EVALUATION OF AN EDUCATION PROGRAM
FOR PARENTS OF CHILDREN
WITH CHRONIC HEALTH PROBLEMS OR DISABILITIES
by
ETHEL LYNDA McLEAN
B.Sc.N., University of British Columbia, 1989
A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING
in
THE FACULTY OF GRADUATE STUDIES
(The School of Nursing)
We accept this thesis as conforming
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA
October 1993
© Ethel Lynda McLean, 1993
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

(Signature)

Department of Nursing

The University of British Columbia
Vancouver, Canada

Date __________________________
ABSTRACT

This study used a quasi-experimental design to determine the effectiveness of a Parent Education Program (PEP) (Canam, 1990) in increasing parental coping, family functioning, and utilization of resources, for parents of children with chronic health problems or disabilities. Twenty-eight parents (20 mothers and 8 fathers) of children with a variety of chronic conditions participated in a 16 hour structured educational program based on the common adaptive tasks facing parents when their child has a chronic condition. Quantitative data were collected using the Coping Health Inventory for Parents (CHIP), the Family Environment Scale (FES), and the Family Inventory for Resources Management (FIRM) questionnaires. These tools were administered to the 28 participants one week before and after program completion. Data were analyzed by applying paired t-tests and an ANOVA to the subjects' pre/post-test mean scores. Results demonstrated that mothers' overall parental coping, family functioning, and utilization of resources increased, and fathers' parental coping and family functioning improved post-intervention. To augment the quantitative findings, nine follow-up interviews with randomly selected program participants were conducted and content analyses were applied to these data. Results demonstrated a change in mothers' coping to one of "sharing the responsibility or burden of care" for their child with the chronic condition, a more active family recreational
orientation, and parent recommendations for future programs. These recommendations included: program participation commence 6 months to one year post-diagnosis; marital dyads attend together when possible; and both general and specific diagnostic group PEP options be available on an ongoing basis.
# TABLE OF CONTENTS

ABSTRACT ................................................................. ii
TABLE OF CONTENTS ....................................................... iv
LIST OF TABLES ............................................................. vii
ACKNOWLEDGEMENTS ....................................................... viii

CHAPTER 1: INTRODUCTION ............................................. 1
  Background to the Problem ............................................. 1
  Purpose of the Study ................................................... 4
  Research Questions .................................................... 4
  Conceptual Framework .................................................. 5
  Significance of the Study .............................................. 7
  Definition of Terms .................................................... 8
  Assumptions ............................................................ 9
  Limitations ............................................................ 9
  Research Method ....................................................... 10

CHAPTER 2: LITERATURE REVIEW .................................... 11
  Noncategorical Approach to Chronic Conditions .................... 11
  Parental Coping ....................................................... 14
  Impact of Child's Condition on Family Function .................... 17
  Parental Resource Needs .............................................. 21
  Evaluative Studies of Parent Education Programs .................. 22

CHAPTER THREE: METHODOLOGY ..................................... 30
  Sampling Procedure ................................................... 31
  Data Collection Procedures ......................................... 32
  The Intervention ..................................................... 33
Concluding Remarks .............................................. 111
REFERENCES ..................................................... 113
APPENDICES ..................................................... 121
Appendix A: Participant Information Letter ........... 121
Appendix B: Notice to Parents ............................... 123
Appendix C: Participation Consent Form .............. 124
Appendix D: Demographic Questionnaire ............. 126
Appendix E: Interview Guide ................................. 128
Appendix F: Interview Categorizing Scheme.......... 130
Appendix G: Control Group's Mean Scores .......... 132
Appendix H: Experimental Groups' Mean Scores .... 133
Appendix I: Mean Scores for ANOVA ................. 134
Appendix J: Questionnaires ................................. 135
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>I.</td>
<td>Description of Experimental and Control Groups</td>
<td>55</td>
</tr>
<tr>
<td>II.</td>
<td>Control Group's Paired t-test Results for CHIP, FES, and FIRM</td>
<td>59</td>
</tr>
<tr>
<td>III.</td>
<td>ANOVA on Differences Between Group Mean Scores for Female Subjects for CHIP, FES, and FIRM</td>
<td>60</td>
</tr>
<tr>
<td>IV.</td>
<td>Mothers' CHIP Paired t-test Results</td>
<td>61</td>
</tr>
<tr>
<td>V.</td>
<td>Fathers' CHIP Paired t-test Results</td>
<td>63</td>
</tr>
<tr>
<td>VI.</td>
<td>Mothers' FES Paired t-test Results</td>
<td>72</td>
</tr>
<tr>
<td>VII.</td>
<td>Fathers' FES Paired t-test Results</td>
<td>73</td>
</tr>
<tr>
<td>VIII.</td>
<td>Mothers' FIRM Paired t-test Results</td>
<td>77</td>
</tr>
<tr>
<td>IX.</td>
<td>Fathers' FIRM Paired t-test Results</td>
<td>84</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

This thesis is dedicated to my three wonderful daughters Tracy, Patricia, and Michelle. With their patience, selflessness, and support, I was able to complete this lengthy endeavour.

My special thank-you to my thesis chairperson, Connie Canam, who played the simultaneous roles of mentor and friend throughout this study. I extend this thank-you to include Tom Sork for his clarity and his expertise in both quantitative and qualitative research methods, and Sally Thorne for giving a critical and helpful third reading.

I wish to acknowledge and thank the parents who participated in this study. Their willingness and commitment, to give of their time and share their experiences, are appreciated.

Finally, a sincere and warm thanks to my family and friends for their endless encouragement and support: Mom, Dad, Mike, Elizabeth, Jenni, Carol, Mary B., Rozina, Ted, Delores, Linda C., Mary I, Linda P., Frances, and Barbara.
CHAPTER ONE

INTRODUCTION

Background to the Problem

In Canada, there are as many as 780,000 children and youth aged 0-19 years with some form of long-term health or functional impairment (Rosenbaum, 1987). The family is the social context within which these conditions occur and are managed (Litman, 1974). From a family's point of view, a chronic condition always threatens; it is an everpresent companion, "a constant shadow" (Massie, 1985). Because the ultimate responsibility for managing a childhood chronic condition lies with the family, the normal struggles of parenting are compounded by additional care-giving demands and stresses that tax parent's existing coping mechanisms and resources (Peterson & Cooper, 1989; Tritt & Esses, 1986). Moreover, recent trends toward deinstitutionalization and home care management of children with complex health problems (Wegener & Aday, 1989) have compounded the pressing need for resources for parents of these children in their communities (Aday & Wegener, 1988; Nelkin, 1987).

To cope effectively with the demands of parenting a child with a chronic condition, researchers have identified a number of adaptive tasks (Canam, 1986, 1987, 1993; Hymovich, 1976; Moos & Moos, 1977) that all parents must complete regardless of their child's medical diagnosis (Stein & Jessop, 1989). While some parents successfully
negotiate these tasks on their own by utilizing available resources, many parents have difficulty and require assistance in order to accept and manage the demands presented by their child's chronic condition (Drotar, Crawford, & Bush, 1984; Feeman & Hagan, 1990; Tritt & Esses, 1986).

Although health professionals are becoming increasingly aware of the needs of parents of children with chronic conditions (Coffman, 1983; Horner, Rawlins, & Giles, 1987; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989), resources for this population have been slow to develop. In response to a perceived need within Vancouver's health-care community and previous research findings, Canam and Chung developed the Parent Education Program (PEP), using a 'Common Adaptive Task' framework (Canam, 1993) as its basis. This structured educational program was designed to assist parents in developing the specialized knowledge, skills, and support they need to successfully complete the identified adaptive tasks and, thus, enhance parents' ability to cope with their child's chronic condition (Canam, 1993).

According to Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne, and Weeks (1984), child care and parent education are the two instruments most readily available "to increase a nation's capacity to achieve its human development aspiration and fulfil its human development needs" (p. 2). As such, Canam's program represents a health promotion strategy for nurses caring for children with chronic conditions and
their families in the community. This strategy promotes the family's ability to cope with persistent stress of relatively high intensity (Stein, Jessop, & Ireys, 1985).

In light of the present economic pressures on the health care system, the Royal Commission's report on health-care and costs deems "outcomes" a guideline for determining government expenditures (Royal Commission, 1991). This guideline states:

"The focus of the health-care system must be on providing those services which improve health outcomes. These outcomes must be defined, measurable, subject to analysis, and able to be independently evaluated. Services which cannot be shown to improve health should not be funded by the health-care system" (p. A-6).

The above guideline delineates the socio-political mandate for a study of the effectiveness of the PEP for parents of children with a chronic condition.

The PEP has been implemented and evaluated with forty-eight parents of children with a variety of chronic conditions (Canam, 1990). The outcome measures the researchers used were Coping Health Inventory for Parents (CHIP) (McCubbin & Patterson, 1983) and Parenting Stress Index (PSI) (Abdin, 1983). While the CHIP results demonstrated a significant increase in parental coping post PEP, there was no significant change in stress levels, as measured by the PSI, post intervention. Follow up interviews with 15 of the
48 participants showed that the program was not only effective in enhancing parental coping but parents perceived their family as functioning better and utilizing resources more effectively.

**Purpose of the Study**

Since utilization of resources and family functioning were not measured quantitatively, a recommendation of Canam's (1990) study was that the intervention be repeated with parental coping, family functioning, and utilization of resources as outcomes to be measured. Therefore, the purpose of this study was to evaluate the effectiveness of PEP in increasing parental coping, functioning, and parents' utilization of resources. Thus, Canam's (1990) study was replicated utilizing one prior measure and two additional measures to determine the scope of PEP's effectiveness. According to LoBiondo-Wood (1986), an independent replication of a research study is "a valuable component of building the theory base for nursing practice" (p.14).

**Research Questions**

The study was designed to answer the following questions about parents of children with chronic conditions who participated in the PEP:

1. Does program participation significantly increase parental coping?

2. Does program participation demonstrate a significant improvement in family functioning?
3. Does program participation significantly increase parental use of resources?

Conceptual Framework

The conceptual framework chosen for this study was McCubbin and Patterson's (1983) double ABCX model. This model used Hill's (1949) ABCX family crisis model as a base. Hill's (1949) model conceptualized A, the stressor event interacting with B, the family's crisis meeting resources and C, the family's perception of the seriousness of the event and how it will effect them based on their values and previous experience. These three factors influence the development of X, or a crisis within the family (McCubbin, 1984).

