Desirability and Denial. Each scale yields a total score and seven subscale scores.

The FAM III General Scale was used in the current study as the dependent outcome variable measuring adaptation. Each subject rated the 50 item questionnaire on a four point Likert-type scale. The total score ranges are from 7 to 105, and each subscale score ranges from 0 to 15, with the Social Desirability subscale ranging from 0 to 21, and the Defensiveness subscale ranging from 0 to 24.

There are normative data for adults and adolescents (separately) from 'normal' families. Normative data from over 2000 clinical families are available from the authors. The clinical population includes families with a chronically ill member (cystic fibrosis) which increases FAM's relevancy to the current study population.

The FAM III was developed according to a construct validation paradigm. It was administered to 475 families which produced high internal consistency reliability. The alpha reliability coefficients (which measure the consistency and stability of an instrument), ranged from .89 to .95 for the three scales. The median reliability for the 9 subscales from the General Scale was .73. In a sample of clinical families, the intercorrelations among the subscales of the General Scale ranged from .39 to .70. The median correlation of the subscales with social desirability was -.53 (General Scale), and -.48 for defensiveness.

The diagnostic utility of this instrument is evident in its discriminating ability between clinical and nonclinical families, i.e. problem families being those having one or more members receiving professional help for psychiatric/emotional problems, alcohol/drug problems, school-related problems, or major legal problems. The external validity of the FAM III is currently being researched.

Statistical Analysis

The analysis involved the following components:

(1) Means and standard deviations were computed on all questionnaire summary scores for each variable.

(2) Correlation analysis of all the independent objective measures was performed to determine to what degree these measures correlated with each other and the outcome dependent variable, family adaptation (i.e. FAM III).

(3) A rotated varimax factor analysis was carried out on the summary scores of the independent variables in order to isolate the dimensions within these measures which accounted for the patterns of correlations.

(4) Spearman rho nonparametric correlation analysis was computed between the Perception of Severity of Illness: Serious item and the Medical Classification of actual degree

of seriousness of the congenital heart defect in order to determine degree of agreement between these two sets of values. The non-parametric correlation was accompanied by an exact test based on binomial distribution which tested whether the proportion of discordant pairs in which the parental rating was greater than the medical classification occurred mainly by chance, i.e. $p = .5$. (5) One-way Analysis of Variance (ANOVA) was performed on the independent measures as well as the descriptive, demographic and medical variables to determine significant differences between the groups.

([illegible] square analysis for comparison of frequencies [illegible] the groups was used on several occasions.

(7) Step-wise multiple regression analysis was then performed to determine the predictors of family adaptation (i.e. FAM III) from the global summary scores on the independent variables, as well as specific family and child descriptive, demographic and medical variables described in the literature as contributing to family coping and adjustment to illness in a child. The number of variables entering the regression equation was determined by examining a plot of the coefficient of multiple determination versus the number of variables. The cut-off was determined at the point when the residuals leveled off and the independent variables were no longer adding significantly more to the prediction of the dependent variable.

Because of the large number of variables in the study and the relatively small number of subjects, it was necessary to establish a more conservative significance level to control the chance of error. The method used in this study was the Bonferroni method. This involves dividing the generally accepted significance level of .05 by the number of tests within the analysis to establish a new significance level to be applied to the analyses (Godfrey, 1985).

The statistical program used throughout the analysis was Number Cruncher Statistical System (NCSS), versions 5.01 and 5.3 (Hintze, 1987, 1988).

Chapter IV

Results

In this study the impact on parents of an interventional procedure on their child with congenital heart disease (CHD) was explored with respect to how family adaptation is related to perception of severity of illness, concerns, coping resources and strategies, family hardiness, beliefs and feelings. Specific descriptive, demographic and medical variables, i.e. age of child, age of child at diagnosis, time since intervention, number of interventions, number of hospital admissions, parental marital status, and degree of marital satisfaction were also examined in relationship to these variables. Three groups of parents were contrasted, a group of parents whose child received interventional surgery, a group of parents whose child received interventional catheterization, and a control group of parents whose child was examined for CHD and was diagnosed with a benign heart murmur. In this chapter the results of the study are reported.

Study Population

Of the 220 questionnaire sets which were sent out, 20 were returned by the Post Office due to incorrect addresses and were unable to be resent. Fifty-eight (58) sets were returned to the author over a period of two months, representing a twenty-nine percent (29%) return rate. This response rate included thirty-five (35) from the surgery group, representing thirty-five percent (35%) of this sample population; eight (8) from the catheterization group, representing forty percent (40%) of this sample population; and fifteen (15) from the benign murmur group, representing fifteen percent (15%) of this sample population. Of the fifty-eight subjects completing the questionnaires, fifty-five were mothers of the children. The other three questionnaires were completed by the fathers, two in the Surgery group and one in the Murmur group. Two of these fathers were living in a separated or divorced marital situation and shared custody and time with their child(ren) with their ex-spouse. The analysis reported here is based on these fifty-eight subjects.

The families participating in the study were fairly homogenous in their backgrounds with respect to age of parents, years of education, family income, number of years married (excluding single parents), and number of children per family. Analysis of variance did not yield significant differences between the groups on these variables (see Table 1).

Table 2 describes the occupational status and categories for the subjects and their spouses. A large percentage of the responding subjects in the Surgery and Catheterization groups, i.e. mothers, do not work outside

TABLE 1: Means, Standard Deviations, and ANOVA p-values per group for Parental Age, Education, and Income Variables

	GROUPS													
	SURGERY N=35				CATHETERIZATION N=8				MURMUR N=15				ANOVA P-VALUES	
	SUBJECTS		SPOUSES		SUBJECTS		SPOUSES		SUBJECTS		SPOUSES			
	+MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	SUBJ	SPOUSE
VARIABLES:														
AGE	31.57	6.14	35.53	6.37	32.00	5.59	37.00	3.78	35.67	4.67	38.33	6.18	.077	.353
YRS. OF EDUC.	13.23	2.04	12.87	2.21	12.63	1.65	13.29	3.95	14.33	1.49	14.47	2.25	.085	.158
FAMILY INCOME (YEARLY X $1000)	34.49	12.96			3[illegible].00	12.12			40.86	10.01			.253	
NO. YRS. MARRIED	8.11	3.60			7.93	3.86			8.97	3.39			.745	
NO. YRS. SEPARATED ‡	2.80	1.47			1.00	0.00			6.33	3.77				
NO. CHILDREN/FAMILY	2.20	1.58			2.63	1.49			2.00	.63			.607	

+The Mean values are estimated means drawn from categorical data, i.e. the mid-points for each category range were summed and averaged.

‡ These values apply only to those subjects who are separated or divorced within each group.

TABLE 2: Employment And Occupational Information

GROUPS:	SURGERY				CATHETERIZATION				MURMUR			
	SUBJECTS		SPOUSES		SUBJECTS		SPOUSES		SUBJECTS		SPOUSES	
	#	%	#	%	#	%	#	%	#	%	#	%
EMPLOYMENT STATUS:												
EMPL. OUTSIDE HOME	18	51.4	31	96.9	2	25.0	7	87.5	13	86.7	15	100.0
NOT OUTSIDE HOME	17	48.6	1	3.1	6	75.0	0	0.0	2	13.3	0	0.0
MISSING INFO:	3	8.6					1	12.5				
AMOUNT OF WORK:												
FULL TIME	5	14.3			2	100.0			5	33.3		
PART TIME	11	31.4			0	0.0			8	53.3		
MISSING INFO.	2	11.1							2	13.3		
JOB SATISFACTION:												
UNSATISFIED	5	14.3			1	16.6			3	20.0		
NOT SURE	3	8.6			2	33.3			3	20.0		
SATISFIED	18	51.4			3	50.0			8	53.0		
TOTAL (INCL. HOMEMAKERS)	26				6				14			
MISSING INFO.	9				2				1			
OCCUPATION:												
LABOURER	1	2.9	2	6.5	0	0.0	1	14.3	0	0.0	1	6.7
SALES CLERK	2	5.7	2	6.5	0	0.0	0	0.0	0	0.0	0	0.0
CLERICAL	5	14.2	0	0.0	0	0.0	0	0.0	6	40.0	0	0.0
TRADES	1	2.9	7	22.6	0	0.0	1	14.3	0	0.0	3	20.0
TECHNICAL	5	14.2	1	3.2	1	12.5	0	0.0	0	0.0	0	0.0
SALES AGENT	0	0.0	2	6.5	0	0.0	0	0.0	1	6.7	1	6.7
PUBLIC SERVICE	0	0.0	3	9.7	0	0.0	0	0.0	0	0.0	0	0.0
MANAGEMENT	0	0.0	2	6.5	1	12.5	1	14.3	0	0.0	2	13.3
SELF EMPLOYED	1	2.9	5	16.3	0	0.0	1	14.3	0	0.0	0	0.0
PROFESSIONAL	3	8.6	5	16.3	0	0.0	3	42.9	5	33.3	8	53.3
HOMEMAKER	17	48.6	0	0.0	6	75.0	0	0.0	2	13.3	0	0.0
TOTAL	35		31		8		7		15		15	

the home (49% and 75% respectively), whereas only 13% of the Murmur group's parents are Homemakers. Fifty-one percent of the Surgery group's responding parents work outside the home, in jobs ranging from labour to professional categories. The majority of these individuals are working part time. Only two out of eight (25%) responding subjects in the Catheterization group work outside the home, both full time, one in the technical area, and the other in management. In the Murmur group, eight of thirteen working outside the home are working part-time, and five full-time. Forty percent (8) are in clerical positions, and thirty-three percent (5) are professionals. The majority of subjects are currently satisfied with their employment status and position.

The three groups indicate a relatively high degree of marital stability. Twenty-seven (77%) of the Surgery group are currently married, as are six (75%) of the Catheterization group and fourteen (93%) of the Murmur group (see Table 3). Seven (14%) in the Surgery group are currently single parents, being either separated, divorced or never married. At least one of these individuals is currently re-engaged. One other individual from this group lives in a long-term common-law relationship. Two responders (25%) from the Catheterization group are currently single parents, one being separated and the other never having married. Two (13%) subjects from the Murmur group are

TABLE 3: Descriptive Statistics re: Marital Information

	GROUPS					
	SURGERY		CATH+		MURMUR	
	#	%	#	%	#	%
MARITAL STATUS:						
MARRIED	26.00	74.28	5.00	62.50	12.00	80.00
REMARRIED	1.00	2.85	1.00	12.50	2.00	13.33
SEPARATED	4.00	11.43	1.00	12.50	2.00	13.33
DIVORCED	1.00	2.85	0.00	0.00	0.00	0.00
COMMON LAW	1.00	2.85	0.00	0.00	0.00	0.00
TOTAL	35		8		15	
TIMES MARRIED:						
ONCE	30.00	85.71	6.00	75.00	13.00	86.67
TWICE	2.00	5.71	1.00	12.50	2.00	13.33
TOTAL	32		7		15	
# SEPARATED:						
BEFORE DIAGNOSIS	2.00	5.71	0.00	0.00	2.00	13.33
AFTER DIAGNOSIS	3.00	8.57	1.00	12.50	1.00	6.67
TOTAL	5		1		3	

DIVORCE RATE	%
PER 100,000 :1987	
BRITISH COLUMBIA	1.57
CANADA	1.37
REMARRIAGES: 1985	
CANADA	16.19

+CATH : CATHETERIZATION

separated (see Table 3). Thirty subjects (86%) from the Surgery group, 6 (75%) from the Catheterization group, and 13 (87%) from the Murmur group have been married once, while two (5.7%) from the Surgery group, one (12.5%) from the Catheterization group, and two (13%) from the Murmur group have been married twice. Of those separated or divorced, two (5.7%) from the Surgery group and two (13.3%) from the Murmur group did so <u>prior</u> to the diagnosis of CHD in their child. Three (8.6%) from the Surgery group, one (12.5%) from the Catheterization group, and one (6.7%) from the Murmur group separated <u>after</u> the diagnosis (see Table 3).

With regard to religiosity, 22 (64%) from the Surgery group, 6 (75%) from the Catheterization group, and 11 (73%) from the Murmur group described themselves within the context of a particular religion (see Table 4). The Surgery group had the highest percentage (37%) with "no religion" indicated on the questionnaire. Church attendance does not appear to be an important aspect of this population's lives as the majority of respondents in the Surgery and Murmur groups circled "rarely" or "never attend" on this item. The Catheterization group is evenly divided on this issue, with this group also rating Spiritual Support (subscale from the F-COPES measure) a slightly but not significantly more important resource than the other two groups.

The majority of the subjects participating in the study are Caucasian, with three (8.6%) subjects from Asian

TABLE 4: Descriptive Staistics re: Religiosity

	GROUPS					
	SURGERY		CATH		MURMUR	
	#	%	#	%	#	%
RELIGION:						
CATHOLIC	8.00	22.85	3.00	37.50	4.00	26.67
PROTESTANT	9.00	25.70	1.00	12.50	6.00	40.00
OTHER	5.00	14.20	2.00	25.00	0.00	0.00
NO RELIGION	13.00	37.14	1.00	12.50	4.00	26.67
TOTAL:	35		7		15	
MISSING INFO.:			1			
CHURCH ATTEND.:						
OFTEN	3.00	8.57	2.00	25.00	3.00	20.00
SOMETIMES	4.00	11.43	2.00	25.00	4.00	26.67
RARELY	4.00	11.43	1.00	12.50	1.00	6.67
NEVER	23.00	65.71	3.00	37.50	7.00	46.67
	MEAN	S.D.	MEAN	S.D	MEAN	S.D.
SEEK SPIRITUAL SUPPORT	10.73	4.63	13.38	4.69	10.40	4.98 *
MAXIMUM POSSIBLE SCORE:	20.00					

*ANOVA p-value = .335

background, and one (12.5%) of East Indian background. One subject reported that her spouse was of a different ethnic origin than herself (i.e. spouse is a Native Indian) (see Table 5). All of the children were living with their natural parents (see Table 5). Table 5 also indicates that 53 percent of the children in the study are male and 46 percent female.

All three groups reported the health of other family members, including the respondees, spouses, and other children, to be primarily good, very good or excellent (see Table 6). Three (8.57%) subjects from the Surgery group and two (13.33%) from the Murmur group rated their own health as "poor/fair". With respect to spouses, three (11.11%) from the Surgery group, one (16.66%) from the Catheterization group, and two (13.3%) from the Murmur group were rated as experiencing "poor/fair" health.