Rather than focus on the crisis variable, the double ABCX model added post-crisis variables which have an impact on family adaptation to stress over time. These include aA, the cumulative nature or "pile-up" of demands for change within the family unit as it is faced with normative and situational events. In the family of a child with a chronic condition, this "pile-up" could include the management of that child's home care regimen, normative transitions, the consequences of family efforts to cope, and intrafamily and social role ambiguity. Another post crisis variable in the double ABCX model is the bB factor or existing and new resources. Existing resources are already part of the family's repertoire and can be individual, family, or com-
munity-based, whereas expanded family resources are new resources strengthened or developed in response to the crisis. The cC factor, or the family's perception of the total situation, is a critical component of family coping. This factor includes the family's definition of the major stressor event, the meaning of the associated hardships, and the effort by the family to redefine the situation and restore family balance. Finally, the xX factor, or the adaptation factor, is considered to be composed of three elements. These elements are the individual family member, the family system, and the community in which the individual and family live. Family adaptation reflects family efforts to achieve a balance or fit between and among the demands and capabilities of reciprocal relationships. In the double ABCX model, coping denotes an interaction of resources, perceptions, and behavioral responses used by family members to deal with stressor events. Moreover, the model presents coping skills as the product of an interaction among the factors previously listed and as a predictor of the adaptability of the family to a stressful experience.

This conceptual framework was useful for understanding the adaptation process of families confronted with an enduring stressful situation embodied in a chronic condition. This conceptualization acknowledges: the variability in internal and external coping resources; the interpretation or perception of the stressful situation represents a power-
ful, though changeable, force in the family's ability to cope; and the importance of both external and internal resources to a family's vulnerability and regenerative power (Krauss, 1988).

Significance of the Study

The knowledge derived from this study has implications for two aspects of professional nursing. First, an independently replicated study contributes to nursing theory. In nursing, the nature of client care research makes it difficult to obtain large samples or to select them randomly and control for variables that might confound the findings (Tournquist, 1986). Thus, a replication of Canam's (1990) study will help to establish the generalizability of the findings. Second, by providing additional data through outcome measures, the study will document the effectiveness of a program that provides knowledge and skills for parents of children with chronic conditions. In response to economic pressures, the Royal Commission's report on health-care and costs deems "outcomes" (Royal Commission, 1991, p. A-6) a guideline for determining government expenditures. Given this socio-political climate and assuming that PEP efficacy will be supported, the study's findings will increase the likelihood of the utilization of PEP for these parents on a wider and more frequent basis throughout British Columbia. Therefore, the study has significance to nursing practice.
Definition of Terms

Chronic Condition

Any anatomic or physiologic impairment that interferes with the individual's ability to function fully in the environment. Chronic conditions are characterized by relatively stable periods that may be interrupted by acute episodes requiring hospitalization or medical attention. The individual's prognosis varies between a normal life span and unpredictable early death. Chronic conditions are rarely cured, but they are managed through individual and family effort and diligence (Thomas, 1984).

Coping

The cognitive and behavioral efforts used to master conditions of harm, threat, or stress when a routine or automatic response is neither readily available nor a natural part of the individual's or family's repertoire as measured by the CHIP tool (Hill, 1949; Lazarus, 1966; McCubbin, Cauble, & Patterson, 1980).

Family Function

The level of adaptive functioning between interdependent parts of the family as measured by the FES tool (Moos & Moos, 1986; Royal Commission, 1991).

Parent Education Program

A series of eight, two hour sessions based on the common adaptive task framework, and designed to provide parents with the knowledge and skills needed to cope with
their child's chronic condition.

Program Participation

To be considered program participants, parents must attend a minimum of five of the eight scheduled sessions.

Resources

Existing and new knowledge and skills that are a part of the family's capabilities for resisting crises as measured by the FIRM tool (McCubbin et al., 1983).

Assumptions

The study was based on the following assumptions:

1. It was assumed that the Parent Education Program would have similar effects on parents' coping, family functioning, and utilization of resources regardless of the specific medical diagnosis of their child.

2. It was assumed that the parents would understand and respond honestly to the questionnaires and the semi-structured interview.

Limitations

The depth and richness of the data for the study was limited by time constraints and other issues surrounding a Master's Thesis study. These constraints accounted for the absence of a process evaluation of the PEP, and the limited number of participants in the control group and in the qualitative aspect of the study.
Research Method

The methodological strategy for this study was a non-equivalent control group, quasi-experimental design (LoBiondo-Wood & Haber, 1990). Within this quantitative method, there were two components. The first component involved the administration of three pre- and post-intervention questionnaires. The second component utilized semi-structured interviews, four to five months post intervention. These interviews augmented the interpretation of the findings of the questionnaires and determined the maintenance of change to that point in time.
CHAPTER TWO
LITERATURE REVIEW

This chapter reviews the theoretical and research based literature which is pertinent to assessing the influence of the PEP on parental coping, family functioning, and utilization of resources. Given that the references specific to education programs for parents of chronically ill children are limited, literature which is relevant to parenting a child with a chronic health condition and linked to the purpose of the study are reviewed.

This chapter is organized into five major sections. Since the PEP is based on a noncategorical approach to children's chronic health conditions, the initial section discusses this theoretical perspective. The second section focuses on parental coping strategies used to manage the impact of a child's chronic condition. The third section reviews literature regarding the impact of a child's chronic condition on family functioning. The fourth section addresses parental resource needs. The fifth section reviews evaluative studies of formal parent education programs.

Noncategorical Approach to Chronic Conditions

In recent literature, researchers have attempted to find common threads among chronic conditions. Rather than considering individual problems unique to particular disease processes, the noncategorical approach views chronic condi-
tions as an entity (Phillips & Brostoff, 1989; Stein et al., 1989; Woods, Yates, & Primomo, 1989). Pless (1985) asserted that "from the point of view of either service or research, a strong case can be made for viewing all chronic conditions, regardless of their individual characteristics, as one group having many problems in common ..." (in Hobbs & Perrin, 1985, p. 42). The focus of Walker et al.'s (1989) questionnaire survey of 910 parents was whether parents of children with different chronic conditions have different perceived needs as opposed to similar ones. The results, from parents of children with 23 different chronic conditions, revealed that the perceived needs and rankings of important services by these parents are more similar than different. Despite the large sample, the researchers used a purposive study sample and respondents were representative of a white, well-educated, and insured population. Therefore, the results have limited generalizability. The findings of Horner et al.'s (1987) study of 164 parents of children with a variety of chronic conditions indicated common areas of concern across conditions. Stein et al. (1989) examined 2 longitudinal data sets. First, the institutional sample of 209 children from birth to 11 years of age with a wide range of chronic conditions was urban, poor, and from minority groups. Second, the national (USA) probability sample, from the Health Examination Survey, consisted of 329 parents of children with 6 categories of
illness. These researchers examined the following hypothesis: the diagnosis itself does not provide a great deal of descriptive information about psychological and social parameters because the variability within each diagnostic category is as great or greater than variability between these categories. The study results upheld this hypothesis and showed that diagnosis was related to differences only on traditional medical variables. According to Stein et al. (1989), since local communities are more likely to have children with a range of conditions and have only a small number within each disease category, a noncategorical approach facilitated the development and evaluation of service programs targeted to meet the diverse types of special needs of parents dealing with the impact of their child's chronic condition.

In contrast to the noncategorical approach to chronic conditions, Holroyd and Guthrie (1986) demonstrated, in a quantitative questionnaire study, that across the clinical groups of neuromuscular disease, cystic fibrosis, and renal disease, different patterns of stressful responses were noted for each of the physical disorders. Similarly, in an earlier study, Holroyd and McArthur (1976) investigated parents' responses to three different types of mental retardation using the QRS. The study results supported the hypothesis that the mothers of autistic children reported more problems for themselves and their families than mothers
of Downe's Syndrome or general psychiatric clinic children. Bouma and Schweitzer (1990) asserted that each disease has great variability in its clinical expression, chronicity, severity, and the associated hardships imposed on individual families. Bouma et al.'s (1990) study compared the different patterns of stress reported by 24 mothers with children with either a chronic physical illness (cystic fibrosis), a chronic psychological disorder (autism), and children without a physical or psychological disorder. The results provided empirical support for the suggestion that chronic mental disorders in children contribute more to family stress than chronic physical illness. Therefore, Bouma et al. (1990) stated that the results "highlight the need for family-based intervention programs specifically tailored to suit the psychological or physical nature of the child's disorder" (p. 729).

Clearly, the literature is ambiguous in its conclusions with regards to the question of whether a non-categorical approach to chronic conditions is an appropriate one.

Parental Coping in Response to a Child's Chronic Condition

While there are a number of studies available on parental coping few of these focus on the identification of parental coping strategies to manage the impact of a child's chronic condition on the family.

Schulman (1983), in a study of parents of children with
leukemia, noted that approximately 85% of families coped well. These families shared the following common characteristics: a history of prior good coping, good quality of marital and familial relationships, good support system, religious faith, and trusting relationships with health professionals. These findings were further supported by the studies of Rodebush (1986), Athrey and McCormick (1987), and Scharer and Dixon (1989). In McCubbin, Nevin, Cauble, Larsen, Comeau, and Patterson's (1982) study of how families cope with and adapt to their child's chronic condition, the researchers studied 217 families who had a child with cerebral palsy using four quantitative measures. The study identified three major coping patterns which were the same for both mothers and fathers. The data indicated that the parental coping to keep the family together, to gain friendships and extended family social supports, and to consult with the medical team were all-important. The researchers concluded that it is as important to care for family members and the family itself as it is to attend to the specialized needs of the child with cerebral palsy.

Frey, Greenberg, and Fewell's (1989) quantitative study, of 48 mothers and fathers of handicapped children, determined the relations of (a) child characteristics, (b) family social network, (c) parent belief systems, and (d) coping styles to parental stress and coping outcomes. While parental beliefs were the single most powerful correlate of
parent outcomes, parents differed dramatically in the degree to which they viewed their child's disability as a negative and stressful occurrence.

Venter's (1981) study of 100 families with cystic fibrosis children identified two major coping strategies which promoted a higher level of family functioning: (a) when parents share the burden of illness, both with family members and with someone outside the family; and (b) the family's ability to endow the child's illness with meaning (either philosophical or religious). Both strategies helped families manage the hardships of the child's illness over time. Moreover, Van Cleve's (1989) study explored how 100 parents coped with their child's spina bifida. From the results of the mailed study instrument, significant positive relationships were found between coping and (a) marital satisfaction, (b) quality of the relationship between husband and wife, and (c) attending a spina bifida support group.

An additional aspect of parental coping with a child's chronic condition, parenting skills, was described in the literature. Haladay (1978) reported on problems in parenting a child with a chronic condition faced by 11 pairs of interviewed parents. From the study results, the researcher asserted that for the parents of these children the appropriateness of the old rules and approaches to child rearing were called into question. The results of this study,
although non-generalizable beyond the small study population, illustrated the need for added appropriate parenting skills. According to Klein and Simmons (1979), parents often reported the loss of confidence in their parenting skills and discipline patterns because they are unclear about how to raise their child with a chronic condition. Moreover, they are confused by the sick role. Similarly, Austin (1990), in an opinion article, asserted that parenting a child with a chronic condition required specialized parental knowledge. McCubbin (1984), in her mailed questionnaire study of 100 families of children with cystic fibrosis, assessed parental coping. Based on the study's results, McCubbin (1984) asserted that participation in support groups with parents in similar situations provides parents with much needed parental support.

Although coping strategies are individualized and mothers and fathers differ in their adjustment to and ability to cope with their child's chronic condition, the studies indicated that parents require knowledge and skills that will enhance their ability to cope.

Impact of a Child's Chronic Condition on Family Functioning

Various researchers have studied the impact of a child's chronic condition on family functioning (Sabbeth, 1984; Strauss & Munton, 1985; Venters, 1981). Economic burdens, family communications, and marital adjustments were the recurring themes throughout these studies. According to
Stein and Reissman's (1980) definition, impact is the effect of a child's illness on the family system. Early studies on the emotional and familial impact of a chronic condition on the family focused on the psychopathology and dysfunctional effects on the child and family (Lawlor, Nakielny, & Wright, 1966; Troupauer, Franz, & Dilgard, 1970). Turk's (1964) study of 25 families documented increased family stress levels as a result of communication problems. Parents avoided discussing the child's illness with each other, friends, and relatives. The results from Meyerowitz and Kaplan's (1967) study of 111 families of children with cystic fibrosis revealed a parental sense of social isolation due to perceived negative attitudes from the community and their lack of time for community involvement. McCollum and Gibson (1970), from their study of 56 families, asserted that parent's adaptation to cystic fibrosis progressed through four major stages: prediagnostic, confrontational, long-term adaptive, and terminal. Severe psychological reactions of the parents during these stages included denial, anxiety, guilt, hostility, anger, and depression. In addition to these emotions, parents experienced confusion with regard to childhood developmental phases. According to Lewis and Rachelefsky (1984), mothers assume the major responsibility of caring for the chronically ill child. In a survey conducted by Damrosch and Perry (1989), it was reported that mothers of children with Down's syndrome had a
higher frequency of behaviors such as expression of negative affect and self-blame, as well as chronic sorrow. These researchers found that 83% of fathers described adjustment in terms of gradual steady recovery and 68% of the mothers reported periodic peak- and -valley crisis patterns.

Bregman (1980) studied six families whose children had Duchenne muscular dystrophy and Wednig-Hoffmann disease. The investigator lived with each family to learn the main concerns of parents and the ways in which they managed these concerns. Even though six families was a small sample and the results are not generalizable, the research showed positive behaviors performed by families, with parents as the primary managers. Bregman suggested that this positive focus is useful for the subsequent design of education that builds on family strengths and enables parents to share, with each other, behaviors that work.

Athreya et al. (1987) studied the impact of 3 different childhood chronic conditions on families. In this study, researchers interviewed 483 families and the results showed that limitations of activities of the child add to parental strain which has a greater impact than the actual medical diagnosis. Families most vulnerable to these stresses were those with a child requiring care disproportionate to the resources (physical and financial) available to the parent(s). The impact of a child's chronic condition on the marital relationship was identified as a significant factor
that affected parents' stress levels. Gath (1977) compared 26 parents of children with Downe's Syndrome with 26 matched control parents using a semistructured interview and rating scales. Study findings showed that parents of chronically ill children had significantly poorer marital relationships than the matched control parents. In Tew, Payne, and Laurence's (1974) longitudinal study, which assessed the marital harmony of 59 parents of children with spina bifida and 58 control couples, findings revealed that marital harmony increased over a period of time in control couples and decreased in couples with spina bifida children. In contrast to the findings of the previous two studies, Koocher and O'Malley (1981) presented evidence that illness brings parents closer. Of the 176 parents whose children were survivors of childhood cancer, 74% reported the illness brought them closer as a couple and 92% reported that the illness brought them closer as parents. In support of these findings, Finley, Putherbough, and Netley (1977) compared the number of divorces in 40 families of children who had surgical correction of tetralogy of Fallot with matched families of children who had undergone an appendectomy. The divorce rates in the two groups were not significantly different. These results refuted the findings of Tew et al., Payne, and Laurence (1974) and Gath's (1977) studies.

From the reviewed studies, the literature on the effects of a child's chronic condition on marital relation-
ships is contradictory. While marital function is challenged by a child's chronic condition, there is no difference in divorce rates. Because an intact family is the most appropriate caregiver and the most important influence on the child (Royal Commission, 1991; Shelton, Jeppson, & Johnson, 1987), actual and potential distress requires amelioration by increasing parental coping strategies (Royal Commission, 1991).

**Parental Resource Needs**

Horner et al. (1987) conducted a survey of parents of 164 children with a variety of conditions to discover their perceived needs. Appropriate educational opportunities for their child, help with medical bills, and recreation for their child were the three major needs identified by parents. Moreover, Walker et al.'s study (1989) revealed that parents need: parent education on rights and entitlements (74%), help in getting needed services (72%), information on community resources (61%), parent support groups (49%), and parent training for child health needs (49%). In Diehl's (1991) qualitative study, focus group interviews with 80 caregiving parents were used to obtain in-depth information of the needs of parents with medically complex children. Even though a selection bias towards a population that enjoys group activities existed in this study, support groups were lauded for the invaluable services provided to the care-giving parents.
From the results of the above studies, the common threads of parent education and support groups as important resources were evident.

Evaluative Studies of Parent Education Programs

Although there is a paucity of nursing literature on the evaluation of group, structured education programs for parents of children with chronic conditions, this segment of the literature review includes articles that discuss the effects of parent education groups for parents of children with chronic conditions.

In 1981, Rudolph, Pendergrass, Clarke, Kjosness, and Hartmann developed and pilot tested a structured education program for parents of children with cancer. By educating parents of children with cancer in group situations, researchers believed they could reach more parents, provide emotional support, disseminate information, possibly reduce stress, and build coping skills. Eighteen families participated in this study, with a total of 28 participants divided into two education programs. Several forms were used to assess the impact of the program and these included: (a) knowledge tests, consisting of 44 multiple choice and true/false questions, assessed knowledge gain in pre-, immediate post-, and 3 month post-test situations; (b) 'my response to my child's disease' questionnaire addresses parental stress levels and perceived coping abilities; (c) individual evaluation forms for each session gather opinions
about the speakers, reading materials, self-instructional exercises, program format, and the session in general; and (d) 'The State Trait Anxiety Index' evaluates levels of distress before and after the program. Results showed that parents learned new information as a result of program participation. However, the analyses of the effects of the program on coping abilities and stress levels were inconclusive, even though researchers state that "positive effects on coping and stress are suggested" (p. 53). The change in coping abilities and stress levels were limited to subjective reports rather than quantitative measures. In these reports, fathers described their appreciation of the opportunity to learn about the medical aspects of cancer and all subjects felt they had gained from the opportunity to meet with others to share feelings and experiences. Moreover, changes in the communication patterns between husbands and wives occurred in some families and several wives described their husbands as "opening-up" for the first time. Since the terms "some and several" have no numerical value, it was difficult to determine the significance of this change and the reliability and validity of the study's measures was not addressed. Furthermore, the study lacked a control group, and demographic details of the study population, such as age, ethnic origin, socioeconomic variables, and education levels of participants were missing. While the applicability of the study's findings is limited to its
population, the positive knowledge outcome, the sharing of feelings and experiences, and the change in communication patterns indicated that the participants had benefited from the program.

Hornby and Murray (1983) studied four large (22-52) group programs for parents of children of school-aged, physically handicapped, hearing impaired, and mildly and moderately mentally handicapped children. Between six and eight weekly 2 hour semi-structured group sessions were held. During these sessions, various condition-specific and undisclosed issues, concerns, and communication strategies were presented and discussed. Each parent program was evaluated using an attendance record, a self-report post-program questionnaire concerning the benefits and limitations of the program, and the clinical impressions of the group leaders. The researchers reported that: the vast majority of parents felt more confident in their ability to parent their handicapped child, most parents commented that they appreciated the opportunity of sharing problems and feelings with other parents who understood them, and many parents commented on the increased knowledge which they had gained. With the exception of the attendance records, the measures were subjective and, while the results cannot be generalized, it is interesting to note that parents perceived themselves as having increased knowledge and confidence.
Gaudet and Powers (1989) evaluated the effects of parent participation to determine the impact of their "parent group program". This program consisted of 13 2-hour sessions led by the program developer. Three groups of 5 parents', of children with a variety of chronic physical, mental, or emotional conditions, attitudes were measured in pre- and post-test situations using 'The New Beginnings Survey'. This survey tool consisted of 10 items to be rated using a Likert scale. Evidence of face and consensus validation for this survey was absent and reliability was not addressed. Although the researchers determined that a change in parental attitude occurs, they extrapolated this change in attitude to conclude that the "results indicate that parents' knowledge about coping with pediatric chronic illness and their coping skills did change from the beginning of the program" (Gaudet et al., 1989, p.97). Because the validity and reliability of the tool were not addressed, the small sample, and the erroneous conclusions, the study results were not useful.

Duffy and Halloran (1987) studied the effect of a 4 week, lecture and discussion focused, community-based education and support program on knowledge and perceptions of 35 parents who have children with asthma. Pre- and post-program tools were administered to measure changes from baseline parameters. Knowledge specific to anatomical structures, precipitating conditions, and medications significantly
improved during the period of the study. While perceptions about their understanding of asthma had changed, this understanding varied by sex. Female ratings increased and male ratings had dropped. Meanwhile, parental perceptions of confidence in dealing with and attitudes towards their child with asthma showed significant changes but this change was at differing rates across gender. Due to the absence of explicit details about the study's community setting and recruitment, the lack of a control group, and few details on which to determine the validity and reliability of the Asthma Knowledge and the Asthma Perceptual tools, the generalizability of results to the population was limited and, adding further to these limitations, the maintenance of changed knowledge and attitudes was not addressed.

Lewis, Hatton, Salas, Leake, and Chiofalo (1991) conducted a large cross-national randomized control trial of a family-focused educational program, for parents of seizure disordered children, which was based on a helping and counselling model. The questionnaires were administered pre- and 5 months post-intervention. The experimental (n=185) and control (n=180) groups attended four-1&1/2 hour differently designed sessions. Whereas the control group's parents and children together attended a program on chronic conditions that was specifically designed for their children, the experimental group's children and parents attended age specific separate sessions. While both experi-
mental and control groups increased their knowledge about seizures and seizure care, only the experimental group demonstrated a significant decrease in anxiety. The investigators noted that in both pre- and post-testing, the fathers rated lower anxiety levels than the mothers. This was a well planned and executed study in two nations. While an established tool was used to measure parental anxiety, the instrument used to examine knowledge was designed by the researchers and evidence of their reliability and validity was not included in the report. However, the strengths of this study included: the large and randomized experimental and control groups, the cross-national samples, the groups from Chile were 98 to 100% of low socio-economic status, 1/3 of each group was male, and the 5-month post-test.

Canam (1990) designed, implemented, and evaluated an education program (PEP), with 48 parents of children with a variety of chronic conditions. The researcher used two quantitative tools, in this quasi-experimental repeated measures study, to determine the changes in parental coping and stress from before and after participation in the program and when compared to a control group. Results demonstrated a significant increase in parental coping and a decrease in parental stress levels. In addition, follow-up guided interviews were conducted with 15 of the 48 subjects and the results showed that the program was effective in enhancing parental coping, family function, and use of
resources. Recommendations from that study were that it be repeated using measures of family coping, family functioning, and family utilization of resources. In addition, it was recommended that both parents attend the program together and that the program be opened to parents of children with mental disabilities.