The final descriptive category relates to the marital or partner relationship. The majority of couples in each group are rated by the subjects themselves as being very satisfied with their respective relationships (see Table 7). Only three (11.11%) of the Surgery group, one (16.66%) of the Catheterization group, and one (6.67%) of the Murmur group rated themselves as being very dissatisfied with their relationship. Two more from the Surgery group rated their relationship as being "somewhat dissatisfying". The majority of the subjects also felt that the diagnosis of congenital

TABLE 5: Ethnic Origin, Birth Origin, and Gender of Children in Study (Identified Patients)

	GROUPS					
	SURGERY N=35		CATH N=8		MURMUR N=15	
	#	%	#	%	#	%
CAUCASIAN	32.00	91.43	7.00	87.50	15.00	100.00
ASIAN	3.00	8.57	0.00	0.00	0.00	0.00
EAST INDIAN	0.00	0.00	1.00	12.50	0.00	0.00
CHILD'S BIRTH						
BIOLOGICAL	35.00	100.00	8.00	100.00	15.00	100.00
GENDER:						
MALE	19.00	54.29	6.00	75.00	6.00	40.00
FEMALE	16.00	45.00	2.00	25.00	9.00	60.00

TABLE 6: Health of Other Family Members

	GROUPS					
	SURGERY N=35		CATH N=8		MURMUR N=15	
	#	%	#	%	#	%
SELF HEALTH:						
POOR/FAIR	3.00	8.57	0.00	0.00	2.00	13.33
GOOD	10.00	28.57	4.00	50.00	7.00	46.67
VERY GOOD	12.00	34.28	3.00	37.50	5.00	33.33
EXCELLENT	10.00	28.57	1.00	12.50	1.00	6.67
TOTAL:	35		8		15	
SPOUSE HEALTH:						
POOR/FAIR	3.00	11.11	1.00	16.66	2.00	13.33
GOOD	9.00	33.33	4.00	66.66	4.00	26.67
VERY GOOD	8.00	29.63	0.00	0.00	8.00	53.33
EXCELLENT	12.00	44.44	2.00	33.33	1.00	6.67
TOTAL:	32		7		15	
OTHER CHILDREN:						
POOR/FAIR	0.00	0.00	0.00	0.00	0.00	0.00
GOOD	4.00	16.60	3.00	42.80	5.00	33.33
VERY GOOD	6.00	25.00	2.00	28.57	4.00	26.67
EXCELLENT	14.00	58.30	2.00	28.57	3.00	20.00
TOTAL:	24		7		12	

TABLE 7: Relationship Factors between Subjects and their Partners

	GROUPS					
	SURGERY N=35		CATH N=8		MURMUR N=15	
	#	%	#	%	#	%
SATISFACTION:						
VERY DISSATISFIED	3.00	11.11	1.00	16.66	1.00	6.67
SOMEWHAT DISSAT.	2.00	6.45	0.00	0.00	0.00	0.00
SOMEWHAT SATISFIED	6.00	17.44	0.00	0.00	2.00	13.33
VERY SATISFIED	20.00	57.14	5.00	83.33	12.00	80.00
TOTAL:	31		6		15	
MISSING INFO.:	1					
EFFECT OF DIAGNOSIS ON RELATIONSHIP:						
MOVED US APART	1.00	3.22	0.00	0.00	0.00	0.00
NOT SURE	3.00	9.67	1.00	14.29	0.00	0.00
NO CHANGE	13.00	41.94	3.00	42.86	13.00	86.67
CLOSER TOGETHER	15.00	48.39	3.00	42.86	2.00	3.57
TOTAL:	32		7		15	
DECISIONS RE:						
CHILD CARE:						
DECIDE ALONE	9.00	27.77	2.00	28.57	1.00	6.67
DECIDE TOGETHER	24.00	72.72	5.00	71.43	14.00	93.33
TOTAL:	33		7		15	
MISSING INFO.	2		1		0	

heart disease (CHD) on their child either did not change their relationship with their spouse/partner, or brought them closer together (see Table 7). Of the Surgery and Catheterization groups 46 percent reported that the diagnosis had brought the couple closer together, and in 41 percent there was no change. Only 3.6 percent of the Murmur group reported that the diagnosis had affected the marital relationship at all and this was in a positive direction. One subject from the Surgery group (3.22%) felt that the diagnosis had moved the couple apart, and three more (9.67%) from the Surgery and one (14.29%) from the Catheterization groups were "not sure". When the two Intervention groups were combined and compared with the Murmur group on the basis of the issue of the diagnosis bringing them closer together, there was a significant difference in the frequency of families drawn closer together in the Intervention groups compared with the Murmur group (p = .02).

The majority of the subjects reported that they and their spouses/partners made decisions together regarding the care of their ill child. Some married subjects who answered "decide alone" to this item, noted other reasons for this, e.g. husband often working away from home.

Table 8 describes the information regarding the child with CHD. The age of the children with congenital heart disease differed significantly between the groups (p = .042)

TABLE 8: Means and Standard Deviations per Group
for Identified Child/Patient Variables

			GROUPS					
	SURGERY		CATH		MURMUR		ANOVA	
	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	p-values	
CHILD AGE (I.P.)	4.75	4.74	2.44	1.03	7.35	4.29	.042	
AGE AT DIAGNOSIS (YRS)	.67	.99	0.00	0.00	3.14	3.69	.0005 ***	
# CATHETERIZATIONS	1.31	.89	2.25	.97	0.00	0.00	.014 *	!
# DIAGNOSTIC CATHS	1.06	.79	1.00	.87	0.00	0.00	.861	!
# TREATMENT CATHS	.20	.40	1.25	.43	0.00	0.00	.0001 ***	!
(% of group)	20.00		100.00					
# OF SURGERIES	1.66	1.14	1.38	1.23	0.00	0.00	.547	!
# MONTHS SINCE INTERVENTION	9.76	3.53	5.63	3.46	N/A		.006 **	!
# HOSPITAL ADMISSIONS	3.66	2.29	4.25	2.44	1.00	1.13	.0004 ***	

!These p-values are computed for the Surgery and Catheterization groups only

* $p < .05$
** $p < .01$
*** $p < .001$

with the Murmur group children being older than the two Intervention groups. The Surgery group's age ranged from six months to eighteen and one-half years with a mean of 4.75 years and a standard deviation of 4.74, and for the Catheterization group the mean was 2.44 years with a standard deviation of 1.03. The age range for the murmur group was 1.4 years to 13.9 years with a mean of 7.35 and a standard deviation of 4.29.

The age at diagnosis did not differ significantly between the Surgery and Catheterization groups, with the former group having a mean age of .67 years and a standard deviation of .99, and the latter group all being diagnosed at birth. The mean age of diagnosis for the Murmur group was 3.14 years with a standard deviation of 3.69. There is a significant difference between the Murmur group and the other two groups on this variable ($p = .0005$).

With respect to medical procedures, the comparisons reported here relate to the Surgery and Catheterization groups. As presented in Table 8, both groups experienced diagnostic and interventional catheterizations, with 20 percent of the Surgery group and 100 percent of the Catheterization group having interventional catheterization. The Catheterization group experienced significantly more interventional catheterizations than the Surgery group ($p < .0001$). The mean number of surgeries was 1.7, with a standard deviation of 1.14 for the Surgery group and a range of one to five; and a mean of 1.4, with a standard deviation of 1.23 for the Catheterization group with a range of one to four. No children in the Murmur group experienced Catheterization or surgical intervention for their condition. The mean number of months since the intervention is significantly different between the Surgery and Catheterization groups (p = .006). For the Surgery Group the time since intervention was 9.76 months with a standard deviation of 3.53 and a range of three to fifteen months (N.B. the time since diagnosis was calculated at the time of the return of the questionnaires, and therefore is longer than one year for some subjects); and for the Catheterization group, 5.63 months with a standard deviation of 3.46 and a range of two to twelve months. Table 8 also summarizes the mean number of hospital admissions, with the Catheterization group having significantly more admissions than the Surgery and Murmur groups (p = .0004), with a mean of 4.25 and a standard deviation of 2.44, and a range of one to eight admissions.The Surgery group had an average of 3.66 admissions with a standard deviation of 2.29 and a range of one to eight, while the Murmur group had an average of 1.0 hospital admission with a standard deviation of 1.13 and a range of one to three, (unrelated to the murmur).

In the next section the results of the five research questions formulated for this study will be discussed in turn.

Research Questions

Hypothesis One. Subjects whose children have experienced interventional procedures for congenital heart defects (CHD) will report more difficulty with family adaptation than subjects whose children were investigated for CHD and diagnosed with a benign murmur.

Research question 1: Is there a significant difference between the groups studied with respect to family adaptation?

The dependent variable, adaptation, was measured using the General Scale of the Family Assessment Measure (FAM III). Overall rating scores (T-scores) ranged from 32 to 65 for the Surgery group, 31 to 62 for the Catheterization group, and 32 to 57 for the Murmur group. The overall rating score was derived from the average of the seven clinical scales with scores falling between 40 and 60 considered to be within the average range, scores below 40 indicating a well adjusted family and scores above 60 indicating a family with possible problems. The means and standard deviations for each group for each of the nine scales and the overall rating scores are reported in Table 9. ANOVAs carried out on the overall rating mean scores, as well as each of the other nine scales do not indicate significance. While there is variability within each group regarding degree of perceived adjustment, the majority of the subjects see themselves as at least adequately adjusted as a family. The scores on the

TABLE 9: Family Assessment Measure, General Scale Means, Standard Deviations, and ANOVA p Values

	SURGERY		CATHETERIZATION		MURMUR		ANOVA
SCALES:	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	p value +
OVERALL RATING	45.97	8.37	46.69	9.46	46.32	7.82	.976
DEFENSIVENESS	51.76	13.94	51.14	10.15	47.47	8.59	.548
SOCIAL DESIRABILITY	54.12	11.06	50.86	8.66	49.07	7.96	.275
VALUES/NORMS	45.45	9.65	44.29	10.29	45.99	8.72	.934
CONTROL	43.73	11.15	46.00	13.09	43.47	11.27	.883
INVOLVEMENT	44.42	10.14	45.57	10.14	44.13	7.71	.943
AFFECTIVE EXPRESSION	45.94	13.43	46.71	9.94	48.47	10.4	.814
COMMUNICATION	46.3	8.67	52.43	7.09	44.67	7.65	.135
ROLE PERFORMANCE	50.64	12.70	44.43	12.16	48.20	9.59	.448
TASK ACCOMPLISHMENT	45.58	9.78	47.29	8.63	49.67	11.06	.446

+ Bonferroni Correction states that p values < .002 are significant at overall .05 level.

scale measuring Role Performance may represent a trend for the Surgery and Catheterization groups in that 32 percent rated this scale in the problem range, whereas only 13 percent of the Murmur group rated this scale in the problem range.

Since there are no significant group differences on the FAM III, hypothesis number one related to interventional procedures and subsequent difficulty with adaptation is not supported.

Hypothesis two. Subjects whose children have had interventional procedures for CHD will perceive their child's illness to be more severe, have more concerns, lower family hardiness, more negative beliefs and feelings, and use fewer coping resources and strategies than parents of children investigated for a heart murmur.

Research questions 2 and 2a: Is there a significant difference between a group of parents whose children experience therapeutic intervention for congenital heart disease and a group of parents whose children were investigated for CHD and diagnosed with a benign heart murmur in the degree to which they perceive the severity of their child's illness, report concerns, report and utilize coping resources and skills, report degree of family hardiness, report negative beliefs and feelings? 2a) Is there a significant difference on these measures between the two CHD groups?

The measures for these independent variables were described in Chapter III. The first step in this section of the analysis involved a Pearson Product-Moment Correlational analysis of the above stated variables with one another on the total sample. The overall alpha reliability coefficient was .45. A Bonferroni correction was applied due to the number of variables in relationship to subjects and the significance level was established at .0001. The results of the correlation analysis between the independent measures are illustrated in Table 10.

Factor analysis was carried out on these independent variables in order to obtain a simplified interpretation of the correlation matrix. The dimensions within the independent variables which accounted for the correlation results were determined by the factor analysis and four factors explain 78 percent of the data. The first factor, which explains 40 percent of the data includes parental concerns regarding the ill child and experienced emotional feelings; the second factor, explaining approximately 18 percent of the data, includes the coping frequency and coping helpful variables; the third factor, explaining approximately 10 percent of the data includes parental beliefs regarding their role as a parent; and the fourth factor, explaining approximately 9 percent of the data, includes the specific coping strategies used by the families in crisis situations (see Table 11).