Similar to the literature reviews of Tramontana, Sherrets, and Authier (1980); Fine (1989); and Dembo, Sweitzer, and Lauritzen (1983), which critically reviewed evaluative studies of healthy-child parent education programs, the results from the preceding reviewed studies indicated changes in knowledge, parental involvement, and attitude as a result of various parent education programs. In accordance with Tramontana et al. (1980) observations, research has been limited in scope and the methodological deficiencies in many of these studies render positive results subject to alternative interpretations. In addition to the methodological deficiencies, only Lewis et al. (1991) and Canam (1990) addressed the issue of maintenance of changed knowledge, beliefs, or behaviors. Moreover, with the exception of Gaudet et al (1989) and Canam's (1990) studies, these studies considered diagnosis specific samples.

This quasi-experimental study was designed to provide empirical evidence that either supported or refuted the hypothesized effects of Canam's (1990) study. Using three
quantitative tools to test the single control and four experimental groups and nine randomly selected subjects for a four to five month post-intervention interview, the study explored the effectiveness of the PEP in increasing parental coping, family functioning and utilization of resources for parents of children with a wide variety of chronic conditions and determined the stability of those effects to this point in time.

The application of the quasi-experimental methodology used in this study is described in the following chapter.
CHAPTER THREE

METHODOLOGY

This study used a quasi-experimental, pretest/posttest, non-equivalent control group design to determine if the PEP intervention increased parental coping, family functioning, and utilization of resources. In addition to this quantitative design, a qualitative component, which consisted of follow-up interviews with selected program participants, was implemented to augment the quantitative findings. In this chapter, the sampling procedure, data collection procedures, the intervention, the variables, data collection tools, ethical considerations, and data analysis procedures are considered.

The research questions were as follows:

1. Does program participation significantly increase parental coping?
2. Do program participants demonstrate a significant improvement in family functioning?
3. Does program participation significantly increase parental use of resources?

Statistical null hypotheses were used to test these research questions and it was hypothesized that:

1. There would be no significant difference in parental coping after program participation.
2. There would be no significant difference in family functioning after program participation.
3. There would be no significant difference in parental use of resources after program participation. Given that coping, family functioning, and utilization of resources have 20 patterns/subscales, the above statistical hypotheses for each variable was extended to each of these patterns/subscales.

**Sampling Procedure**

In order to be included in this study, subjects must have had a child with a chronic condition and that child's diagnosis must have been made a minimum of 6 months prior to program commencement. In addition, subjects had a verbal command of English, a grade 9 reading and comprehension level, and consented to participate in the study.

The sample for this study was a convenience sample of 28 volunteer parents who attended four separate group presentations of the PEP. While each group size varied, the four groups of parents originated from three different sources. First, two groups of parents were recruited from the neurological clinic of an urban pediatric hospital. These parents had children who are mentally, physically, and socially challenged due to difficult epilepsy. Second, parents were selected on a first come, first serve basis from an in-patient and out-patient pediatric hospital population. Third, the parents were drawn from an in-school placement program within a community health department. These parents had children who are from Greater Vancouver's
mainstreamed school population. A nurse who worked in each of these settings sent or gave out a participant information letter to all eligible participants (Appendix A & B). In turn, interested parents contacted the group leaders by phone and if they met the selection criteria, they were invited to join the program. The non-equivalent control group was obtained from the neurologic clinic's Spring PEP wait list.

For the interview segment of this quasi-experimental study, a sample of nine subjects was selected. This sample was selected using a random number table (Wilson & Bright, 1952). According to LoBiondo-Wood et al. (1990), the advantages of this simple random sampling method include: the sample selection is not subject to the conscious biases of the researcher; the representativeness of the sample in relation to the population characteristics is maximized; and the differences in the characteristics of the sample and the population are purely a function of chance. The interview participants were selected from the subjects who had completed the three initial winter PEP sessions. Further, 3 subjects were selected from each of these three groups. This sub-sample of 9 parents was interviewed by the researcher, using a semi-structured interview format.

Data Collection Procedures

The pretest data collection took place one week before each of the four programs began. At this time, subjects
signed consent forms (Appendix C) and filled out the three questionnaires (Appendix G) and the demographic form (Appendix D). The second data collection took place one week after completion of the program and the procedure was the same. Moreover, the control group was tested during the same pre-test and one week post-test times. The interviews were conducted four to five months after program completion. While the researcher administered the tools and the semi-structured interviews, she was not involved in the presentation of the program.

The Intervention

The details of the intervention are presented in five segments. These segments include the program description, the program facilitators, the length, frequency, and time of the sessions, the attendance requisites, and the venue.

The Parent Education Program

The intervention that was evaluated in this study was an education program (PEP) for parents of children with any chronic condition. The program was based on the common adaptive task framework delineated by Canam (1993). The eight common adaptive tasks identified by Canam include: accepting the child's condition; managing the child's condition on a daily basis; managing ongoing stress and periodic crises; meeting the child's developmental needs; meeting the needs of other family members; assisting family members to manage their feelings; educating others about the child's
condition; and developing and utilizing resources.

According to Canam (in press), PEP presents families with a competency-based coping model which is base on the premise that

"there are a number of psychosocial tasks to be completed when a family has a child with a chronic condition. If parents develop the knowledge and skills they need to complete these tasks, they will cope effectively with their situation (p.3)".

The rationale for this conceptualization is based on the individual's need for mastery. According to Canam (in press), presenting the issues as tasks to be completed gives parents the idea that they can manage the situation and have control over it. Therefore, the purpose of the program is to enhance parental coping with their child's chronic condition and decrease their stress by teaching them the knowledge and skills they need to complete the adaptive tasks facing them (Canam, in press).

The program consists of eight two-hour sessions held once a week for eight weeks with each session focusing on one of the adaptive tasks (Canam, in press). The program is structured to offer a minimum of lecturing and a maximum of parental involvement. In order to facilitate this parental involvement and consistency within the program, Canam has developed both a teacher and a parent manual that includes detailed information and exercises for each of the eight
sessions. Each parent is given a copy of the upcoming session and asked to read it before they come so they are familiar with the topic. By the end of the program, they have a completed copy of the manual to use as a future reference source. To evaluate the program content, Canam sent the completed manuals to six experts in the field of childhood chronic health problems and child and family education. These individuals included a prominent nurse educator and researcher, a pediatrician, a social worker, a psychologist, and two parents of children with chronic conditions. They were asked to respond to the relevancy and inclusiveness of the content and the process of implementing the program. Based on the feedback received, Canam made minor changes and the program was implemented.

The outline of the program is as follows: (Canam, in press)

Session 1: Introduction and exploring personal meaning.

This session includes an overview of the program and begins the process of developing group cohesion. This is accomplished by parents introducing themselves and their family, including the child with the chronic condition and talking about what they hope to get out of the program. This session also focuses on helping parents to explore the personal meaning that their child's condition has for them. To do this, parents are asked to form groups of three and tell each other what it is like to be the parent of a child
with a chronic condition. They then reconvene and discuss what it was like for them to talk about the effect of their child's illness on themselves and their family. The skill taught in this session is that of reframing, to help parents who have a negative outlook of their situation to think about other ways of looking at it.

**Session 2: Managing your child's condition on a daily basis.**

To manage their child's health condition effectively, parents need complete and accurate information about the disease and its treatment. This session focuses on the kind of information parents need and when it is needed, factors that affect communication of information, and how to request and remember information. The skills taught in this session are communication and memory skills.

**Session 3: Managing ongoing stress and periodic crisis.**

This session examines the common stressors affecting families of children with chronic conditions, helps parents to examine the stressors and responses to stress in their own families, and explores effective and ineffective ways of coping with stress including techniques for coping with a child's hospitalization. It also presents the tasks that parents need to complete in order to cope effectively with their child's chronic condition. Skills taught in this session are those related to stress management such as relaxation techniques and thought-stopping techniques.
Session 4: Meeting your child's developmental needs.

This session discusses the normal developmental needs of children at different ages, how a chronic condition can interfere with those needs, and ways in which parents can help their child to meet his or her needs within the context of a chronic condition. One of the skills focused on in this session is learning how to discipline effectively which includes parents' attitudes toward discipline as well as techniques such as natural and logical consequences and teaching the child how to problem solve.

Session 5: Meeting the needs of other family members.

When a child has a chronic condition, the parents' time, energy, and attention can be focused on the child to the detriment of other relationships within the family. This session focuses on the needs of all family members including the siblings of the child with the chronic condition, the parents' needs as individuals, and their needs as a couple. Ways of meeting these needs are explored. Parents are also asked to assess the strengths of their family to help them focus on their positive qualities. Communication and problem-solving skills are taught in this session.
Session 6: Assisting family members to manage their feelings.

Families of children with chronic conditions share many common experiences and feelings. One of the most important factors in helping their family cope is for parents to deal openly with their own feelings and to help their children to deal with theirs. Learning to express feelings honestly and appropriately and communicating with children about their feelings requires skills. This session focuses on helping parents to identify, accept, and express their feelings appropriately. The point that is emphasized is that children take their cues from parents and if parents communicate openly and honestly the children are more likely to do so also. The skills taught during this session are communication skills, particularly active listening and empathy.

Session 7: Educating others about the child's condition.

Once parents have a good understanding of their child's condition, they often need to explain it to others including the child if he or she is old enough, siblings, relatives, friends, neighbours, teachers, and other people in the community with whom the child has ongoing contact. In essence, parents become the educators about their child's chronic condition. To take on this role, parents not only need a good understanding of the condition but also skill in
communicating with others. This session focuses on communication skills and provides information on age appropriate explanations to help parents explain the child's condition to the child and siblings of different ages.

Session 8: Developing and utilizing resources.

Having a viable support network can buffer or reduce stressors that the family experiences. Yet, parents are often unable to make the best use of the potential support available to them because of a reluctance to ask others for help and because of a lack of experience in dealing with bureaucracies and health care agencies. This session focuses on helping parents to know their rights as well as their responsibilities and teaches them how to mobilize and utilize their support systems. The skills taught in this session are assertiveness and negotiation skills.

The Program Facilitators

According to Sternlicht & Sullivan (1974), group procedures are most effective when two leaders are used. Two coleaders were present for each program session and assumed facilitator roles. The qualifications of these facilitators varied. The two neurology clinic group facilitators were expert pediatric nurses with experience in group techniques. The facilitators of the general pediatric hospital group had diverse background qualifications. While one person had a masters of nursing preparation and was an expert pediatric nurse clinician, the other person was an experienced teacher
of handicapped children at a pediatric long-term care facility, a mother of a child with a chronic condition, and a former PEP participant from Canam's (1990) initial program presentation. Of the two community in-school program group facilitators, one person was the administrator of the in-school program and the other person was one of three community health nurses responsible for the integration of these children into the school system. With the exception of the community health facilitators, these coleaders donated their expertise to promote the program. In order to provide consistent instruction, Canam conducted a three-hour pre-program review of the course content, teaching and learning strategies, and group processes.

**Frequency, Length, and Time**

The program consisted of eight consecutive sessions that were two hours in length. These sessions were presented during the evening from 7:30 to 9:30. While three of the programs were offered in the Fall of 1992, the fourth was given in the Spring of 1993.

**The Attendance Requisites**

In order to be considered a study subject, program participants had to attend five of the eight sessions. Moreover, these parents attended the two additional sessions that were required for the evaluation of the PEP.

**The Venue**

The two neurology clinic groups and the general pediat-
ric hospital group presentations of PEP were held in a hospital board room donated by this institution's administrators. The fourth program site was the lunch room of an urban community health unit.

The Variables

The independent variable for this study was PEP. The dependent variables were coping behaviors, family functioning, and utilization of resources. The effects of the independent variable on these three dependent variables were initially tested quantitatively with the quasi-experimental pre-test/posttest design. The data were collected pre- and post-intervention and differences in the dependent variables were evaluated (Roberts, 1989).

According to Goodwin and Goodwin (1984), adding a qualitative component to a quantitative design increases the meaning of the obtained data. Within the double ABCX framework, the family's perception (cC) of the total situation is a critical component of family coping (McCubbin et al., 1983). Therefore, the qualitative constituent of this study generated vital and enriching data pertaining to meaning of the changes in parental coping, use of resources, and family function for parents. In addition, because the interviews followed 4 to 5 months post intervention, they supported the maintenance of change to that point in time.

Data Collection Tools

The questionnaire and interview data collection tools
utilized in this study are presented separately and in order. Three instruments were employed in the quantitative component of this study.

The Coping Health Inventory for Parents

First, "The Coping Health Inventory for Parents (CHIP)" (McCubbin, McCubbin, Nevin & Cauble, 1979) was utilized to measure subjects' coping behaviors (Appendix J). This measure was a 45-item self-report questionnaire checklist that provided information on how parents perceive their overall responses to the management of family life when a child has a chronic health problem.

The 45 items are divided into three coping patterns. Coping Pattern 1 consists of 19 behavioral items which focus on family dynamics and the parents' outlook on life and the illness. Coping Pattern 2 consists of 18 behavioral items which focus on parents' coping efforts to maintain a sense of their own well being through social relationships, involvement in activities which enhance their self-esteem, and management of psychological tensions. Coping Pattern 3 consists of eight behavioral items which focus on parents' coping efforts to understand the medical situation and master the information needed to care for their child at home through communication with other parents and consultation with medical staff.

These three coping patterns were derived from factor analysis representing 71.1% of the variance of the original
correlation matrix. Chronbach's alpha, computed for the items on each coping pattern, indicated reliabilities of .79, .79, and .71, respectively (McCubbin et al., 1983).

**Family Environment Scale**

The second instrument was the "Family Environment Scale" (FES) (Moos & Moos, 1986) (Appendix J). The FES was designed to measure three broad content dimensions of social climate in both normal and distressed families. First, the relationship dimension was measured by the Cohesion, Expressiveness, and Conflict subscales, which assess the degree of commitment, openness, and disagreement, respectively, among family members. Second, the growth dimension was described by five subscales (Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active Recreational Orientation, and Moral Religious Emphasis) that measure the family's concern with aspects of personality and social development. Finally, the third dimension, termed system maintenance, was assessed by the subscales of Organization and Control, which measure the extent of formality and hierarchy, respectively, in the family structure. The 10 subscales are scored as the sum of endorsed items; higher scores indicate greater degrees of the characteristics. These subscales have an internal consistency ranging from .64 to .79, and show average subscale intercorrelations around .20, indicating that they measure distinct, though somewhat related aspects of family social environments (Moos
& Moos, 1976). In addition, the test-retest reliabilities are acceptable, ranging from a low of .68 for independence to a high of .86 for cohesion (Moos et al., 1986).

The Family Inventory of Resources for Management

The third instrument, the "Family Inventory of Resources for Management (FIRM)" (McCubbin, Comeau, & Harkins, 1981), was a 69 item self-report questionnaire checklist which assessed the family's social-psychological, community and financial resources, the family system and social support dimensions (Appendix J). The 69 items are divided into the following four sub-scales.

Family Strengths 1: The "Esteem and Communication Scale" assesses parents' social-psychological resources in six areas. These areas include: (a) family esteem (report from friends, relatives, co-workers, and among family members); (b) communication (sharing feelings, discussing decisions); (c) mutual assistance (helping each other and relatives); (d) optimism; (e) problem-solving ability; and (f) encouragement of autonomy of family members. The reliability (Chronbach's alpha) is .85.

Family Strengths 2: The "Mastery and Health Scale" assesses social-psychological resources among three dimensions. These dimensions include (a) a sense of mastery over family events and outcomes (fate control, flexibility, managerial abilities); (b) family mutuality (emotional support, togetherness, cooperation); and (c) physical and
emotional health. The reliability (Chronbach's alpha) is .85.

The "Extended Family Social Support Scale" contains items which show giving and receiving help from relatives in terms of physical and material help as well as through supportive communication (esteem, respect, appreciation). The reliability of this scale (Chronbach's alpha) is .62. While this alpha is relatively low, the authors of the FIRM have not provided a rationale.

The "Financial Well-Being Scale" assesses the family's sense of well-being surrounding finances covering six areas: (a) ability to meet financial commitments; (b) adequacy of financial reserves; (c) ability to help others financially; (d) optimism about the family's financial future (adequacy of insurance, financial benefits from employment, retirement income, earning power, financial progress); and (e) effective financial management practices. The reliability of this scale (Chronbach's alpha) is .85.

Interview

Between 4 and 5 months after program completion, the semi-structured interviews were administered and a set of trigger questions guided the interviews (Appendix E). In order to elicit the subjects' perceptions of changes in parental coping, family functioning and utilization of resources since taking PEP, the interviews were as non-directive as possible. These interviews were conducted in
the subject's home or in a comfortable environment selected by her or him. Each interview was 60 minutes in length and was tape recorded. Following each interview, the audio tape recording was transcribed verbatim.

Since the researcher was the data collection and interpretive instrument in this component of the study, the findings were filtered through her perceptions and perspectives (LoBiondo-Woods et al., 1990). Therefore, instead of using "a priori" or preconceived ideas, about the outcomes of participating in the PEP, the practice of "bracketing" was employed (Munhall & Oiler, 1986) and the truth value of the proposed study was subject-oriented rather than researcher-defined (Sandelowski, 1986). Data was collected and analyzed in the natural language of the subjects (Duffy, 1985).

**Ethical Considerations**

This researcher ensured protection of the rights of subjects by:

1. Obtaining approval from and adhering to the standards set by the ethical screening committees of the University of British Columbia, Children's Hospital, and the Vancouver Public Health Department.

2. Explaining to subjects the study's purpose, duration, and expectations of informants.

3. Advising subjects that participation was voluntary and that they could withdraw from the study at any time and
that should they decided to withdraw, it would not jeopardize the present or future medical care of their child.

4. Assuring subjects that confidentiality was ensured. These measures included: an assigned code to each subject's questionnaire and interview transcript, data were only reviewed by the researcher and the thesis committee members; and audio-tapes were erased following transcription.

5. Obtaining subjects written consent (Appendix C) and giving them a copy.

6. Explaining who to contact for answers to pertinent questions about the research and subjects' rights.

Data Analysis

After the questionnaires were administered, responses were compiled, coded, and placed on a computer file. Following this, the study subjects' raw scores on parental coping, family functioning, and utilization of resources were compared to the normative range graphs for each tool. This comparison established the subjects' baseline levels on each dependent variable.

Descriptive statistics, including means, standard deviations, and standard errors were calculated from the entered data using the Statistical Package for Social Sciences which is a data analysis and statistics package.

Threats to the study's internal validity include history, maturation, and repeat testing. In order to allay the concerns about these threats, dependent t-tests were con-
ducted on the control group's (n=5) data.

Six wife and husband pairs attended the PEP. In order to avoid the confounds that could result from the attending marital dyads' influence and dependence on each other, rather from the intervention itself (Glass & Hopkins, 1984), statistics have been separately calculated for both female (n=20) and male (n=8) subjects. These statistics included the means, standard deviations, standard errors. Paired t-tests were done using these measures to determine the degree of probability that the null hypotheses were supported (Knapp, 1985; Kaye, Bray, Gracely, & Levison, 1989; Roberts & Burke, 1989). The degree of risk of a type-I error was set at alpha=.<.05 and any result below this level was considered significant and the statistical null hypothesis was not tenable.

Since each experimental group contained only a small number of fathers who attended with their wives, it was not possible to conduct an ANOVA on these subjects (Glass and Hopkins, 1984). Therefore, an ANOVA was conducted only on the female subjects to determine whether the differences among the four experimental group means on each of the 3 measured variables and, subsequently 20 patterns and subscales, were greater than would be expected from sampling error alone.

The transcripts of the audio tapes and their corresponding field notes were analyzed using deductive and in-
ductive content analysis (Field and Morse, 1985). According to Waltz, Strickland, and Lenz (1991), the advantage of a well-delineated coding scheme is that it enhances the likelihood that interpretive reliability will be achieved. In order to deductively develop the scheme for categorizing the interview content, the researcher derived the categories from the conceptual framework and the three questionnaires (Waltz et al, 1991). Two experts, a pediatric nursing professor and a family physician, reviewed this scheme prior to its use and determined that it was valid. The scheme for categorizing the interview content is depicted in Appendix F. Initially, during the analytic process, each transcript was read in its entirety in order to acquire a feeling for subjects descriptions. Using the established scheme for categorizing the data, the researcher surveyed the transcripts for words, phrases, descriptors, and terms central to evaluating the program's outcomes from the subjects' perspective. In addition to the deductive analytic procedure, a continuous inductive content analysis was performed on the data. According to Waltz et al. (1991), inductive categories are derived from the data themselves by identifying clusters of similar data through a data-shuffling-and-sorting procedure. Following both the deductive and inductive data categorizations, the two experts independently, and both deductively and inductively, examined two of the analyzed transcripts. During separate sessions, each expert
compared and discussed their results with the researcher until consensus was reached. This process ensured face validity and intra-rater reliability of the researcher's results.

According to Guba and Lincoln (1981), auditability is the criterion of consistency or reliability in qualitative research and is achieved when the researcher leaves a clear and appropriate "decision trail" from the study's beginning to its end (Sandelowski, 1986). An explicit decision trail supports the method of data analysis and, therefore, the validity of the findings (Field et al., 1985). This auditability was initially determined by the thesis chairperson and, then, by other readers of the study.

According to Guba et al. (1981), the criterion of confirmability is the freedom from bias in the research process. While the researcher was known to the author of the PEP, the researcher was not involved in the presentation of the program and was known to the program participants as the researcher responsible for the program evaluation. Furthermore, this confirmability was ensured by the establishment of credibility, fittingness, and auditability (Younge & Stewin, 1988).