TABLE 10: Correlations of Independent Measures: Total Scale Scores

SCALES +	1	2	3	4	5	6	7	8	9	10	11	12
1. PSI	1.00	.42 **	.43 **	-.27	.03	.13	.30	.27	.17	-.29	.26	.13
2. PPICONC		1.00	.85 ****	-.57 ****	-.01	-.22	.52 ****	.33	.26	.49 ***	.30	.45
3. PPISPCONC			1.00	-.38 **	.04	-.13	.47 ***	.35	.19	-.40 **	.35 **	.36
4. FHI				1.00	.25	.03	-.67 ****	-.39 **	-.11	.44 ***	.25	-.58 ****
5. FCOPES					1.00	-.08	-.18	.12	.28	.16	.13	-.25
6. PPIBELIEFS						1.00	-.16	-.28	-.31	.19	.24	-.03
7. PPIFEELINGS							1.00	.48 ***	.12	-.51 ****	.31	.44 ***
8. PPICOPFRQ								1.00	.73 ****	-.57 ****	.84 ****	.34
9. PPICOHLP									1.00	-.17	.71 ****	.09
10. PPISLFCOPE										1.00	-.43 **	-.38 **
11. PPISPCOPE											1.00	.35
12. FAM												1.00

\+
PSI = PERCEPTION OF SEVERITY OF ILLNESS
PPICONC = PARENT PERCEPTION INVENTORY, CONCERNS SCALE
PPISPCONC = PARENT PERCEPTION INVENTORY, SPOUSE CONCERNS SCALE
FHI = FAMILY HARDINESS INVENTORY
FCOPES = FAMILY COPING ORIENTED PERSONAL EVALUATION SCALE
PPIBELIEFS = PARENT PERCEPTION INVENTORY, BELIEFS SCALE
PPIFEELINGS = PARENT PERCEPTION INVENTORY, FEELINGS SCALE
PPICOPFRQ = PARENT PERCEPTION INVENTORY, COPING FREQUENCY SCALE
PPICOHLP = PARENT PERCEPTION INVENTORY, COPING HELPFUL SCALE
PPISLFCOPE = PARENT PERCEPTION INVENTORY, SELF COPING PERCEPTION SCALE
PPISPCOPE = PARENT PERCEPTION INVENTORY, SPOUSE COPING SCALE
FAM = FAMILY ASSESSMENT MEASURE III

** $p < .01$
*** $p < .001$
**** $p < .0001$

TABLE 11: Factor Analysis of Independent Measures

VARIABLE +	FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4	COMMUNALITY
1. PSI	.63	-.26	.43	-.01	.65
2. PPICONC	.92	-.11	-.14	.06	.88
3. PPISPCONC	.83	-.14	.09	.18	.75
4. FHI	-.66	.11	.20	.46	.70
5. FCOPES	.05	-.18	-.19	.82	.75
6. PPIBELIEFS	-.13	.18	.86	-.12	.81
7. PPIFEELINGS	.72	-.17	-.31	-.34	.76
8. PPICOPFRQ	.31	-.89	-.20	-.08	.94
9. PPICOHLP	.07	-.87	-.13	.25	.84
10. PPISLFCOPE	-.53	.36	.24	.44	.66
11. PPISPCOPE	.14	-.90	.06	-.03	.83

\+

PSI = PERCEPTION OF SEVERITY OF ILLNESS

PPICONC = PARENT PERCEPTION INVENTORY, CONCERNS SCALE

PPISPCONC = PARENT PERCEPTION INVENTORY, SPOUSE CONCERNS SCALE

FHI = FAMILY HARDINESS INVENTORY

FCOPES = FAMILY COPING ORIENTED PERSONAL EVALUATION SCALE

PPIBELIEFS = PARENT PERCEPTION INVENTORY, BELIEFS SCALE

PPIFEELINGS = PARENT PERCEPTION INVENTORY, FEELINGS SCALE

PPICOPFRQ = PARENT PERCEPTION INVENTORY, COPING FREQUENCY SCALE

PPICOHLP = PARENT PERCEPTION INVENTORY, COPING HELPFUL SCALE

PPISLFCOPE = PARENT PERCEPTION INVENTORY, SELF COPING PERCEPTION SCALE

PPISPCOPE = PARENT PERCEPTION INVENTORY, SPOUSE COPING SCALE

Group Differences

With respect to group differences, a one-way analysis of variance was carried out on the means between the groups on the independent variables listed in Table 12. Perception of Severity of Illness (PSI) indicated a significant difference ($p = .003$) with the Catheterization group perceiving their child's illness as significantly more severe than both the Surgery and Murmur groups, and the Surgery group perceiving their child's illness as significantly more severe than the Murmur group. (see Table 12). Further analysis within this measure indicated that there was also a significant difference between the groups with respect to the item measuring perceived seriousness of illness ($p<.01$) (see Table 13), with the Catheterization group seeing their child's illness as significantly more serious than the Surgery and Murmur groups, and the Surgery group seeing their child's illness as significantly more serious than the Murmur group ($p<.01$).

Hypothesis two relating to perception of severity of illness was thus supported.

Hypothesis three: Subjects whose children have experienced interventional procedures for CHD will perceive their child's illness as more serious than the actual medical diagnosis.

Research question 3: Is there a significant difference between parental perception of severity of illness and

TABLE 12: Means, Standard Deviations, and ANOVA p-values for Total Scores on Independent Variables

	GROUPS						
	SURGERY N=35		CATHETERIZATION N=8		MURMUR N=15		ANOVA p-value+
	MEAN	S.D.	MEAN	S.D.	MEAN	S.D.	
PSI	17.69	7.06	23.50	7.98	13.07	4.23	.003 *
PPI CONCERNS	46.83	28.25	52.88	21.86	44.80	25.91	.796
PPI SP. CONCERNS	32.38	22.53	43.00	15.70	31.46	20.28	.410
FAMILY HARDINESS	47.17	7.58	43.88	7.85	44.27	7.56	.355
F-COPES	108.41	15.20	105.75	12.15	101.20	13.90	.308
PPI BELIEFS	22.29	2.98	22.63	2.23	20.93	2.21	.233
PPI FEELINGS	19.54	12.38	23.38	12.59	22.27	11.45	.734
PPI COPING (FREQUENCY)	41.74	12.74	45.25	10.00	41.67	17.22	.807
PPI COPING (HELPFUL)	29.18	9.72	27.63	8.76	27.00	12.14	.552
PPI COPING (SOURCES USED)	5.43	2.35	5.63	2.78	4.67	2.33	.795
PPI COPING (PERSONAL COPE SC.)	14.00	2.66	11.38	2.12	12.93	3.84	.080
PPI SP. COPING	36.45	9.69	39.00	7.71	39.27	16.30	.721

* $p < .01$

+ Bonferroni Correction states that p values < .004 are significant at overall .05 level.

TABLE 13: Analysis of Variance between the groups regarding the Serious factor on the Perception of Severity of Illness Scale

Group	Mean	S.D.	prob>F
Surgery	2.91	.241	.0049 **
Catheterization	3.25	.504	
Murmur	1.53	.368	

**p < .01

actual medical classification of the congenital heart defect in their child?

<u>Research question 3a:</u> Is there a significant difference between the Surgery and Catheterization groups regarding medical classification of seriousness of illness?

Nonparametric correlation was used to determine the degree of agreement between the subjects' and the Cardiologists' classification for this question. A Spearman's rho correlation was .262 (p= 0.1) which indicates a slight but insignificant degree of association in the two ratings (see Table 14). Table 14 also presents a 5 by 5 table depicting the scores on this item compared with the medical classification values. Ten out of forty-three subjects agreed with the medical classification, nine out of thirty-three subjects saw their child's defect as less serious than the medical classification, and twenty-four out of thirty-three saw their child's defect as more serious. Within the total sample of 43 subjects experiencing interventional procedures, 56 percent of the subjects post-intervention continue to see their child's condition as moderately to severely serious while 44 percent no longer consider their child's condition to be serious. In comparison, the actual medical classifications rate 40 percent of the sample population in the moderate to severe category post intervention. A method of looking at these results is analogous to McNemar's Test for agreement in

TABLE 14: Comparison between Parental Perception of Seriousness of their Child's Illness and Medical Classification of seriousness of CHD for both the Surgery and Catheterization groups

		MEDICAL CHD CLASSIFICATION					
		1	2	3	4	5	TOTAL
PARENTAL PERCEPTION OF SERIOUSNESS	1	5	2	3	0	0	10
	2	4	2	2	1	1	10
	3	2	3	1	0	0	6
	4	2	1	1	1	0	5
	5	1	5	4	1	1	12
TOTAL		14	13	11	3	2	43

MEAN of CHD CLASSIFICATION = 2.21
SD = 1.13
MEAN of PARENT PERCEPTION = 2.98
SD = 1.57

Spearman's rho = .261524 (N.S.)
p = 0.1

matched pairs which tests the significance of the difference between two correlated qualitative outcomes (Ferguson, 1971). Within the two sets of observations reported here regarding parental perception of seriousness of illness and actual medical classification, if there is no difference in perception of seriousness the chance of observing nine or fewer out of 33 cases where medical classification was more serious than parental perception is .007. In other words, if we flip a coin 33 times, it is unlikely that we will see 9 or fewer heads (see Table 14). Hypothesis three was thus supported.

When the Surgery and Catheterization groups are compared with regard to medical classification of seriousness of CHD, a chi-square test indicates a difference in proportions in the five categories with the Catheterization group exhibiting a propensity towards higher, or more severe classification (p=.0074) (see Table 15).

Predictors of Adaptation

The remaining questions concerning predictors of adaptation from the independent variables were answered by means of regression analysis. Because of the significance of the difference between the groups on the Perception of Severity of Illness factor, it was also decided to run another regression analysis, with the PSI as the dependent variable. Because of the small size of the groups, the regression analysis was run on the whole sample combined,

TABLE 15: Comparison between the Surgery and Catheterization Groups regarding Medical Classification of Seriousness of CHD

MEDICAL CLASSIFICATION:	1	2	3	4	5	TOTAL
SURGERY GROUP	13	12	7	3	0	35
CATHETERIZATION GROUP	1	1	4	0	2	8
TOTAL	14	13	11	3	2	43

CHI-SQUARE: p = .0074

and therefore the results here reflect both responses by subjects whose children had interventional procedures performed for their heart defect, as well as subjects whose children were only investigated for a suspected heart defect.

Hypothesis four: Subjects who report more concerns will have greater difficulty with family adaptation than subjects with less concerns.

Hypothesis five: Subjects who perceive their family as having a high degree of hardiness will have less difficulty with family adaptation than subjects low on family hardiness.

Hypothesis six: Subjects who utilize more coping resources and skills and report satisfaction with their own coping ability will have less difficulty with family adaptation than subjects who report dissatisfaction with their coping skills.

Hypothesis seven: Subjects who experience more negative feelings associated with their experience regarding their child with CHD will have more difficulty with family adaptation than subjects who report a higher degree of positive feelings.

Research question 4: What is the relationship among the groups between the dependent variable of family adaptation and the independent variables of concerns, family hardiness, coping resources and skills, beliefs and feelings, and perception of severity of illness?

Research question 4a: Is there a relationship between specific descriptive and medical variables, i.e. age of the child, age at diagnosis, time since intervention, number of interventions, number of hospital admissions, parental marital status, and degree of relationship satisfaction, to the degree of family adaptation?

The variables included followed the conceptual model of the study design, i.e. the factors measuring pile-up of stresses and strain, situation and global appraisal, resources and coping measures, and specific child medical and descriptive variables. In all, twenty-one variables were used in the first regression analysis. The results of the first regression analysis are presented in Table 16.

The results of the regression analysis indicated Family Hardiness was a significant predictor of adaptation in this sample ($p = .0001$). The Family Hardiness Inventory (FHI) had a p value of .000002 and a multiple R-squared value of .3489 in relation to the outcome variable. After adjusting for FHI, no other variable had an effect on the overall rating score of the FAM III. Hypothesis five regarding the positive effect of family hardiness on the outcome variable, adaptation, was thus supported, i.e. the FAM III scores decreased (indicating more effective adaptation) with higher FHI scores.

TABLE 16: Regression of the Independent Variables with the Overall Rating Score of the Family Assessment Measure

VARIABLES	PARAMETER ESTIMATE	STANDARD ERROR	P-VALUE
INTERCEPT	76.36901	5.744618	0.0000
FAMILY HARDINESS	-.656589	.123193	0.0000 ****

**** p < .0001

Hypotheses four, six, and seven were not supported as being predictive of family adaptation.

It is noted here that although the Correlation Analysis indicated either a significant correlation or trend between other hypothesized variables (concerns, feelings, and coping satisfaction) and FAM III, these variables did not prove to be predictive of the outcome variable when entered into a regression equation after accounting for family hardiness.

Research question 5: What is the relationship among the groups between parental perception of severity of illness and the other independent variables, i.e. concerns, family hardiness, coping resources and skills, beliefs and feelings, as well as the dependent variable, family adaptation ?

Research question 5a: What is the relationship between parental perception of severity of illness and the descriptive demographic and medical variables listed in question 4a?

The results of the second regression analysis, which examined which factors might be predictive of perception of severity of illness (PSI), indicated that the number of diagnostic catheterizations, and number of parental concerns (PPICONC) were most significantly predictive with a p-value of .000001 and a multiple R-squared of .5017. The number of interventional catheterizations was also predictive of the PSI score (p=.01). After adjusting for parental concerns

(PPICONC), and number of Diagnostic and Treatment Catheterizations, no other variables had an effect on the PSI (see Table 17).

Parental Feelings

Parents were encouraged to comment on any aspect of their experience regarding their child with CHD or a benign murmur. There were a few subjects in each group who wrote comments regarding their personal experience, the stresses they felt were most difficult, and what helps them to continue coping. The following summarizes these comments from the Surgery and Catheterization groups:

1) Concerns about behavioral changes in self in relation to degree of stress and frustration experienced regarding CHD, eg. a parent described feeling at times out of control, less able to manage misbehavior in other children, physically lashing out at husband (who she considered to be extremely supportive), and having childlike temper tantrums, especially when child ill or when another child with CHD she knows is not doing well or dies. This parent questionned her own "normalcy" and found her reactions frightening not only to herself, but others around her. 2) Financial concerns were raised by a few parents, especially single parents, since they did not feel they could leave their child to go out of the home to work. These parents remained dependent on their family of origin for

TABLE 17: Regression of the Independent Variables with the Summary Score of the Perception of Severity of Illness Scale

VARIABLES	PARAMETER ESTIMATE	STANDARD ERROR	P-VALUE
INTERCEPT	7.218914	1.629997	0.0000
DIAGNOSTIC CATHETERIZATION	4.314463	.8557213	0.0000 ****
INTERVENTIONAL CATHETERIZATION	3.434675	1.351125	.0139 *
PARENT PERCEP. INV: CONCERNS	.1213341	.263	0.0000 ****

*p=.01

**** p < .0001

support or Social Services. Other parents who felt there were financial concerns related these to having to travel for medical care, as well as requiring special foods and vitamins for their child they would not normally have required. 3) One parent wrote about the stress she felt to be overwhelming when her child was diagnosed at birth and transferred from another community to BCCH for treatment, and there was no accomodation for her as a new mother close to her child. 4) Another parent noted that the regular trips to Doctors and the Hospital are painful reminders of her child's condition, and are found also to be stressful because of the expense and the fact that the family is divided for periods of time.

Some parents also took the time to comment about what has helped them cope with the stresses of the interventions, eg. having a deep faith in God and their religion and a strong belief that their child was given to them by God and therefore it was God's decision how long they would have her to enjoy. Another parent expressed ambivalence regarding the interventions, feeling thankful for the existence of the medical technology which has saved her child, despite the emotional suffering she experiences whenever her child has undergone an intervention.

Parents of children diagnosed with a benign murmur more often stated that the heart "problem" was not a concern for them since it did not affect their children's lives, nor the family's. However, five of these families were dealing with illnesses in their children which were more of a concern, i.e., asthma, severe food allergies, juvenile diabetes, and learning disabilities. One parent made note of her own serious health problems and significant concern regarding her child(ren) developing the same illness later on in life as well. Other parents in this group made note of the day to day stresses of looking after preschool children, which they felt could be overwhelming at times.

Two case studies which illustrate bonadaptive and maladaptive coping are presented below:

Case Study 1

Family A consists of two parents and three children, ages five, three, and 17 months at the time of the interview. The youngest child (B) was the identified patient, his congenital heart defect having been diagnosed at the age of eight weeks. The two older children have no health problems. The father is a career police officer, and the mother is a full time homemaker.

At the time the questionnaire package was completed by the mother, the family had just experienced the death and funeral of the child of close friends, who had had his first surgery for a congenital heart defect at the same time as B, and the families had become close friends over the ensuing year. Mrs. A. noted that she felt that she and the other mother provided a great deal of support for one another, despite living in different communities in the province. The A's felt their friends' loss very deeply, since their situations were so similar, despite the difference in actual diagnosis. Mrs. A described the difficulties she had in handling the stress she was experiencing, and felt frustrated with the way in which she expressed her tension. She found that since B's first surgery, she had experienced numerous occasions when she would lose control and become hysterical, physically hitting out at her husband, throwing things, slamming doors, and on one occasion she hit one of her other children unusually hard for misbehavior. Mrs. A. described this behavior as previously alien to herself and she now questionned her own normalcy. She also noted that her marriage was very stable, and that her behavior was frightening both to herself and her husband. She described her husband as extremely supportive and understanding, feeling that "he is the best husband anyone could have."

B's congenital heart defect (CHD) is rated medically as being corrected, after two surgeries in the first seven months of life. Currently he is small for his age and has experienced numerous viral infections which are described by Mrs. A. as always being severe and long-lasting. While B's physicians feel that his health problems are not significant and are unrelated to his CHD, Mrs. A is not convinced of this factor and feels that if any immunological deficits exist, they are directly related to his heart rather than being maturational in nature. B has undergone many further tests and x-rays in response to his mother's continued concerns about him. Her lack of confidence in medical opinion is related to two experiences with physicians in her own community in which her child's condition was misdiagnosed. She has not yet found medical support in her own community she feels she can trust. On the other hand, Mrs. A. expressed a good deal of trust in all the staff at the BCCH, stating she felt they were more like family to her, in particular the nurses, technicians, and nurse clinician since she had spent so much time there. Although she also expressed trust in her child's Cardiologist, she still remained unconvinced of his opinion regarding B's current health status.

The scores on the questionnaires reflect some of Mrs. A's difficulties, being significantly higher than the mean for the study population on Perception of Severity of Illness, Concerns, Spouse Concerns, and F-Copes. This latter scale measures effective problem-solving attitudes and behavior which families develop to respond to problems, a high score being indicative of a family making significant use of external supports, both professional, spiritual, and community, as well as reframing their situation in a more favorable manner. Mrs. A. rated her family slightly above the mean on Family Hardiness, slightly below the mean for beliefs which influence her family's way of living, and slightly above the mean on Feelings. With regard to the latter, Mrs. A's feelings reflect ambiguity, describing herself as feeling confident and in control, yet at the same time also feeling guilty about her child's condition and helpless. Other feelings acknowledged as occurring often were anger, anxiety, disappointment, sadness, and uneasiness as well as some positive feelings such as happiness, hopeful, pleased, and satisfied. Mrs. A's emotional lability was tied very closely into her child's wellbeing, feeling positive and encouraged when he showed no signs of illness, and feeling totally depleted when he contracted a virus. On the PFI Coping Questionnaire, Mrs. A noted that although she felt satisfied with the way in which she had been coping, she would still like help with some problems. On the Spouse Coping section, Mrs. A rated her spouse as coping "fairly well", noting that the coping skills he utilized most often were avoidance methods, such as keeping busy with other things (i.e. finishing their basement in their home), hiding his feelings, exercising, trying to relax, and sleeping more. On the Fam III, Both the Defensiveness and Social Desirability Scales were slightly elevated. No other scales were elevated and the overall rating presented an extremely well functioning family.

At the time of the interview, a few months later, Mrs. A did not feel she was coping as well as she had described herself previously on the questionnaires and was feeling worn out. She remained very concerned about her child's health, and felt that residual problems were significant and related to his CHD. She noted with the author that the time when she completed the questionnaires was one of relative stability regarding B's health and she was feeling encouraged. She was more recently experiencing stresses and strains emotionally, physically, and financially due to her child's needs. She also had not allowed anyone other than her spouse to care for B. and consequently, she and her spouse had not spent any time together as a couple since B's birth. She was finding it difficult to meet her other children's emotional needs, in particular the next oldest child, and felt in a state of constant fatigue. Her bond with B had grown to be abnormally close, and she recognized that she was not giving him enough space to become more independent. For example, B, at seventeen months still did not go to bed before very late at night and did not sleep through the night, waking two or three times, even when not ill. It was difficult for Mrs. A to see some of B's behavior as being developmentally normal manipulative behavior which required a firm parenting structure rather than the overindulgence and overprotectiveness that was occurring. Mrs. A also realized that she had gotten into a habit of using B as a crutch in order to avoid outside commitments.

The Cardiologist involved in this case considered Mrs.

A to be having the most difficulty of any parent he had dealt with regarding coping with her child's condition and expressed concern not only for her and B but also for the medical staff with respect to feeling manipulated into doing unnecessary tests on B. in order to placate Mrs. A's concerns.

* * N.B. Because of the author's concern regarding Mrs. A subsequent to our interview, a follow-up telephone call was made to her approximately one month post with the intent of providing some further suggestions regarding counselling other than those discussed at our interview. Mrs. A reported that since our discussion she had decided to begin to do more things for herself personally, and was feeling encouraged with her child's progress. A recent lung x-ray had indicated no changes or deterioration, and she was feeling more positive about his recovery. Mrs. A noted with the author that she had found our interview therapeutic since she felt it had been the first time she could fully unload all her worries, have an objective perspective and not feel judged. One month later however, the author received three distress calls regarding this subject, from her Family Physician, a Cardiology staff member, as well as Mrs. A. Her child had experienced another round of viral infections and Mrs. A. had requested an admission to hospital for him. When she disagreed with the advice given

she discharged him herself. Mrs. A. agreed that she needed counselling and steps were taken to ensure that this occur.

Case Study 2

Family R consists of two parents and three children, ages nine, six and three. The three year old was the identified patient, having been diagnosed with CHD in utero. This child had a twin who died a few days after birth from another congenital abnormality. This family had also lost another infant seven years previously from the same congenital abnormality. The father in this family is a police officer and the mother, currently a homemaker, had been a nurse for ten years and stopped nursing between the births of her first and second children. Mrs. R also volunteers as a teacher's aide one day a week at her children's school as well as teaching Sunday School. Religious beliefs play a primary role in this family's life in all respects.

At the time that the questionnaire was completed, the family had recently completed a move involving change of home, location, husband's job, and children's school. Mrs. R noted on the Parent Perception Inventory, Concerns Questionnaire that her responses reflected these issues as well as issues concerning the care of her children and ill child.

The identified patient, D, has, since birth, experienced two diagnostic catheterizations, one interventional catheterization, and two surgeries, four months apart. She will require more surgery in the future. D has also been hospitalized a few other times due to emergent need of medical care directly related to her CHD. Mrs. R, because of her extensive nursing background, feels capable of caring for most of her child's needs at home and noted that the medical staff trust that she will bring D to hospital when necessary. Mrs. R feels that had she not had the medical background she does have, her child would be more closely followed by the medical staff. Her own goal is to normalize her child's life as much as possible in order to provide her with the emotional strength to withstand future interventions. She currently sees the prognosis as poor, but has strong faith that whatever possible can be done for her child will be. In the meantime, while D's health is monitored closely, the family does not overprotect her or have behavioral expectations of her that are different from the other children.

Mrs. R's responses on the questionnaires reflect both her realistic perspective regarding her child's illness and the strong religious beliefs shared by the family which have helped them cope with not only the crises experienced with this child's health, but also their previous losses. Mrs. R noted that she feels better able to deal with D's condition and each crisis that occurs because of having had to deal with loss and grieving twice before. Although Mrs. R's scores are primarily close to the study population mean, there are a couple which deserve mention. Spouse Concerns, as rated by the primary caregiver, reflect a somewhat higher score than the group mean, with "wondering what our child's future is likely to be" the greatest concern. The F-Copes score is significantly higher, reflecting more reaching out to others for support, including family, friends, spiritual community, and professional community than others in the study population. Mrs. R describes feeling content, good, thankful, happy, and pleased very often, and often feels in control, confident, and hopeful, as well as noting that she also often experiences anger, anxiety, and frustration. Her spouse reportedly uses numerous coping methods, such as very often asking questions, trying to figure out what he can do, seeking information, praying, keeping busy, and sometimes talking with others, trying to forget, hiding feelings, trying to relax, reading about the problem, and trying to change things. She rates their family as being extremely well adjusted on the FAM III, with the Defensiveness and Social Desirability Scale scores falling within the normal range for validity.

Summary of Results

The results of this study found that one independent variable, family hardiness, was predictive of family adaptation within the sample population which included parents of children who had interventional procedures for CHD and parents of children who were investigated for a heart murmur. Three hypotheses were supported by the findings in this study. Hypothesis 2 which stated that subjects whose children have had interventional procedures for CHD will perceive their child's illness as more severe than parents of children investigated for a heart murmur was supported, indicating a significant difference between the groups. Also the hypothesis stating that subjects whose children have experienced interventional procedures for CHD will perceive their child's illness as more serious than the actual medical classification of seriousness of the defect(s) was supported. The third hypothesis supported stated that subjects who perceive their family as having a high degree of hardiness will have less difficulty with family adaptation than subjects low on family hardiness. Three independent variables - number of diagnostic catheterizations, number of interventional catheterizations, and number of parental concerns - were found to be predictive of perception of severity of illness. The feelings documented by several parents are summarized, and two illustrative case studies are presented. In the next chapter a discussion of these results is presented.

Chapter V

Discussion

In this chapter the findings of the study and the theoretical implications of the results will be discussed. Conclusions, limitations, practical implications, and suggestions for future research will also be presented.

Discussion of Findings

The purpose of this study was to examine adaptation in parents whose child with a congenital heart defect (CHD) had one or more invasive interventional procedures within the previous year. A secondary aspect of the study was to compare the adaptational ability of these parents with parents of children investigated for CHD and diagnosed with a benign heart murmur.

The current study examined parental adaptation to a potential crisis situation -interventional procedures on their child with CHD - through the application of five factors derived from the Family Adaptation phase of the T-Double ABCX Model of Adjustment and Adaptation: Pile -up of stresses and strains, family strengths and resources, the family's appraisal of the situation, the family's schema or world view, and family problem-solving and coping responses.

The results of the study will be discussed on a hypothesis-by-hypothesis basis.

Family Adaptation

The first hypothesis which stated that parents whose child experienced an interventional procedure for CHD will report more difficulty with adaptation than parents whose child was investigated for a heart murmur was not supported. The majority of parents in the study scored within the average range on the adaptation measure, with only three subjects (7.5 percent) in the intervention groups having overall rating scores in the problem range, and none in the Murmur group. This would appear to present an extremely well functioning sample.

It is important to note here that 60 percent of the Intervention group (i.e. Surgery and Catheterization) and 40 percent of the Murmur group had T-scores over 50 on the Defensiveness Scale, and 53 percent of the Intervention group and 46 percent of the Murmur group had standard scores over 50 on the Social Desirability Scale. The author feels that the high defensiveness scores may be explained in light of an ongoing process of denial which, when incorporated as a response to stress as a coping strategy, is self-protective by means of helping the individual to avoid feeling overwhelmed while gathering the strength to develop other coping resources.

Denial also enables an individual to have temporary distance from painful memories. Many of the parents in this study, despite agreeing to take part by completing the questionnaires, may have realized the questions aroused unexpected emotions or were surprised with their actual emotional response regarding a situation they thought had been ameliorated, i.e. their child's heart defect having been successfully or at least partially corrected.

Another explanation for this outcome may involve parental need to present themselves to others (e.g. medical community) as stronger than they actually are or feel in the hopes that this will become a self-fulfilling prophecy. These parents may also be aware of the effect of their own emotions on the emotional and medical stability of their child. For example, Janis (1951), in studies regarding coping during World War II, determined that children's responses to the horrors around them reflected their parents' level of emotional upset. This hypothesis was also made later by Kitchen (1973) regarding the child described earlier in this study who died post-intervention despite successful surgery - hypothetically because of ongoing family disruption and a lack of hope that his environment would change.

Another factor for parents who present themselves as strong and coping well may be the perceived necessity that they <u>have</u> to be strong in order to help their child, and therefore put their own needs on a shelf until it is either safer or permissable to express them, e.g. "when this is all over (i.e. child is well) I will look after myself."

Many researchers and writers (Bettelheim, 1943; Chodoff, 1986; Garbarino, 1989; Moos, 1986; Pines, 1989) explain successful coping and adaptation in terms of a strong ideological focus which has been shown to sustain individuals under extreme stress, for example Nazi concentration camp survivors, and more recently, those on both sides of the Palestinian conflict. Although a strong ideological focus with regard to religious belief was not a common element within the current study population, it certainly was a 'pillar of strength' for those for whom it was, e.g. "We believe that things will work out for the better if we work together as a family...and trust in God", "We know God's hand designs our lives".

Perception of Severity of Illness

The second hypothesis regarding differences between the groups on the independent measures of perception of severity of illness, concerns, family hardiness, beliefs and feelings, and coping resources and strategies was supported only for perception of severity of illness, with the Catheterization group subjects perceiving their child's illness as significantly more severe than the other two groups. The Surgery group subjects perceived their child's illness to be significantly more severe than the Murmur group. Hypothesis three, regarding parents of children with CHD perceiving their child's illness as more serious than the actual medical classification of seriousness was also supported, even with the Intervention Catheterization group receiving a significantly more serious medical classification overall than the Surgery group.