**Summary**

This chapter outlined the research design used in this study. The sampling and data collection procedures, the intervention and variables, data collection tools, ethical
considerations, and the data analysis procedures were described. The following chapter presents a detailed discussion of the study findings.
CHAPTER FOUR

FINDINGS

From the quantitative analysis of the data, parental coping, family functioning, and utilization of resources increased after taking the eight session PEP. The variables in which change was ascertained differed for mothers and fathers. Moreover, the deductive content analysis of the interview data demonstrated changes in coping and family functioning that were not evident in the quantitative analysis. Further to these ancillary findings, the inductive content analysis identified parents perceptions of program variables.

The results of the analyses of the demographic questionnaire, the pre and post tests, and the semi-structured interviews are presented in this chapter in two sections. First, the characteristics of the sample are delineated. Following this delineation, the findings that resulted from the analysis of the three pre/post questionnaires are outlined and the information obtained from the semi-structured interviews is described.

Characteristics of the Sample

The characteristics of the sample are described under three headings. These headings include: description of experimental and control groups; demographic, social, and economic characteristics; and description of interview subjects.
Description of Experimental and Control Groups

The four experimental groups were comprised of 20 mothers and 8 fathers of children with chronic conditions, who participated in four separate group presentations of the PEP.

Two of the four experimental groups of parents were recruited from the neurological clinic of an urban pediatric hospital. The first of the neuro-focus groups consisted of 7 parents of 5 children, aged 2 1/2 to 4 1/2. The children's diagnoses included: infantile spasms (2), hypertonic spasticity and multiple seizures, hypotonic cerebral palsy with multiple seizures, and an intractable seizure disorder. The parents of these children were from 25 to 38 years of age. The second neurology clinic group of 6 parents had 6 children, aged 2 to 18. These children had the following diagnoses: uncontrolled seizure disorder with developmental delays; Lennox Gastalt Syndrome; a head injury with difficult epilepsy; an intractable seizure disorder; Down's syndrome with seizures, and a severe epilepsy. The parents ages ranged from 24 to 52.

The third experimental group of 7 parents was selected on a first come, first serve basis from an in-patient and out-patient pediatric hospital population. The 5 children, aged 3 1/2 to 18, of these parents had diagnoses that ranged from cerebral palsy and Duchene's muscular dystrophy, to epilepsy and phetylketonurea. These parents' ages ranged
from 26 to 60.

The fourth experimental group of 8 parents was drawn from an in-school placement program within a community health department. These parents had 7 children, aged 7 to 20, whose diagnoses included autism, retinitis pigmentosa with an unknown muscle degenerative disease, spinal chord injury (2), spina bifida, hemophilia and Down's syndrome, and a learning disability. The parents' age range was 32 to 50.

Of the 28 subjects in the experimental group, 12 consisted of wife and husband pairs and included three couples in group 1, none in group 2, two in group 3, and one in group 4. Due to the small numbers in each group, the plan to treat a couple as one parent and therefore, independent, in data gathering and analysis was aborted. As a result, each parent filled out a set of 3 pre and post program questionnaires and adjustments were made to the statistical analysis of the data.

The control group was drawn from the second neurology clinic group who awaited the spring program presentation. While the anticipated number of controls was 10, the actual number who completed the pre- and post-program questionnaires was 5. The control group attrition was due to parent's spring scheduling which did not allow them to participate as they had planned.

The inclusion criteria delineated that subjects must
have experienced the diagnosis of their child's chronic condition 6 months prior to taking the course. Therefore, the duration of the subjects' child's chronic condition varied from 8 months to 20 years.

Given that subjects were required to attend five of the eight sessions, the attendance rates were high (80 to 100%). Moreover, the majority of parents attended all of the sessions. Absences were attributed to overcommitment and illness. The program attrition consisted of one neurology clinic marital dyad who ceased coming after two sessions and the reason for this withdrawal was unknown to the facilitators. Table I summarizes the description of the experimental and control groups.

Table I: Description of Control and Experimental Groups

<table>
<thead>
<tr>
<th>Group Number</th>
<th>Sample Size</th>
<th>Number of Children with CC</th>
<th>Childrens' Age Range</th>
<th>Attended with Spouse</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7</td>
<td>5</td>
<td>2 1/2 to 4 1/2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>6</td>
<td>2 to 18</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>7</td>
<td>5</td>
<td>3 1/2 to 18</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>7</td>
<td>7 to 20</td>
<td>1</td>
</tr>
<tr>
<td>Control Group</td>
<td>Sample Size</td>
<td>Number of Children with CC</td>
<td>Childrens' Age Range</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>5</td>
<td>5</td>
<td>2 1/2 to 7</td>
<td></td>
</tr>
</tbody>
</table>
Demographic, Social, and Economic Characteristics

Demographic, social, and economic data were collected from the subjects during the initial testing of each group. This data included their ethnic background, marital status, education, employment status, and income level.

Most of the subjects were Caucasian (20). The remaining participant's ethnic background included Japanese (3), Italian (3), Brazilian (1), and Chinese (1).

The majority (26) of subjects were married for periods ranging from 5 1/2 to 26 years. The 2 remaining parents were separated from their spouses.

All but one of the subjects had at least a high school education. While over two thirds had grade 12 or some college or university, less than one quarter of subjects were college or university graduates.

Employment characteristics revealed that nearly two thirds of the subjects (64%) were employed. Only 2 subjects had combined incomes of under 20 thousand dollars. The remaining subjects combined incomes included: 20 - 40 thousand (34%), 41 - 60 thousand (48%), and above 60 thousand (11%).

Description of the Interview Subjects

The qualitative portion of this study consisted of 9 semi-structured interviews. Three members from each of the experimental groups 1, 3, and 4 were selected using a random number table. All selected participants consented to a one
hour interview.

Quantitative and Qualitative Findings

The results obtained from the quantitative data analysis are reported under the three research questions. First, did program participation significantly increase parental coping? The second question asked: do program participants demonstrate a significant improvement in family functioning? Finally, did program participation significantly increase parental use of resources? From the continuous inductive content analysis of the interview data, a fourth category, program variables evolved from within the interview content.

When compared to the normative range graphs for each tool, the subjects' baseline scores showed that the subjects were at or above the mid-range for each of the 3 dependent variables.

During statistical analysis and the presentation of the results abbreviations were used for the tools and their patterns/subscales. These abbreviations and their corresponding terms include: CHIP, Coping Health Inventory for Parents; FAM, Family; SUPP, Support; MED, Medicine; FES, Family Environment Scale; C, Cohesion; EX, Expressiveness; CON, Conflict; IND, Independence; AO, Achievement Orientation; ICO, Intellectual Cultural Orientation; ARO, Active Recreational Orientation; MRE, Moral-Religious Empasis; ORG, Organization; CTL, Control; FIRM, Family Inventory of
Resources for Management; FS, Family Strengths 1 (Esteem and Communication); RS, Family Strengths 2 (Mastery and Health); SS, Extended Family Social Support; SFS, Sources of Financial Support; and FIRM, Total Score (FS + RS + SS + SFS). In addition, the corresponding values of the means for each test are found in Appendices G, H, and I.

The paired t-tests, conducted on the control group's data, showed a level of significance of $p \geq .05$ (see Table II). Therefore, any change in perceptions on each of the 3 dependent variables was likely due to chance. Although this non-significant result allayed concerns about threats to the study's internal validity, the small number of control subjects lessened the power of the statistical test to show significant change.
Table II: Control Group's Paired t-test Results for CHIP, FES, and FIRM

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pattern/Subscale</th>
<th>SD</th>
<th>SE</th>
<th>T-value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>5.495</td>
<td>2.458</td>
<td>.73</td>
<td>.275</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td>5.050</td>
<td>2.258</td>
<td>1.33</td>
<td>.127</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td>1.949</td>
<td>.872</td>
<td>.46</td>
<td>.335</td>
</tr>
<tr>
<td>FES</td>
<td>C</td>
<td>.707</td>
<td>.316</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>1.140</td>
<td>.510</td>
<td>.78</td>
<td>.238</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>1.095</td>
<td>.490</td>
<td>-.41</td>
<td>.352</td>
</tr>
<tr>
<td></td>
<td>IO</td>
<td>1.000</td>
<td>.447</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>-.400</td>
<td>.548</td>
<td>-1.63</td>
<td>.089</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>.000</td>
<td>.640</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>1.304</td>
<td>.583</td>
<td>.34</td>
<td>.374</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>2.000</td>
<td>.894</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>1.304</td>
<td>.583</td>
<td>1.37</td>
<td>.121</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>-.837</td>
<td>.545</td>
<td>-1.45</td>
<td>.098</td>
</tr>
<tr>
<td>FIRM</td>
<td>SFS</td>
<td>1.414</td>
<td>.632</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>3.209</td>
<td>1.435</td>
<td>1.81</td>
<td>.072</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>3.507</td>
<td>1.568</td>
<td>.38</td>
<td>.361</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>2.793</td>
<td>1.249</td>
<td>.32</td>
<td>.382</td>
</tr>
<tr>
<td></td>
<td>FIRM</td>
<td>8.899</td>
<td>3.980</td>
<td>.95</td>
<td>.197</td>
</tr>
</tbody>
</table>

The null hypothesis for each ANOVA was that the means of dependent variables of the 4 groups of mothers were not different. The results supported the null hypothesis since p=>.05 (see Table III). Since this result indicated that the experimental groups were similar on the 3 variables, the concern of confounds within the groups are diminished.
Table III: ANOVA on Differences Between Group Means for CHIP, FES, and FIRM Scores

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>F</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>.841</td>
<td>3,16</td>
<td>.491</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td>.546</td>
<td>3,16</td>
<td>.658</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td>.052</td>
<td>3,16</td>
<td>.984</td>
</tr>
<tr>
<td>FES</td>
<td>C</td>
<td>.723</td>
<td>3,16</td>
<td>.553</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>2.835</td>
<td>3,16</td>
<td>.071</td>
</tr>
<tr>
<td></td>
<td>IND</td>
<td>1.347</td>
<td>3,16</td>
<td>.294</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>1.496</td>
<td>3,16</td>
<td>.253</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>1.483</td>
<td>3,16</td>
<td>.257</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>1.404</td>
<td>3,16</td>
<td>.278</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>.203</td>
<td>3,16</td>
<td>.893</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>.686</td>
<td>3,16</td>
<td>.574</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>.197</td>
<td>3,16</td>
<td>.897</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>.075</td>
<td>3,16</td>
<td>.973</td>
</tr>
<tr>
<td>FIRM</td>
<td>SFS</td>
<td>.607</td>
<td>3,16</td>
<td>.620</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>.531</td>
<td>3,16</td>
<td>.667</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>.995</td>
<td>3,16</td>
<td>.420</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>.409</td>
<td>3,16</td>
<td>.749</td>
</tr>
<tr>
<td></td>
<td>FIRM</td>
<td>.354</td>
<td>3,16</td>
<td>.787</td>
</tr>
</tbody>
</table>

For each research question, the quantitative findings will precede the qualitative data and the results for all female subjects will be presented first, followed by the results for male subjects. Further, when the qualitative data is presented, the subject's code number and the quote's line number will be placed in brackets following each quote.