These results corroborate earlier studies which have found perception of severity of illness to be directly related to the occurrence of surgery (Offord, 1972; Perry, 1982; Jessop & Stein, 1985;), with parents of children having major surgical procedures more prone to perceiving their child's illness as more severe, as well as the presence of surgery having other negative effects on the family. Other studies involving handicapped and chronically ill children (Jessop & Stein, 1985; Bristol, 1987) found that more marginally handicapped and ill children with normal appearance had more negative effects on the parental coping and tended to be seen as more sick and caused more frequent disagreements between the parents than more severely handicapped or ill children.

The findings of the current study temper earlier studies which concluded that maternal anxiety and overprotection were primarily related to poor psychological adjustment and anxiety in the child. Perception of severity of illness appears to be the pivotal aspect for adjustment. The theme running through these studies, including the present study, appears to relate to the concept of ambiguity or uncertainty. Parents may reflect this uncertainty especially when faced with an unpredictable prognosis or current medical status. Uncertainty is emotionally unsettling and can interfere with an individual's ability to stabilize their situation. Chodoff (1986, p.407), in his treatise regarding the survivors of the Nazi Holocaust, provides an insight from Viktor Frankl, who himself was a prisoner in Auschwitz, "...the absolute uncertainty of (their) condition was a barrier to the erection of adequate psychological adaptive measures..." In the current study, the result obtained of 76 percent disagreement between parents' perception of seriousness of illness and the actual medical classification of seriousness appears to point towards feelings of uncertainty regarding the post-intervention diagnosis and prognosis of their child's illness for these parents, regardless of the outcome of the intervention. The more ambiguous the parent feels the child's health status to be, the more difficulty the parent has in accepting the diagnosis.

For example, in Case Study 1, the mother continues to believe that her child is not well (and that his health status is directly related to his heart defect which has been corrected) despite consistent feedback from the child's physicians to the opposite. Her feelings of uncertainty are reinforced each time the child contracts a virus, and consequently she has not been able to allow the child to develop normally, as well as not being able to adequately attend to her own needs as well as her other two children.

Another point made by this mother involving uncertainty was her feelings regarding long term coping and her own self-confidence in this regard. Mrs. A stated that she had guilt feelings regarding thoughts about another family she knew well whose child had died during heart surgery. Mrs. A felt that even though their friends' loss was so devastating and she did not know if she personally could withstand such a loss, at the same time she perceived her friends' position as enviable in terms of seeing them as being able to get on with a normal life once their active grieving was behind them.

Another example of uncertainty as a basis for how the illness is perceived comes from Case Study 2. This parent also rated her child's illness as more severe than the actual medical classification, stating as the reason the family's knowing how fragile their child's health is now, and not knowing what lies ahead in terms of further interventions the child will certainly require.

It was beyond the scope of this study to determine more specifically just how the degree of uncertainty relates to perception of severity of illness, both pre and post-intervention(s), but this would be an important area to research further since it can impact so directly on many facets of the parent-child relationship as well as the family's emotional recovery and subsequent development through the life-stages.

Perception of Severity of Illness and Medical Classification

With respect to the support given to the hypothesis regarding perception of seriousness of illness being greater than actual classification of seriousness for the two intervention groups, it is evident that a factor affecting parental perception is the child's post-intervention recovery process. Even with medical reassurance that the intervention was successful, parents will perceive the degree of success in terms of their own operational definition of normalcy and the child's ability to now develop according to parental expectations. If there is a discrepancy between the child's rate of development and parental expectations, there will be a greater tendency for the parent to perceive their child's lags in terms of the original defect and diagnosis, which may not necessarily be valid.

It is important to note here that, unlike Offord's (1972) study, the presence of surgery per se and perception of severity of illness do not serve as predictors of either effective or ineffective family adaptation within this sample, but interventions with ambiguous outcomes do appear to have an effect on perception of severity of illness. Results of regression analysis indicated that three factors were predictive of perception of severity of illness - number of diagnostic catheterizations, number of parental concerns, and number of interventional catheterizations, in that order. From these results it is safe to assume that the greater the number of parental concerns the greater the perception of severity of illness, and this could be a logical conclusion.

There was no significant difference between the two intervention groups regarding the number of diagnostic catheterizations, and these proved more predictive of perception of severity than the actual interventional catheterization. One explanation may again lie in the degree of uncertainty parents experience at the time of diagnosis of their child's heart defect, coupled with the stage of grieving they may be in at this time. Any invasive procedure, especially on infants, is distressful for parents, especially at a point when they have not had enough time to integrate the information they have received about their child. Emotionally they would conceivably be experiencing shock, denial, and feelings of guilt, while also trying to determine the cause of their child's illness. It is also conceivable then, that if more than one invasive diagnostic procedure were required to accurately diagnose the extent of the defect, the degree of uncertainty would increase, thereby increasing the parental perception that their child's illness must INDEED be extremely serious.

The third factor which was predictive of perception of severity was interventional catheterizations. In this study both intervention groups received interventional catheterizations, but the Catheterization group received significantly more than the surgery group. There was no significant difference between these two groups regarding number of surgical procedures, indicating then that the Catheterization group would have received significantly more interventional procedures than the Surgery group. It follows, therefore, that the greater the number of interventions a child experiences, the greater the perception of severity of illness, which is supported in the literature as described previously. With respect to interventional catheterizations per se increasing perception of severity, it may be that parents perceive this procedure as having been unsuccessful, especially if their child required surgery as well. Because an interventional catheterization does not necessitate a procedure requiring opening of the chest and the heart, it carries less risk of infection and faster recovery post-intervention. Therefore, if it is possible to correct a defect by means of this procedure, it will be used. The expectation is, however, that surgery would most often follow an unsuccessful catheterization procedure. Another perspective is that catheterization may be a necessary palliative procedure until such time that the child is ready for further intervention. All of these variables can produce uncertainty for parents, who may not only not have the degree of sophisticated understanding that the Cardiologists have in order to make the medical decisions regarding their child, but also tend to be in a state of emotional upheaval at the time that these decisions are being made.

Family Hardiness

The final hypotheses examined four independent variables felt to have a direct effect on adaptation in this sample. It was hypothesized that parents with more concerns, low family hardiness, less coping resources, strategies, and less satisfaction with their coping ability, and more negative feelings associated with their experience will have more difficulty with adaptation. The regression analysis indicated that only family hardiness was significantly predictive of family adaptation, and that subjects who rated their family as high on this factor also tended to rate their family as better adjusted or experiencing more effective adaptation. That the other variables listed above did not significantly effect the outcome variable of adaptation in this sample may be attributed to the measures used in the study or the fact that these other variables imply negative effects on adaptation, and as reported previously, a substantial percentage of the subjects had defensiveness and social desirability scores above average. It is a salient factor that within the correlation analysis there was a trend towards a significant association between parent concerns, feelings, and degree of satisfaction regarding coping ability and family adaptation.

The variable of family hardiness did have a highly significant correlation with family adaptation as well as indicating significance with regard to its predictive value in the regression analysis. This result supports both Kobasa's (1985) and McCubbin et al's (1986) contention that the characteristic of hardiness is a key mitigating factor in an individual's or family's ability to cope with intense stress or crisis, and facilitates adjustment and adaptation over time. Family hardiness is viewed both as a resource in terms of being a mediating factor in coping with stresses, as well as being linked to the concept of family schema (Patterson, 1989), or a family's global belief system. In the current study, Case study 2 illustrates the positive effect of strong family hardiness and can be viewed as this family's key resource in their functional adaptation to their child's illness and ongoing periods of crisis when the child faces interventions with uncertain outcomes. For this family their strong identification with their religious beliefs can be directly related to their basis of hardiness.

Parent and Child Variables

None of the demographic or descriptive medical characteristics regarding the child or parent were significantly predictive of family adaptation. Characteristics such as child's age, parental ages, and marital stability have been shown in other studies relating to chronically ill or handicapped children to have variable effects (Bristol, 1987; Perry, 1982). In the current study the lack of effect may be attributed to the sample size and homogeneity of the groups, or are not relevant factors in this sample.

Maladaptation and its relationship to Post Traumatic Stress Disorder (PTSD)

In examining the emotional responses of the primary parent in Case Study 1, many of the symptoms exhibited can be compared to those criteria for diagnosis of post-traumatic stress disorder. These criteria include:

"A. A recognizable stressor that would be expected to evoke significant symptoms of distress in almost all individuals.

B. Re-experiencing the traumatic event either by:
   (1) Recurrent and intrusive recollections of the event; or
   (2) Recurrent dreams of the event; or
   (3) Suddenly acting or feeling as if the traumatic event were occurring because of an association with an environmental or ideational stimulus.

C. Numbing of responsiveness to, or involvement with, the external world, beginning some time after the traumatic event(s) as shown by either:
   (1) Markedly diminished interest in one or more significant activities; or
   (2) Feelings of detachment or estrangement from others; or
   (3) Marked constriction of affective responses

D. At least two of the following (not present prior to the traumatic event):
   (1) Hyperalertness or exaggerated startle response

(2) Initial, middle, or terminal sleep disturbance
(3) Guilt about surviving when others have not, or about behavior required to achieve survival;
(4) Memory impairment or trouble concentrating
(5) Avoidance of activities that arouse recollection of the traumatic event;
(6) Intensification of symptoms by exposure to events that symbolize or resemble the traumatic event." (from Task Force on

Nomenclature and Statistics, 1978, pp.N4-N5, in Horowitz et. al., 1980).

The stressful life events which have precipitated the development of a stress response syndrome studied in the literature all have related directly to the victimization of the individual in terms of personal life experiences such as rape, incest, physical abuse, wartime combat experiences, kidnapping, and imprisonment (e.g. concentration camp) to name a few. Post traumatic stress has been examined by numerous researchers from various perspectives, initially as separate traumas with separate consequences to the more recent diagnosis within the DSM III as a specific syndrome, whose etiology includes a category of post-traumatic stress disorders covering a wide range of personal traumas (Horowitz, 1980). Although the loss of someone close through death has been examined as a preceding life event to a stress response syndrome (Horowitz, Wilner, Kaltreider, & Alvarez, 1980), the loss of an expected normal child and the future uncertainty experienced by family members has not been explored in this light. Further examination of the primary parent's emotional responses in Case Study 1 in relationship to the diagnostic criteria for PTSD explain this relationship more clearly:

A. A recognizable stressor which would be expected to evoke significant symptoms of distress in almost all individuals: the birth of a child with a congenital heart defect, not accurately diagnosed until five weeks of age after experiencing significant physical distress.

B. Re-experiencing the traumatic event: each time the child becomes ill, post-intervention, the parent experienced panic and fear, feeling strongly that the child's heart defect continues to be the cause for the illness. This fear is heightened by the history of the child's interventions having been performed under emergent conditions.

C. Numbing of responsiveness to, or involvement with, the external world: This parent expresses a significant amount of distrust for professionals within her community. Also she has withdrawn from numerous social activities in her community, feeling that no one else will understand her difficulties, as well as feeling that no one else can effectively care for her child in her absence.

D. This parent has experienced prolonged periods of sleep disturbance; feelings of guilt regarding the survival of her child when other children have not survived; intensification of her anxiety whenever her child has contracted a virus, and has described frightening episodes of anger and physical aggression when faced with additional unrelated stressors.

It is the author's opinion that Post Traumatic Stress Disorder (PTSD) can be considered as a plausible explanation for maladaptive adjustment in families where there is a child with CHD, especially when one or more interventions are required. Having a diagnostic perspective can be most valuable therapeutically, since these behaviors are extremely frightening to the individual, and can interfere with the healthy recovery and development of the child, as well as the other members of the family. The danger of not considering PTSD in these situations can lead to an erroneous diagnosis, such as personality disorder which implies life-long intractable characterlogical traits, and is difficult to treat. For example, Mrs. A. expressed strong fears about the changes in her own behavior since the birth of her child, as well as the fear that she will never be herself again. On the other hand, PTSD has been shown to be amenable to relatively brief treatment, which is focused on helping the individual to work through the traumatic experience much as one works through grief. The factors which are noted to affect the duration and severity of the trauma response are severity of the stressor, genetic predisposition, the individual's developmental phase, their social support system, prior traumatization, and preexisting personality (van der Kolk, 1987).

Conclusions

From the preceding discussion, the following conclusions are drawn:

1. Parents of children with CHD who have experienced one or more interventions do not present as having more difficulty with adaptation than parents of children examined for an ultimately benign or innocent heart murmur. The majority of parents in the study fell in the average range on the adaptation measure.

2. Parental perception of severity of illness is significantly greater for the two intervention groups than the Murmur group.

3. Parents of children with CHD perceive their child's illness as more serious than the actual medical classification of seriousness.

4. Parental perception of severity of illness is predictable from the number of diagnostic catheterizations, number and intensity of parental concerns, and number of interventional catheterizations.

5. The degree of family adaptation is predictable from the degree of family hardiness, which is considered to be a key resource in mitigating family crisis.

6. Parental maladaptive responses may fit the criteria for a Post Traumatic Stress Disorder diagnosis.

Limitations of the Study

The limitations of this study are as follows:

1. The factor of 29 percent return, though within the expected range for mailed questionnaires, is still low. The actual number of study participants compared to the number of patient families within the Pediatric Cardiology Clinic over a one year period is representative of only approximately 20 percent of that population. Response bias must therefore be considered within the context of the results.

2. Because of the small size of each group, it was not possible to perform specific statistical analyses which could reliably differentiate between the groups with respect to predictors of the dependent variable of adaptation, as well as parental perception of severity of illness.

3. Response bias must also be considered when interpreting the results of the outcome measure of adaptation, especially with regard to the two scales measuring Defensiveness and Social Desirability.

4. Because this was a retrospective study, feelings and emotions experienced at the time of the intervention(s) or diagnostic procedure (in the case of the Murmur group) were not compared with emotional responses after a period of time had elapsed.

5. Only the primary parent's responses were assessed through these questionnaires, including their perceptions of their spouse/partner reactions. It was beyond the scope of

this study to examine and compare both parent's perspectives individually.

6. No direct comparisons were made between single and dual parent families, although both were included in the study.

7. The subjects were from one pediatric cardiology clinic and therefore the results may not be generalizable to other pediatric cardiology clinics in other centres.

8. The control group chosen for this study may not fully represent a healthy comparable sample due to the incidence of other disease factors in this group.