Research Question I: Did program participation significantly increase parental coping?

Parental coping was evaluated using the CHIP inventory questionnaire and the semistructured interviews. The CHIP
questionnaire assessed the parents' perceptions of their response to the management of family life when they have a child member who has a chronic condition. Three coping patterns were measured using these assessment methods. These coping patterns included: behaviors that focus on strengthening family life and relationships and the parents' outlook on life with the child who has the chronic condition (FAM); social support, self esteem, and psychological stability (SUPP); and understanding of the medical situation through communication with other parents and consultation with medical staff (MED).

**Coping Pattern 1**

The null hypothesis concerned with the mothers' perceptions of the first coping pattern, FAM, was supported at a level of $p > .05$ (see Table IV). As a result, the differences in their perceptions on FAM were not significant and are likely due to chance.

Table IV: Mothers' CHIP Paired t-test Results

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pattern</th>
<th>SD</th>
<th>SE</th>
<th>T Value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>4.837</td>
<td>1.082</td>
<td>-1.06</td>
<td>.150</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td>7.015</td>
<td>1.569</td>
<td>-2.26</td>
<td>.018*</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td>3.133</td>
<td>0.701</td>
<td>-2.35</td>
<td>.014*</td>
</tr>
</tbody>
</table>

* = significant difference

Data from the interviews with the mothers, however, clearly indicated a change in maternal coping with their child's chronic condition. This change was one of sharing
the burden as opposed to taking total responsibility for the child's care. Sharing the burden was documented in five of the six interviews. These mothers elaborated:

Funny how, a lot of responsibility, I finally realize, I don't have to do it all. Somebody else can share (5, 344).

But to know that I don't always have to solve everybody else's problem. I'm not thinking "I have to do it all." And that was the other person has to be made to take their responsibilities ... that is something that I have changed and that is being carried on with (27, 885).

Before, I just gave my, almost my whole life, to my daughter and my family. ... you have to take the time to do what you like to do. I don't need to do everything. I can think of ways to rest my responsibility. Somebody else can do it (38, 233 & 654).

One thing I really did get out of it, taking responsibility for other people all the time. What they say, what they do, taking it on yourself. ... not always trying to save everybody. I know I was doing that all the time. Rescue, rescue, rescue (39, 604).

I've tried to think about myself more since doing the program. Just because that's what I feel right now is the best for J. The change would probably be that I'm more ready now to let go (40, 551).

One young mother spoke at great length of how she was training a friend to be her daughter's special care worker. In addition, she was educating her brother, her sister-in-law, and her parents so that she could be relieved of some of the responsibility for her child's care.

In contrast to the mothers' outcome, the results for fathers indicated that the null hypothesis regarding FAM (p=.006) was not tenable (see Tables V). This finding meant that fathers showed a significant change in the FAM pattern
of coping.

Table V: Fathers' CHIP Paired t-test Results

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pattern</th>
<th>SD</th>
<th>SE</th>
<th>T value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>4.175</td>
<td>1.476</td>
<td>-3.39</td>
<td>.006*</td>
</tr>
<tr>
<td>SUPP</td>
<td>6.198</td>
<td>2.191</td>
<td>-.06</td>
<td>.478</td>
<td></td>
</tr>
<tr>
<td>MED</td>
<td>1.389</td>
<td>.491</td>
<td>-3.56</td>
<td>.004*</td>
<td></td>
</tr>
</tbody>
</table>

* = significant difference

This change was in the area of the father's outlook on life and illness toward one of family integration was elucidated in the following interview excerpts.

*It made me reevaluate how I do everything. How I act with my sons and my wife. ... I've noticed that I've developed much more self-awareness. ... It's made me look back at myself and not like what I see. I now try to turn off work. I try not to be as busy and preoccupied. ... I try to relieve her from some of the stresses (2, 473).*

*I am being more caring ... more considerate of what's going on in the household, not just take things for granted. I'm prepared to get involved in it and enjoy it rather than just feel it's another task that has to be done. ... the disability is not so much a concern as it had been, prior to the course. He's more my son, than my son with a disability (25, 132).*

Due to job demands and his work ethic, the third father, finds it impossible to be home to assist his family. As a result of taking the course, this man has hired a live-in housekeeper to help his wife care for their daughter.

**Coping Pattern 2**

The results for mothers indicated that the null hypotheses regarding SUPP (p=.018) coping pattern could not be supported (see Table IV). This result indicated that the
mothers' perception of SUPP showed a significant change after taking the program, a change not likely due to chance.

In accordance with the CHIP questionnaire, the content analysis demonstrated that mothers had changed their perception of support. This change had the following three dimensions.

a) Maintaining sense of own well being through social relationships.

The first dimension of this variable was maintaining sense of own well being through social relationships. While 5 of the 6 mothers responded by saying that this program increased their sense of social support, one mother poignantly expressed:

I wanted to share things. A lot of it is that I just haven't had anybody to talk to. That's one thing that's difficult about moving away from a small town to where you don't know anybody. You can talk with your friends and they really don't know what your going through. I've missed not having a support group or something (40, 528).

Moreover, five of the six mothers expressed the need for a support group after program completion. As one woman said:

I think this is something that could turn into a support group. But, the thing is that people always want parents to run support groups and I think that when you get alot of stressed out parents, it's just not going to happen. So what I felt came out of it was a need for support groups run by people in the community, like the public health nurses, to see the need and organize something like that for parents. They offered the space (for the PEP) and the leadership and just that professional side to it. That parents aren't expected to put out again (39, 1479).
b) Maintaining sense of well being through involvement in activities that increase self-esteem.

The second dimension of change in coping was involvement in activities that increase self-esteem. Since taking the course, of the six women interviewed one has turned a hobby into a home business, one has returned to a job she had worked at before for years, and one has returned to school to take a nurses aid course.

c) Maintaining sense of own well being through managing psychological tensions.

The third dimension of this change in coping was managing psychological tensions. All six of the mothers responded to this aspect of the interview and identified various ways in which they were now managing anxiety and stress. As one mother of two young disabled children explained:

*Instead of flying off the handle, I can be a little bit more logical and calm. ... I put more thought into how I'm going to react which keeps me from reacting spontaneously and blurring anger. Yeah, frustration and stress that was coming out as anger a lot (5, 118).*

In addition, this mother made the following statement about a strategy she used to manage tensions.

*I've always done it (sewing) but I just haven't recognized it as a way to cope and to manage the stress. I just never thought of it as a method. I just thought I was being lazy. Now I realize that it's not so bad (5, 387).*

While all six mothers identified strategies that they now use to relieve stress, two subjects disclosed the following
strategies.

Everyone handled things different. Some wrote in books, some talked, some cried. Eventually, hopefully, all of us, did all those things. Some of us might never have done any of those things until just recently (27, 672).

Hearing how other people cope. For instance, one woman went into the bathroom and she spent two hours in the bathroom and she had a bath and she cared for herself. I came home and I did try it. I do use that on occasion now. ... I'm more aware of coping skills and I'm on the lookout for them now. Whereas, I wasn't before (23, 280).

Another strategy for managing tensions that was voiced by 4 of the mothers was the use of humour to relieve stress. As two of them put it:

... the humor helps. It really does. That helps you to dissolve those harsh feelings (23, 736).

Laughing about some of the crazy things that seizures create in your life that other people don't have a clue (8, 45).

Moreover, four of the six mothers found that the action of recognizing their tension was in and of itself helpful.

Three of them said:

That's one thing that I got from the course is to acknowledge that I'm stressed! That I'm not perfect, super-mom. That I am stressed. So I can say, "It's not a good time right now." (8, 591).

I realized I'm not as strong as I thought. ... all of a sudden when the bottom falls out, you have to take a step back, regroup yourself and then work forward. Number one last year was me getting myself back together (27, 92).

... recognizing stress and identifying when I'm getting to that point where I have to do something like go out. ... Now I'm able to say "I really feel that's between you and so and so, and you'll have to talk to J about it." Whereas, I never would have done that before. I would have got all involved. Yes, stress myself right
out. ... There's nothing I can do to change that (stress). So, it was more dealing with it than chang-
ing it (39, 652).

One mother of an older totally dependent child mentioned that an analogy used by a fellow PEP participant helped her in her most desperate moments.

One thing that this other woman said that stuck with me and I laughed when she said it and I could relate to it so well. She said, "I feel like a balloon. I'm all blown up and I, someone lets the steam out and I fly around the room. Then I land in a corner like a limp blob." I thought that that was a really good analogy. I think of that every now and then. That's one thing that's really stuck with me (39, 1052).

Unlike the mothers' findings, the hypothesis concerned with the fathers' perception of the SUPP coping pattern was supported at a level of p = > .05 (See Table V). This result suggested that any measure of difference was probably due to chance. This quantitative finding was upheld when the results of the content analysis were tabulated.

Coping Pattern 3

The third coping pattern on the CHIP questionnaire, MED, measured parental mastering of information needed to care for the child at home. The paired t-tests determined that the hypothesis for both the mothers' (p = .0145) (see Table IV) and fathers' (p = .004) (see Table V) on the MED pattern was not tenable. This finding means that the mothers and fathers showed a significant change in their perceptions and the parents' ability to cope with family life on the MED variable improved after the intervention.

The results from the content analysis of the 9 inter-
views concurred with and elaborated on the quantitative findings in the following manner. According to the CHIP questionnaire, mastery of information needed to care for the child at home was obtained through communication with parents of children with chronic conditions and consultation with health care professionals.

All nine interview subjects resoundingly expressed opinions that indicated they had increased their abilities to care for their child at home through communication with the other PEP participants. One father voiced:

*I came in thinking... that the people who were in the group didn't have anything to offer. Everytime I went, I found there was something that they did actually offer me, selfishly you know* (25, 277).

One mother shared that:

*It gave us some sort of insight as to what may be coming up in the future. Even though the disabilities may be different, the emotional and psychological side seems to be the same. ... Different suggestions, you know. It might not be something you instinctively would do but you can retrain yourself to do other things. Maybe one of those other things might be the thing that would work. So it was the group input of how everybody does different things* (27, 651).

In addition, the subjects shared specific examples of tips they exchanged that many parents didn't know. These tips included writing off diaper receipts, income tax, property tax, and claiming disability. Three mothers elaborated saying:

*This course was wonderful for information. I've learned about videos to help with speech, I've learned about the Exceptional Parent magazine, hundreds of things, music therapy* (23, 1165).
I think, disabled children, they have their limited ability. If there is a suggestion for their parents that they can be better, like exercise or which place is good for them. Practical things. Dance course for special needs. This helps a lot (38, 1070).

I'm constantly in a state of frustration. But I think going and talking about it with people does help because they don't say, "Oh don't be silly." They try and give you some ideas. Sometimes it's something you've never thought of. ... like hiring somebody, or planning a menu for a week, only going shopping on these days, trying to organize your life (39, 982).