9. Self-report instruments were used to measure the variables studied. The results are therefore representative of the cognitive and emotional state of the subjects at the time of completion of the questionnaires. Behavioral and physiological measures were not included in this study.

Implications of the Study

The results of this study have implications for clinical research and practice. While it is difficult to generalize to other groups of parents who may be dissimilar to the parents in this study, directions for future related research can be drawn from the results of this study. This will be discussed in more detail in the next section of this chapter.

With respect to clinical practice implications, there are several findings in the study which have implications related to the effective adaptation of parents whose child undergoes an invasive intervention for a congenital heart defect. The relevancy of these implications for parents of children who experience interventions for other congenital defects or acute medical conditions would be fertile ground for future research dependent on replication and refinement of the current study.

From the discussion of findings in this study, there are a few areas which, if accurately clinically assessed, can help to ameliorate potential risk factors for maladaptation in families. It is important to point out here that successful interventions on children are at potential risk for complications when family disruption occurs or continues during the rehabilitation phase. An example of this would be noncompliance with medical prescriptions. Also, families who have not adapted effectively tend to make more use of outpatient medical facilities, thereby increasing health care costs in a technologically more expensive arena. Accurate assessment of family adaptation by health care professionals, with sensitivity to families (or individual parents) who may feel it important to present themselves as coping effectively to professionals can be implemented.

It is important to aid parents in developing an <u>accurate</u> perception of their child's illness and the intervention(s) by decreasing the uncertainty and ambiguity of the diagnosis and prognosis whenever possible. A key factor in this aspect would be checking the parent(s) perception at a follow-up appointment to the intervention, when it is more likely that the intensity of the stress has decreased to a level at which the parent is better able to "hear" the information provided. Other sources of information, such as the nurse clinician and/or a team Psychologist could be made available to parents who are either expressing or exhibiting difficulty comprehending or integrating the information provided by the Cardiologist. Many parents may feel uncomfortable in asking clarifying questions of physicians due to time constraints or a perception of imposing unnecessarily on their Cardiologist. This would also be an opportune time for health care professionals to reinforce information regarding support networks.

Finally, learning from parents and families who adapt well - and there appear to be a significant percentage - would be extremely valuable for health care providers. These families can provide the necessary insight into effective long-term adaptation so that professionals can further aid maladaptive families in coping with their dysfunctional areas.

Implications for Future Research

More research is required to further clarify parental ability to adapt to the stress and uncertain aspects of interventions on children with congenital heart defects. Replication and refinement of the present study would strengthen the results obtained. Recommendations for refinement include:

1. Reducing the number of self-report measures used in examining the specific factors of the T-Double ABCX Model of Adjustment and Adaptation in relation to parents of children with CHD. In addition to self-report measures, interview, behavioral, and clinical physiological measures can also be used to increase the reliability of the information obtained.

2. With regard to the first recommendation, it would be prudent to examine no more than one or two factors of the model at a time in order to obtain more indepth insight into how parents adapt successfully, and what may hinder this process. With respect to the present study, the factor of hardiness appears to be a significantly salient aspect of effective coping and adaptation, which has support in the literature. Examining this variable in more depth in relation to family typology for example would be a valuable area to explore further.

3. Larger group numbers would add to the validity of the results, especially with respect to children receiving interventional catheterizations, since this corrective method is still relatively new. Also, broadening the subject population to include those from other hospital clinics would aid in the generalization of the results.

4. Another refinement would be in the choice of a comparison group. A control group of parents whose children

have invasive interventions for acute illness, eg.appendicitis, and another group of parents whose children have never required medical interventions would be possible candidates. Comparisons with these groups could help to clarify the role played by stages of family development within the context of stressful medical procedures and illness compared to medically healthy families.

5. Exploring family adaptation in more depth would be useful. One way this can be accomplished is by using the complete Family Assessment Measure III, including the Dyadic Scale and the Self-Rating Scale, for each family member. This would also provide more global information on how siblings are adapting to the family situation or crisis, and what effect other family member interactions have on family, child, or parental adaptation to the identified problem.

6. Time since the intervention did not prove to be a significant variable within this study. However, it is an important variable to explore further in light of its relevance to any grieving and adjustment process. More accurate information on this variable may be obtained by longitudinal research, i.e. three, six, nine, and twelve months post intervention.

7. Further research relating Post Traumatic Stress symptoms to maladaptive families within this population would be extremely valuable in terms of therapeutic guidelines for these families.

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APPENDIX I

Information Sheets for Parents

INFORMATION SHEET

To the Primary Caregiver (mother or father):

The research study in which you are being invited to participate is being carried out as part of the requirements formy Doctoral Degree in Psychology.

In general, I am interested in learning more about how parents adapt to potentially stressful medical situations involving their child(ren). More specifically, this study will explore parental adaptation to: (1) the impact of surgery or a catheterization procedure on their child with a congenital heart defect and (2) the impact of a clinical investigation of an innocent heart murmur in a child. The more we, as health care providers, know about how families experience potentially stressful medical procedures, the better we will be able to offer guidance and counsel to families in need.

All parents whose children have been investigated regarding innocent heart murmurs within the past year at British Columbia Children's Hospital are being invited to participate in this research study. If you agree to participate, the parent who is the primary caregiver is requested to complete the enclosed package of questionnaires which will take approximately 1 to 1½ hours of your time. This is all that will be required of you.

Your anonymity will be protected by the inclusion of a separate blank envelope in which to seal the completed questionnaires, and return it in the stamped return envelope provided. Your name will in no way be connected with this study. Each questionnaire will be tabulated by an identification number, and all results of the study will be compiled in such a way that answers on any questionnaire cannot be identified.

Thank you for your kind consideration of this request.

Sincerely,

Barbara Rosen-Harris
Ph.D. Candidate
University of Alberta

INFORMATION SHEET

To the Primary Caregiver (mother or father):

The research study in which you are being invited to participate is being carried out as part of the requirements for my Doctoral Degree in Psychology.

In general, I am interested in learning more about how parents adapt to stressful medical interventions involving their child. More specifically, this study will explore parental adaptation to the impact of either surgery or a catheterization procedure on their child with a congenital heart defect. The more we, as health care providers, know about how families experience stressful medical procedures, the better we will be able to offer guidance and counsel to families in need.

All parents whose children have undergone either a therapeutic catheterization or surgical procedure within the past year at British Columbia Children's Hospital are being invited to participate in this research study. If you agree to participate, the parent who is the primary caregiver is requested to complete the enclosed package of questionnaires which will take approximately 1 to 1½ hours of your time. This is all that will be required of you.

Your anonymity will be protected by the inclusion of a separate blank envelope in which to seal the completed questionnaires and return it in the stamped return envelope provided. Your name will in no way be connected with this study. Each questionnaire will be tabulated by an identification number, and all results of the study will be compiled in such a way that answers on any questionnaire cannot be identified.

Thank you for your kind consideration of this request.

Sincerely,

Barbara Rosen-Harris M.A.
Ph. D. Candidate
University of Alberta

APPENDIX II

Consent Form

CONSENT FORM

TITLE OF RESEARCH PROJECT:	An investigation of parental adaptation to the impact of a therapeutic intervention on their child with a congenital heart defect.
INVESTIGATOR:	Barbara Rosen-Harris, M.A. Doctoral candidate in Psychology
INFORMATION SHEET:	Please see attached page.

CONSENT:

I acknowledge that the research procedures described on the Information Sheet (attached) and of which I have a copy are understandable to me. I know that I may contact the person designated on this form, if I have any questions regarding completion of the questionnaires or other general aspects of the study either now or in the future. I am assured that personal records relating to this study will be kept confidential. I understand that I am free to decline from participating in the study without jeopardy to my child's continuing medical care.

The person who may be
contacted about the
research is:
Barbara Rosen-Harris
Telephone:
Home: 538-5206
Office: 875-2147

Name

Signature of Subject

Name

Signature of Witness

Signature of Investigator

Date

APPENDIX III

Letter to Parent

Dear Parent:

Please complete the following questionnaires according to the instructions provided on each questionnaire. Please do not leave any questions out. Feel free to add additional comments regarding any aspect of these questionnaires and attach your comments to the completed package upon returning it.

Your name is not required on the questionnaires. If you wish to be contacted, however, regarding any aspect of this study, please write your name, phone number or address, and question(s) or concern(s) on a separate sheet of paper and include this with the package.

A separate blank envelope is provided for you in which to seal your completed questionnaire package. <u>Please remember to include the signed consent form.</u> Another stamped and addressed return envelope is provided in which to place the sealed questionnaire package. This procedure is to ensure confidentiality and anonymity of your responses.

I greatly appreciate your kind cooperation in this research study.

Sincerely,

Barbara Rosen-Harris, M.A.
Ph.D. Candidate

APPENDIX IV

Information Questionnaire

Date ________________

Information Questionnaire

Please complete all of the following questions. All information is strictly confidential.

1. What is your age?

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

2. How much school have you completed?

    - (1) 7th grade or below
    - (2) 8th or 9th grade
    - (3) 10th or 11th grade
    - (4) high school graduate
    - (5) some college
    - (6) community college or technical school graduate
    - (7) college graduate
    - (8) masters or doctoral degree

3. Are you employed now?

    - (1) No
    - (2) Yes

    3a. If yes, what do you do? (Please put the type of work you do, not where you work.) ____________
    ____
    ____

    3b. Do you work...

    - (1) full-time
    - (2) part-time

4. Are you satisfied with your current employment status?

    - (1) no
    - (2) not sure
    - (3) yes

5. What is your family's yearly income?

    - (1) under $5,000
    - (2) $5,000 - $9,000
    - (3) $10,000 - $19,000
    - (4) $20,000 - $20,999
    - (5) $30,000 - $39,000
    - (6) $40,000 or more

6. What is your current marital status?

    - (1) married
    - (2) remarried
    - (3) widowed
    - (4) separated
    - (5) divorced
    - (6) single (never married)

7. For how many years have you been married?

    - (1) under 2 years
    - (2) 2 - 5 years
    - (3) 6 - 12 years
    - (4) over 12 years

8. How many times have you been married?

    - (1) once
    - (2) twice
    - (3) three or more times

9. If you are separated or divorced, please answer the following questions:

    (a) For how many years have you been separated or divorced?

    - (1) under 2 years
    - (2) 2 - 6 years
    - (3) 7 - 12 years
    - (4) over 12 years

9.(b) Were you separated or divorced before or after your child's condition was diagnosed?

(1) before
(2) after

10. How many children do you have?

1 2 3 4 5
6 7 8 9 10 or more

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

0 1 2 3 4 or more

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

0 1 2 3 4 or more

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

0 1 2 3 4 or more

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

(1) poor/fair
(2) good
(3) very good
(4) excellent

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

(1) poor/fair
(2) good
(3) very good
(4) excellent

16. What is your religion?

(1) Catholic
(2) Jewish
(3) Protestant
(4) Other:___________
(5) No religion

17. How often have you attended religious services in the past three months?

(1) Never
(2) Rarely
(3) Sometimes
(4) Often

18. How would you describe yourself?

(1) White
(2) Asian
(3) East Indian
(4) Native Indian
(5) Black
(6) Other: (please specify)
____

<u>The following questions concern your child with Congenital Heart Disease</u>

19. Is this child:

(1) your biological child
(2) your adopted child
(4) your grandchild

20. Date of Birth:

________ ________ ________
(Day) (Month) (Year)

21. Gender:

(1) Male
(2) Female

22. How old was your child at the time of the diagnosis of congenital heart disease (or a benign heart murmur)?

(1) newborn
(2) 1 month - 2 years
(3) 2 - 5 years
(4) 5 - 10 years
(5) over 10 years

23. What type of congenital heart disease does your child have?

____
____

24. Has you child undergone a catheterization procedure?

(1) Yes
(2) No

24a. If yes, when was this procedure(s) performed? (Please give the date of the procedure, not your child's age):

__________Month________Year
__________Month________Year
__________Month________Year

24b. If yes, what was the purpose of this procedure?

(1 [illegible]ic
(2 [illegible]ment

25. Has your child undergone a surgical procedure for his/her congenital heart defect?

(1) Yes
(2) No

25a. If yes, when was this procedure performed? (Please give the date of the procedure, not your child's age):

__________Month ________Year
__________Month ________Year
__________Month ________Year

26. How often has your child been admitted to hospital?

(0) Never
(1) once
(2) 2-4 times
(3) 5-7 times
(4) 8 or more times

27. How long ago was your child's last admission to the hospital?

(1) under 1 month
(2) 1 to 5 months
(3) 6 to 12 months
(4) over 1 year

28. In the past year, how often have you had to miss work to take care of your child?

(1) I do not work outside the home.
(2) Less than once a month
(3) 1 - 4 times a month
(4) over 4 times a month

29. If you are not presently working outside the home,
(1) Never worked outside home
(2) Stopped working prior to birth of 1st child.
(3) Stopped work with birth of child with CHD.
(4) Stopped workimg when the needs of my child with CHD required someone at home full-time.

General Information About Spouse

30. How old is your spouse or partner?

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

31. Does your spouse or partner work?

(1) yes
(2) no

32. What is your spouse or partner's occupation? (Type of work):

____

____

33. How much school has your spouse or partner had?

(1) 7th grade or less
(2) 8th or 9th grade
(3) 10th or 11th grade
(4) High School graduate
(5) Some college or community college
(6) Community college graduate
(7) College graduate
(8) Masters or Doctorate

34. During the past three months, about how much time has your spouse or partner spent each day taking care of your child?

(1) less than 30 minutes
(2) 30 minutes to 1 hour
(3) 1 to 2 hours
(4) 3 to 5 hours
(5) 6 to 8 hours
(6) over 8 hours

35. During the past year how has your spouse or partner's health been?

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

36. How satisfied are you with your relationship with your spouse or partner?

(1) Very Dissatisfied
(2) Somewhat Dissatisfied
(3) Not Sure
(4) Somewhat Satisfied
(5) Very Satisfied

37. What effect has the diagnosis of your child's condition had on your relationship with your spouse or partner?

(1) It has moved us apart
(2) I am not sure
(3) It has not changed
(4) It has brought us closer together

38. How do you and your spouse or partner usually make decisions about your child's care?

(1) you decide alone
(2) your spouse or partner decides alone
(3) you decide together

*N.B. The author thanks Debra P. Hymovich for permission to include many of the item from the Parent Perception Inventory, Information Questionnaire in this Information Questionnaire.

APPENDIX V

Perception of Severity of Illness Scale

Code ____________

Perception of Severity of Illness Scale

You probably know your child best. Please check the blank that you think best describes your child with congenital heart disease.

1. How much trouble has your child had with being easily tired?

a great deal	a good bit	moderate amount	very little	none

2. How much trouble has your child had with breathing?

a great deal	a good bit	moderate amount	very little	none

3. How much difficulty has your child had with eating?

a great deal	a good bit	moderate amount	very little	none

4. How much sickness has your child had?

a great deal	a good bit	moderate amount	very little	none

5. How much trouble has your child had with his/her growth?

a great deal	a good bit	moderate amount	very little	none

6. How much difficulty has your child had playing like other children his/her age?

a great deal	a good bit	moderate amount	very little	none

7. How much do you have to limit the things that your child does so he/she does not overdo?

a great deal	a good bit	moderate amount	very little	none

8. Overall, how serious do you think your child's illness is?

extremely serious	quite serious	moderately serious	slightly serious	not serious

APPENDIX VI

Parent Perception Inventory: Concerns Scale

PART II. CONCERNS AND RESOURCES

1. All parents have some concerns. During the past 3 months, how much have you been concerned with the following? Circle the number in the column that best explains your concern.

CONCERNS	[0] No/Does not apply	[1] Not sure	[2] Little bit	[3] Quite a bit	[4] Great deal
Extra demands on my time	0	1	2	3	4
Feeling worn out	0	1	2	3	4
Having enough fun and relaxation as I would like	0	1	2	3	4
Having enough time alone with my spouse or partner	0	1	2	3	4
Talking with or understanding my spouse or partner	0	1	2	3	4
Sexual relationship with my spouse or partner	0	1	2	3	4
Making my child comfortable or happy	0	1	2	3	4
Havinge enough time or attention from my spouse or partner	0	1	2	3	4
Getting out of house with spouse or partner but without children	0	1	2	3	4
Getting out of house by myself	0	1	2	3	4
Getting to do activities together as a family	0	1	2	3	4
Whether I am taking care of my child in the best way	0	1	2	3	4
Having to travel too far for medical help or child care	0	1	2	3	4
The weather affecting what my child can do	0	1	2	3	4
Having enough insurance to meet expenses of child care	0	1	2	3	4
Having the right agencies in the community to provide the care my child's needs	0	1	2	3	4
Wondering what my child's future is likely to be	0	1	2	3	4
Worrying about the responsibility of caring for my child	0	1	2	3	4
Having enough money to meet my family's needs	0	1	2	3	4
Having money for extra pleasures	0	1	2	3	4
Having someone to talk with about my worries	0	1	2	3	4
Finding someone to stay with my child	0	1	2	3	4
Wondering about how my child feels about himself or herself	0	1	2	3	4

CONCERNS (continued)	[0] No/Does not apply	[1] Not sure	[2] Little bit	[3] Quite a bit	[4] Great deal
Getting enough sleep for myself	0	1	2	3	4
Talking to my child about his or her condition	0	1	2	3	4
Talking with neighbors or friends about my child's condition	0	1	2	3	4
Wondering whether my other children will develop the same condition	0	1	2	3	4
The cost of my child's medical care	0	1	2	3	4
Wondering whether I will recognize important changes in my child's condition	0	1	2	3	4
Getting enough information about my child's condition	0	1	2	3	4
Helping my child cooperate with taking medicines or doing treatments	0	1	2	3	4
My spouse or partner's health	0	1	2	3	4
My own health	0	1	2	3	4
My child(ren)'s health	0	1	2	3	4

2. Are you a member of a parents' association related to your child's illness or disability?

[1] no [2] yes

2a. If YES, how often do you go to meetings?

[1] never [3] sometimes

[2] rarely [4] often

2b. If you go to meetings how helpful have they been?

[1] not at all [3] somewhat

[illegible]

[illegible] [4] very

3. Do you have someone to take care your child for a day in case of an emergency (such as if you become ill and cannot take care of your child)?

[1] no [2] not sure [3] yes

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

[1] no [2] not sure [3] yes

5. Do you have a regular baby sitter?

[0] do not need

[1] no [2] yes

6. Are you responsible for the care of any other ill family members?

[1] no

[2] yes WHO? ________________

7. How much time do you usually spend taking care of your child's health needs each day?

[1] less than 1 hour [4] 6-8 hours

[2] 1-2 hours [5] over 8 hours

[3] 3-5 hours

****

APPENDIX VII

Parent Perception Inventory: Spouse Concerns

HYMOVICH'S PARENT PERCEPTION INVENTORY: SPOUSE OR PARTNER CONCERN AND COPING

PART I. SPOUSE OR PARTNER CONCERNS

CODE #　　NAME:　　DATE:

---

1. All parents have some areas of concern. During the <u>past 3 months</u>, how much of a concern do you think the following areas been for <u>your spouse or partner</u>? Circle the number in the column that best explains your spouse or partner's concern.

CONCERNS	[0] No/Does not apply	[1] Not sure	[2] Little bit	[3] Quite a bit	[4] Great deal
Extra demands on time	0	1	2	3	4
Feeling worn out	0	1	2	3	4
Having enough fun and relaxation as would like	0	1	2	3	4
Having enough time alone with you	0	1	2	3	4
Talking with or understanding you	0	1	2	3	4
Sexual relationship with you	0	1	2	3	4
Making your child comfortable or happy	0	1	2	3	4
Having enough time or attention from you	0	1	2	3	4
Getting out of house with you but without the children	0	1	2	3	4
Getting out of the house alone	0	1	2	3	4
Getting to do activities together as a family	0	1	2	3	4
Whether taking care of our child in the best way	0	1	2	3	4
Having to travel too far for medical help or child care	0	1	2	3	4
The weather affecting what child can do	0	1	2	3	4
Having enough insurance to meet expenses of child care	0	1	2	3	4
Having the right agencies in the community to provide the care our child needs	0	1	2	3	4
Wondering what our child's future is likely to be	0	1	2	3	4
Worries about the responsibility of caring for our child	0	1	2	3	4
Having enough money to meet the family's needs	0	1	2	3	4
Having money for extra pleasures	0	1	2	3	4
Having someone to talk with about worries or concerns	0	1	2	3	4
The cost of our child's medical care	0	1	2	3	4
His or her own health	0	1	2	3	4
Your health	0	1	2	3	4
The children's health	0	1	2	3	4
Talking to our child about his or her condition	0	1	2	3	4

APPENDIX VIII

Family Hardiness Index

Family Stress, Coping
and Health Project
1300 Linden Drive
University of Wisconsin-Madison
Madison, Wisconsin 53706

FAMILY HARDINESS INDEX ©

Marilyn A. McCubbin Hamilton I. McCubbin Anne I. Thompson

Directions:

Please read each statement below and decide to what degree each describes your family. Is the statement **False (0), Mostly False (1), Mostly True (2), or Totally True (3)** about your family? Circle a number 0 to 3 to match your feelings about each statement. Please respond to each and every statement.

IN OUR FAMILY	*False*	*False*	*Mostly True*	*True*	*Not Applicable*
1. Trouble results from mistakes we make	0	1	2	3	NA
2. It is not wise to plan ahead and hope because things do not turn out anyway	0	1	2	3	NA
3. Our work and efforts are not appreciated no matter how hard we try and work	0	1	2	3	NA
4. In the long run, the bad things that happen to us are are balanced by the good things that happen	0	1	2	3	NA
5. We have a sense of being strong even when we face big problems	0	1	2	3	NA
6. Many times I feel I can trust that even in difficult times that things will work out	0	1	2	3	NA
7. While we don't always agree, we can count on each other to stand by us in times of need	0	1	2	3	NA
8. We do not feel we can survive if another problem hits us	0	1	2	3	NA
9. We believe that things will work out for the better if we work together as a family	0	1	2	3	NA
10. Life seems dull and meaningless	0	1	2	3	NA
11. We strive together and help each other no matter what	0	1	2	3	NA
12. When our family plans activities we try new and exciting things	0	1	2	3	NA
13. We listen to each others' problems, hurts and fears	0	1	2	3	NA
14. We tend to do the same things over and over .... its boring	0	1	2	3	NA
15. We seem to encourage each other to try new things and experiences	0	1	2	3	NA
16. It is better to stay at home than go out and do things with others	0	1	2	3	NA
17. Being active and learning new things are encouraged	0	1	2	3	NA
18. We work together to solve problems	0	1	2	3	NA
19. Most of the unhappy things that happen are due to bad luck	0	1	2	3	NA
20. We realize our lives are controlled by accidents and luck	0	1	2	3	NA

APPENDIX IX

Family Crisis Oriented Personal Scales

Family Health Program
FORM A
1981
© H McCubbin

FAMILY STRESS COPING AND HEALTH PROJECT
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

F-COPES

FAMILY CRISIS ORIENTED PERSONAL SCALES

Hamilton I. McCubbin   David H. Olson   Andrea S. Larsen

PURPOSE

The Family Crisis Oriented Personal Evaluation Scales is designed to record effective problem-solving attitudes and behavior which families develop to respond to problems or difficulties.

DIRECTIONS

First, read the list of "Response Choices" one at a time.

Second, decide how well each statement describes your attitudes and behavior in response to problems or difficulties. If the statement describes your response <u>very well</u>, then circle the number 5 indicating that you STRONGLY AGREE; if the statement does not describe your response at all, then circle the humber 1 indicating that you STRONGLY DISAGREE; if the statement describes your response to some degree, then select a number 2, 3, or 4 to indicate how much you agree or disagree with the statement about your response.

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
1 Sharing our difficulties with relatives	1	2	3	4	5
2 Seeking encouragement and support from friends	1	2	3	4	5
3 Knowing we have the power to solve major problems	1	2	3	4	5
4 Seeking information and advice from persons in other families who have faced the same or similar problems	1	2	3	4	5
5 Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6 Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7 Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8 Receiving gifts and favors from neighbors (e.g. food, taking in mail, etc.)	1	2	3	4	5
9 Seeking information and advice from the family doctor	1	2	3	4	5
10 Asking neighbors for favors and assistance	1	2	3	4	5

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:	Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree
11 Facing the problems "head-on" and trying to get solution right away	1	2	3	4	5
12 Watching television	1	2	3	4	5
13 Showing that we are strong	1	2	3	4	5
14 Attending church services	1	2	3	4	5
15 Accepting stressful events as a fact of life	1	2	3	4	5
16 Sharing concerns with close friends	1	2	3	4	5
17 Knowing luck plays a big part in how well we are able to solve family problems	1	2	3	4	5
18 Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19 Accepting that difficulties occur unexpectedly	1	2	3	4	5
20 Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21 Seeking professional counseling and help for family difficulties	1	2	3	4	5
22 Believing we can handle our own problems	1	2	3	4	5
23 Participating in church activities	1	2	3	4	5
24 Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25 Asking relatives how they feel about problems we face	1	2	3	4	5
26 Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27 Seeking advice from a minister	1	2	3	4	5
28 Believing if we wait long enough, the problem will go away	1	2	3	4	5
29 Sharing problems with neighbors	1	2	3	4	5
30 Having faith in God	1	2	3	4	5

APPENDIX X

Parent Perception Inventory, Beliefs and Feelings Scale

HYMOVICH'S PARENT PERCEPTION INVENTORY: BELIEFS AND FEELINGS

CODE # NAME: DATE:

1. Parents have different beliefs about things that influence their way of living. Please indicate whether or not you agree or disagree with the following statements. There are no right or wrong answers.

BELIEFS	(1) Agree	(2) Not sure	(3) Dis-agree
Parents usually need to take care of their own needs before they can help their children	1	2	3
Sometimes parents need to get out of the house to relieve the strain of child care	1	2	3
It is usually better to talk about one's feelings with others	1	3	3
Sometimes just trying to forget something makes it easier to handle	1	2	3
Taking one day at a time is usually better than making long term plans	1	2	3
Sometimes getting away from something makes it easier to handle	1	2	3
I usually have control over things that happen to me or my family	1	2	3
It is lucky that this is my child's only condition	1	2	3
There isn't much that I can do about my child's condition	1	2	3
Sometimes I think of my child's condition as a nuisance	1	2	3
Parents need someone to talk with about raising children	1	2	3
People should try to handle their problems by themselves	1	2	3

2. Listed below are feelings that people may have. Put a circle around the number of the item that best shows how often you have had these feelings during the <u>past 3 months</u>. There are no right or wrong answers.

FEELINGS	(0) Not at all	(1) Not often	(2) Often	(3) Very often
Angry	0	1	2	3
Anxious	0	1	2	3
Confident	0	1	2	3
Content	0	1	2	3
Defeated	0	1	2	3
Depressed	0	1	2	3
Disapointed	0	1	2	3
Frustrated	0	1	2	3
Good	0	1	2	3
Guilty	0	1	2	3
Happy	0	1	2	3
Helpless	0	1	2	3
Hopeful	0	1	2	3
In control	0	1	2	3
Lucky	0	1	2	3
Overwhelmed	0	1	2	3
Pleased	0	1	2	3
Resentful	0	1	2	3
Sad	0	1	2	3
Satisfied	0	1	2	3
Uneasy	0	1	2	3
Other WHAT?	0	2	2	3

* * *

APPENDIX XI

Parent Perception Inventory, Coping Scale

HYMOVICH'S PARENT PERCEPTION INVENTORY: COPING
(PPICOPE)

CODE # NAME: DATE:

1. Parents cope with their concerns in many different ways. There are times when you may have more problems or concerns because of your child's needs. The first column has a list of some ways people cope. Coping means what a person does in order to make the situation better or to try to make oneself feel better.

   1. If you do not use a coping method in the list, circle the 0 in the first column; and leave the other columns blank.

   2. Circle the number that shows how often you used the coping method in the past 3 months when you had a problem related to your child's needs.

COPING	HOW OFTEN				HOW HELPFUL			
	[0] DO NOT DO THIS	[1] Very rarely	[2] Some-times	[3] Very often	[0] Never helps	[1] Sometimes helps	[2] Almost always helps	[3] Always helps
Cry	0	1	2	3	0	1	2	3
Busy myself with other things	0	1	2	3	0	1	2	3
Talk with someone about feelings	0	1	2	3	0	1	2	3
Ignore/try to forget	0	1	2	3	0	1	2	3
Look at options	0	1	2	3	0	1	2	3
Get away for awhile	0	1	2	3	0	1	2	3
Hide feelings	0	1	2	3	0	1	2	3
Change my expectations	0	1	2	3	0	1	2	3
Blame someone	0	1	2	3	0	1	2	3
Yell/scream/slam doors, etc.	0	1	2	3	0	1	2	3
Exercise	0	1	2	3	0	1	2	3
Ask for help	0	1	2	3	0	1	2	3
Take alcohol or medicine	0	1	2	3	0	1	2	3
Pray	0	1	2	3	0	1	2	3
Blame myself	0	1	2	3	0	1	2	3
Ask questions	0	1	2	3	0	1	2	3
Use advice of others	0	1	2	3	0	1	2	3

COPING	HOW OFTEN				HOW HELPFUL			
	[0] DO NOT DO THIS	[1] Very rarely	[2] Some-times	[3] Very often	[0] Never helps	[1] Sometimes helps	[2] Almost always helps	[3] Always helps
Try to figure out what to do	0	1	2	3	0	1	2	3
Sleep	0	1	2	3	0	1	2	3
Find help	0	1	2	3	0	1	2	3
Smoke	0	1	2	3	0	1	2	3
Try to laugh or joke about it	0	1	2	3	0	1	2	3
Eat	0	1	2	3	0	1	2	3
Try to relax	0	1	2	3	0	1	2	3
Read about the problem	0	1	2	3	0	1	2	3
Wish problem would go away	0	1	2	3	0	1	2	3
Weigh choices	0	1	2	3	0	1	2	3
Get information	0	1	2	3	0	1	2	3
Try to change things	0	1	2	3	0	1	2	3

1. In the past, what sources have you used for information or help related to your child's problems or needs? Circle all that apply.

[1] clergy
[2] Doctor
[3] Friend
[4] Nurse
[5] Teacher
[6] Relatives or spouse
[7] Pharmacist
[8] Other parent
[9] social worker
[10] Nutritionist
[11] Therapist
[12] Library
[13] Newspapers/ magazines
[14] Support group
[15] Community agency
[16] Other

2. How often have there been times when you did not know what to do to get information or help related to your child?

[0] Never
[1] Sometimes
[2] Often
[3] Always

3. In general, how well do you believe you are coping with (managing) problems ~~related~~ related to your child's care?

[0] Not well
[1] Fairly well
[2] Well
[3] Extremely well

4. In general, when you have problems related to your child's needs, how often are they things you can change or have some control over?

[1] Always
[2] Almost always
[3] Not very often
[4] Never

5. In general, how well do you believe you are coping with (managing) your feelings and concerns about your child?

[0] Not well
[1] Fairly well
[2] Well
[3] Extremely well

6. Would you like help with any problems you are having?

[1] No [2] Not sure [3] Yes

7. How satisfied are you with the way you are able to cope with the stresses you have?

[1] Very dissatisfied
[2] Dissatisfied
[3] Satisfied
[4] Very satisfied

APPENDIX XII

Parent Perception Inventory, Spouse Coping Scale

PART II. SPOUSE OR PARTNER COPING

2. In general, how well do you believe your spouse or partner is coping with problems related to your child's needs?

[1] not well [2] fairly well [3] very well

3. Parents cope with their concerns in many different ways. There are times when your spouse or partner may have more problems or concerns because of your child's needs. The first column is a list of some ways people cope (manage their problems). Circle the number in the column that shows how often your spouse or partner uses each of the coping methods.

		HOW OFTEN		
COPING	[0] DOES NOT DO THIS	[1] Very rarely	[2] Some- times	[3] Very often
Cry	0	1	2	3
Busy self with other things	0	1	2	3
Talk with someone about feelings	0	1	2	3
Ignore/try to forget	0	1	2	3
Look at options	0	1	2	3
Get away for awhile	0	1	2	3
Hide feelings	0	1	2	3
Change my expectations	0	1	2	3
Blame someone	0	1	2	3
Yell/scream/ slam doors, etc.	0	1	2	3
Exercise	0	1	2	3
Ask for help	0	1	2	3
Take alcohol or medicine	0	1	2	3
Pray	0	1	2	3
Blame self	0	1	2	3

		HOW OFTEN		
COPING	[0] DOES NOT DO THIS	[1] Very rarely	[2] Some- times	[3] Very often
Ask questions	0	1	2	3
Use advice of others	0	1	2	3
Try to figure out what to do	0	1	2	3
Sleep more	0	1	2	3
Find help	0	1	2	3
Smoke	0	1	2	3
Try to laugh or joke about it	0	1	2	3
Eat	0	1	2	3
Try to relax	0	1	2	3
Read about the problem	0	1	2	3
Wish problem would go away	0	1	2	3
Weigh choices	0	1	2	3
Seek information	0	1	2	3
Try to change things	0	1	2	3

APPENDIX XIII

Family Assessment Measure, III

Family
Assessment
Measure

GENERAL SCALE

Directions

On the following pages you will find 50 statements about your family as a whole. Please read each statement carefully and decide how well the statement describes your family. Then, make your response beside the statement number on the separate answer sheet.

If you STRONGLY AGREE with the statement then circle the letter "a" beside the item number; if you AGREE with the statement then circle the letter "b".

If you DISAGREE with the statement then circle the letter "c"; if you STRONGLY DISAGREE with the statement then circle the letter "d".

Please circle only one letter (response) for each statement. Answer every statement, even if you are not completely sure of your answer.

Please do not write on this page.
Circle your response on the answer sheet.

1. We spend too much time arguing about what our problems are.
2. Family duties are fairly shared.
3. When I ask someone to explain what they mean, I get a straight answer.
4. When someone in our family is upset, we don't know if they are angry, sad, scared or what.
5. We are as well adjusted as any family could possibly be.
6. You don't get a chance to be an individual in our family.
7. When I ask why we have certain rules, I don't get a good answer.
8. We have the same views on what is right and wrong.
9. I don't see how any family could get along better than ours.
10. Some days we are more easily annoyed than on others.
11. When problems come up, we try different ways of solving them.
12. My family expects me to do more than my share.
13. We argue about who said what in our family.
14. We tell each other about things that bother us.
15. My family could be happier than it is.
16. We feel loved in our family.
17. When you do something wrong in our family, you don't know what to expect.
18. It's hard to tell what the rules are in our family.
19. I don't think any family could possibly be happier than mine.
20. Sometimes we are unfair to each other.
21. We never let things pile up until they are more than we can handle.
22. We agree about who should do what in our family.
23. I never know what's going on in our family.
24. I can let my family know what is bothering me.
25. We never get angry in our family.

Please do not write on this page.
Circle your response on the answer sheet.

26. My family tries to run my life.
27. If we do something wrong, we don't get a chance to explain.
28. We argue about how much freedom we should have to make our own decisions.
29. My family and I understand each other completely.
30. We sometimes hurt each others feelings.
31. When things aren't going well it takes too long to work them out.
32. We can't rely on family members to do their part.
33. We take the time to listen to each other.
34. When someone is upset, we don't find out until much later.
35. Sometimes we avoid each other.
36. We feel close to each other.
37. Punishments are fair in our family.
38. The rules in our family don't make sense.
39. Some things about my family don't entirely please me.
40. We never get upset with each other.
41. We deal with our problems even when they're serious.
42. One family member always tries to be the centre of attention.
43. My family lets me have my say, even if they disagree.
44. When our family gets upset, we take too long to get over it.
45. We always admit our mistakes without trying to hide anything.
46. We don't really trust each other.
47. We hardly ever do what is expected of us without being told.
48. We are free to say what we think in our family.
49. My family is not a perfect success.
50. We have never let down another family member in any way.

Answer Form for FAM General Scale

	a = strongly agree	b = agree	c = disagree	d = strongly disagree		a = strongly agree	b = agree	c = disagree	d = strongly disagree		a = strongly agree	b = agree	c = disagree	d = strongly disagree		a = strongly agree	b = agree	c = disagree	d = strongly disagree		a = strongly agree	b = agree	c = disagree	d = strongly disagree
1.	a	b	c	d	11.	a	b	c	d	21.	a	b	c	d	31.	a	b	c	d	41.	a	b	c	d
2.	a	b	c	d	12.	a	b	c	d	22.	a	b	c	d	32.	a	b	c	d	42.	a	b	c	d
3.	a	b	c	d	13.	a	b	c	d	23.	a	b	c	d	33.	a	b	c	d	43.	a	b	c	d
4.	a	b	c	d	14.	a	b	c	d	24.	a	b	c	d	34.	a	b	c	d	44.	a	b	c	d
5.	a	b	c	d	15.	a	b	c	d	25.	a	b	c	d	35.	a	b	c	d	45.	a	b	c	d
6.	a	b	c	d	16.	a	b	c	d	26.	a	b	c	d	36.	a	b	c	d	46.	a	b	c	d
7.	a	b	c	d	17.	a	b	c	d	27.	a	b	c	d	37.	a	b	c	d	47.	a	b	c	d
8.	a	b	c	d	18.	a	b	c	d	28.	a	b	c	d	38.	a	b	c	d	48.	a	b	c	d
9.	a	b	c	d	19.	a	b	c	d	29.	a	b	c	d	39.	a	b	c	d	49.	a	b	c	d
10.	a	b	c	d	20.	a	b	c	d	30.	a	b	c	d	40.	a	b	c	d	50.	a	b	c	d

APPENDIX XIV

Letters of Permission:

Hymovich's Parent Perception Inventory

929 Longview Road
Gulph Mills, PA 19406
Phone (215) 525-4289
July 18, 1988

Barbara Rosen Harris
13688 Coldicutt Avenue
White Rock, B.C.
V4B 3A9

Dear Ms Rosen Harris:

Thank you for your recent request for Hymovich's Parent Perception Inventory. Enclosed are several pieces of information. These materials are:

1) Copy of the PPI instuments.
2) Information regarding the instruments, suggestions for use, and the reliability data.
3) Codebook with information regarding scoring the scales.
4) Contract to be signed and returned prior to using the PPI.

You have my permission to use and duplicate the PPI once you have returned the contract. If you wish to modify the instrument, I would appreciate your contacting me about it first, and sharing a copy of the modified version with me.

When data on the psychometric properties of the CICI:PQ become available, I shall send them to you. The PPI is a modification of the CICI:PQ and I am in the process of completing the analyses.

I am particularly interested in the fact that you are using some of McCubbin's tools as well as mine. Marilyn McCubbin and I have discussed the need to look at the psychometric properties of our tools particularly for concurrent validity. Do you think plan do do any of this, or would be interested in collaborating on a project of that natrue when your data have been collected?

If you have any questions about the instrument or its use, please feel free to contact me.

Sincerely,

Debra P. Hymovich

Debra P. Hymovich, RN, PhD, FAAN
Postdoctoral Fellow
University of Pennsylvania

929 Longview Road
Gulph Mills, PA 19406
Phone (215) 525-4289
May 31, 1989

Barbara Rosen Harris
13688 Coldicutt Avenue
White Rock, B.C.
CANADA V4B 3A9

Dear Ms. Harris:

Thank you for returning the agreement for use of the PPI.

I have reviewed the changes you plan to make with regard to the general information form. Becasue so many of the items are from the PPI, I request that you insert a statement on the bottom of the questionnaire stating the origin of many of the items and that the source be identified in all written materials regarding the work.

Thank you for sharing the information with me. I wish you well with your research.

Sincerely,

Debra P. Hymovich

Debra P. Hymovich, RN, PhD, FAAN
Postdoctoral Fellow
University of Pennsylvania
Office: (215) 898-8281

APPENDIX XV

Letter of Permission:

McCubbin Scales

SCHOOL OF FAMILY RESOURCES AND CONSUMER SCIENCES
University of Wisconsin-Madison, 1300 Linden Drive, Madison, WI 53706 608-262-4847

OFFICE OF THE DEAN

July 20, 1988

Barbara Rosen Harris, M.A.
13688 Coldicutt Ave.
White Rock, B.C.
CANADA V4B 3A9

Dear Ms. Harris:

I am pleased to give you my permission to use the **FIRM: Family Inventory of Resources for Management; FHI: Family Hardiness Index; SSI: Social Support Index;** and **F-COPES: Family Crisis Oriented Personal Scales** instruments. We have a policy to charge $5.00 (one time charge only) *per instrument* to individuals who seek permission. We apologize for this necessity. We also ask that you please fill out the enclosed abstract form and return it to this office.

The manual, **Family Assessment Inventories for Research and Practice,** should be cited when using these instruments. The publication was printed at the University of Wisconsin-Madison in 1987 and edited by Hamilton I. McCubbin and Anne I. Thompson. A brochure is enclosed.

Also enclosed is a sample copy of each instrument. Additional copies can be obtained at this address for 10 cents each. When large quantities are requested, the cost of postage is also added to the order. However, when you obtain permission to use an instrument, you also receive permission to photocopy the material.

If I could be of any further assistance to you, please let me know.

Sincerely,

Hamilton I. McCubbin
Dean

HIM/cjd

Enclosures

Child and Family Studies Consumer Science Environment, Textiles, and Design
Home Economics Education Home Economics Communications

APPENDIX XVI

Letter of Permission:

Family Assessment Measure III

Addiction Research Foundation
Fondation de la recherche sur la toxicomanie

Central Office
33 Russell Street
Toronto, Ontario
Canada M5S 2S1
(416) 595-6000

July 14, 1988

Barbara Rosen-Harris
13688 Coldicutt Avenue
White Rock, B.C.
V4B 3A9

Dear Barbara:

Enclosed is the FAM kit that you requested. Your dissertation proposal sounds quite interesting. I know that one group in Pittsburgh are currently using FAM to study family dynamics while one member of the family is undergoing a liver transplant operation. Obviously, I would be quite interested in learning of your findings.

You have my permission to make copies of FAM for your project. However, the hand-scorable answer sheets would certainly facilitate data collection. Since you are only looking at 80 subjects, I could make some copies of the FAM booklets available (which are reusable) as well as the necessary number of answer sheets. Please let me know if you want to take me up on this offer.

Best wishes in your research.

Sincerely,

Harvey Skinner

Harvey A. Skinner, Ph.D.
Senior Scientist

HAS/rs

Encl.