One common aspect of caring for their children was dealing with doctors. One mother expressed:

Dealing with doctors. ... Everyone has the same complaints. We were brainstorming because one of the girls had a problem. ... So she wrote a letter and she'll probably have the problem solved (23, 224).

Finally, one mother's statement echoed the sentiments expressed by all the other subjects:

I really enjoyed being able to come together as a group of parents who had children with disabilities. I haven't ever had that opportunity. Just to understand that even though our disabilities varied, but there was a lot of similar feeling that we had. I guess the word validation came up quite a few times. I just really enjoyed the fact that you could sit with other parents and understand. ... The information that was shared there was always pertinent to what was going on in our lives (40, 5).

Seven of the nine interviewed subjects expressed the view that health care professionals were very important in enabling them to care for their child at home. These professionals included: the PEP facilitators, a social worker, an occupational therapist, a special education therapist, and their doctors. The major theme with regards to the medical system was one of the development of skills to
better negotiate with the health care system. One father expressed the view that:

_We've changed that much that we can deal with every one in the system. ... we've consulted with the doctors ... we've agreed that (son) be operated on here ... because no one knows (him) better than the staff here (2, 105)._ 

To illustrate this concern further, one mother said:

_I've been more assertive with the doctors on one occasion since taking the course. ... I just think with time and thought that I might be able to put some of the knowledge into dealing with the professionals a bit more. Being more assertive. Saying "this is what I want done and I want to see it done." (5, 898)_

Despite these positive changes in assertion, several subjects talked of a lack of communication with health care professionals. As one mother, of a child with an intractable seizure disorder who was very much involved with many readmissions to the hospital, identified how her sense of mastery of information could be enhanced. She said:

_I would like to see a nurse liaison between parents and the staff and doctors. That would be a really good thing to have because when you have problems or you can see something needs to be changed or could be changed for the better, but you just have no one to talk to. It would be a big help, especially for people whose children have chronic problems and they're constantly in and out of hospital (23, 205)._ 

Summary

To summarize, both parents' perceptions of their ability to cope increased. For mothers, this increase in coping was in maintaining their sense of well being and mastering information needed to care for their child at home. For fathers, their outlook on family life and their mastery of
information needed to care their child at home improved after participation in the PEP. In addition to these questionnaire results, the analysis of interview data revealed that mothers were sharing the burden of caring for their child with the chronic condition.

**Research Question II: Do program participants demonstrate a significant improvement in family functioning?**

The FES measured the subjects' perceptions of their conjugal or nuclear family environments on the ten FES subscales. These subscales included: cohesion, expressiveness, conflict, independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis, organization, and control. In order to answer this research question using the FES, the null hypothesis, that there would be no difference due to the intervention, on each of these ten subscales was tested. A paired t-test was used to test each hypothesis separately for mothers and fathers.

For the mothers, nine of these null hypotheses were supported at the level of $p=>.05$ (see Table VI). These results indicated that the mothers' perceptions of these variables was unchanged.

However, the first null hypothesis concerned with cohesion was rejected ($p=.0275$) (see Table VI). Therefore, the mothers' perception of cohesion showed a significant change post-intervention.
Table VI: Mothers' FES Paired t-test Results

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>SD</th>
<th>SE</th>
<th>T value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FES</td>
<td>C</td>
<td>1.314</td>
<td>.294</td>
<td>-2.04</td>
<td>.027*</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>1.789</td>
<td>.400</td>
<td>-1.50</td>
<td>.075</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>1.806</td>
<td>.404</td>
<td>0.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>IND</td>
<td>1.348</td>
<td>.302</td>
<td>-1.50</td>
<td>.312</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>1.261</td>
<td>.282</td>
<td>-1.06</td>
<td>.150</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>1.348</td>
<td>.302</td>
<td>-1.50</td>
<td>.312</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>1.317</td>
<td>.294</td>
<td>-1.53</td>
<td>.071</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>1.294</td>
<td>.289</td>
<td>0.35</td>
<td>.366</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>1.164</td>
<td>.260</td>
<td>-.96</td>
<td>.174</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>1.468</td>
<td>.328</td>
<td>-.15</td>
<td>.440</td>
</tr>
</tbody>
</table>

* = significant difference

Each of the interview subjects were married. Five of the six mother's expressed the opinion that their marital relationship was stronger as a result of the course. Two mothers explained:

*When you take such a close look through that course at what it means to have a child and the stresses, I think that that's strengthened our commitment of staying together and keeping the family as a unit (8, 768).*

*We're more unified. ... That's one thing I learned from the course, that we really need time together (23, 1047).*

The fathers' FES results differed from the mothers. The null hypotheses concerned with the cohesion, expressiveness, and independence were rejected. The probability values for these subscales were: cohesion (p = .032); expressiveness (p = .030); and independence (p = .019) (see Table VII). Therefore, the fathers' perceptions on these subscales altered significantly after taking the program.

However, the results on the 7 remaining FES subscales
supported the null hypotheses at probability levels of $p = \text{>.05}$ (see Table VII). These results meant that the fathers' perception on these subscales did not significantly change after taking the program.

**Table VII: Fathers' FES Paired t-test Results**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>SD</th>
<th>SE</th>
<th>T value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FES</td>
<td>C</td>
<td>1.126</td>
<td>.398</td>
<td>-2.20</td>
<td>.032*</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>1.581</td>
<td>.559</td>
<td>-2.24</td>
<td>.030*</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>1.061</td>
<td>.375</td>
<td>1.00</td>
<td>.175</td>
</tr>
<tr>
<td></td>
<td>IND</td>
<td>1.246</td>
<td>.441</td>
<td>-2.55</td>
<td>.019*</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>.916</td>
<td>.324</td>
<td>-1.16</td>
<td>.142</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>1.506</td>
<td>.532</td>
<td>-.70</td>
<td>.252</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>1.604</td>
<td>.567</td>
<td>.00</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>1.753</td>
<td>.620</td>
<td>-.40</td>
<td>.349</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>1.753</td>
<td>.620</td>
<td>-.40</td>
<td>.500</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>1.195</td>
<td>.423</td>
<td>1.18</td>
<td>.137</td>
</tr>
</tbody>
</table>

* = significant difference

With the exception of the questions that assessed the subscale concerned with active recreational orientation, the deductive content analysis results concurred with the qualitative results.

Two of the three interviewed fathers confirmed that their marital relationships were positively altered since taking the program. One of these fathers elaborated saying:

*I'm more considerate of my spouse. ... I'm very fortunate to have (her) as my wife. Sometimes I lose track of that. I'm focusing more. ... We want to spend time together. Whereas, before, we may not have been as interested (25, 554).*

Of the three fathers interviewed, two described themselves as more expressive since taking the program. They
explained by verbalizing:

I'm more patient with (my wife) and understand her point of view. ... I'm listening to people and saying, instead of ignoring it, I appreciate what she's saying. I find that I'm prepared to put a lot of other things aside in order to be able to discuss things (25, 33).

I really do attempt to listen more now. Before my mind was always busy, and she would talk to me and I would nod and say "yeah, yeah." Now I really make more of an effort to listen to (my wife) (2, 290).

Two mothers, who attended the program with their husbands, reported that:

There was stuff that came out that I didn't know that he was feeling. I thought he was really cold hearted or he just didn't care... But he actually did. It just wouldn't have come out otherwise (23, 962).

What I wanted from it (PEP) for him was the talking. ... You can't keep all this stuff inside. That's what he tended to do. ... So the actual bringing up of a lot of these issues, and he did. ... The thing that sticks out is the fact that my husband was participating and was talking in all of them (PEP sessions) which was good (27, 625).

An ancillary finding that evolved from the deductive analysis of the interview data was on the active-recreational subscale of the FES. Eight of the nine interviewed parents noted changes in their recreational activities following the PEP. These included changes with both their spouses and children.

Fathers and mothers who took the course portrayed the following changes in their spousal recreational activity.

Every Monday night we go somewhere as a management method (5, 768).

Now, every Thursday night, in fact last night we went to a movie together. Once a week at least, go out together without kids (25, 542).
Two couples had just recently been away for a weekend together. As one mother elaborated:

I've just come back from a vacation in Palm Springs. Which I could never have done before (39, 1752).

Five of the parents described activities that they participated in post intervention. These included:

We're spending more time doing family things outdoors, such as riding bikes. We bought a pull cart for (son) and now (other son) pulls him and feels more a part of things. Besides riding bikes, we all go for walks in the park and that (2, 411).

You have to make a special effort to get kids over. So, we just recently organized a little group of people that we've touched over the years. ... A group of people that we meet on a Sunday afternoon. Two Sundays ago we were over at one of the houses, just to share experiences and talk, let the kids to know each other and play. We've got a picnic planned in April... So, that's working out (25, 624).

We're getting them (two of the PEP's children) involved in an at home Karate program. (son) thinks he's Bruce Lee. In his mind he's normal. If this is a thing that normal kids do, let's do it (27, 1519).

At the community centre, there's a dancing program that starts from April. (daughter) can do it on her own. She likes to dance. I'll send her to the dancing program (38, 920).

Summary

To summarize the findings of the FES questionnaire, overall family functioning had improved post-intervention. Again, mothers and fathers differed on the variables in which change was noticed. While mothers increased in family cohesion, fathers increased in their perceptions of family cohesion, expressiveness, and independence. An additional finding arising from the interview data showed that both
mother's and father's active recreational orientation increased after participating in the program.

Research Question III: Did program participation significantly increase parental use of resources?

The FIRM tool was used to assess the parents' perceptions of what social, psychological, community and financial resources they have available to them in the management of family life. This tool measured 5 subscales pertaining to family resources. These subscales scales included: Family Strengths 1 - esteem and communication, Family Strengths 2 - mastery and health, extended family social support, sources of financial support, and a total FIRM result. The FIRM result was calculated by adding the values on Family Strengths 1, Family Strengths 2, financial well being, and extended family support. The null hypotheses used to test each of these 5 scales stated that there would be no difference pre- and post intervention. Paired t-tests were used to test each of these hypotheses.

On the basis of the mothers' results the null hypotheses of three scales were rejected. These scales and their probability levels included: Family Strengths 1 (p = .007); Family Strengths 2 (p = .001); and FIRM (p = .003) (see Table VIII). Therefore, the mothers' perceptions of esteem and communication, mastery and health, and total repertoire of resources showed significant improvement after taking the program.
Table VIII: Mothers' FIRM Paired t-test Results

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>SD</th>
<th>SE</th>
<th>T value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIRM</td>
<td>SFS</td>
<td>1.957</td>
<td>.438</td>
<td>-.91</td>
<td>.186</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>2.732</td>
<td>.611</td>
<td>-3.44</td>
<td>.001*</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>3.144</td>
<td>.703</td>
<td>-2.70</td>
<td>.007*</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>2.342</td>
<td>.524</td>
<td>-1.34</td>
<td>.098</td>
</tr>
<tr>
<td>FIRM</td>
<td></td>
<td>6.485</td>
<td>1.45</td>
<td>-3.10</td>
<td>.003*</td>
</tr>
</tbody>
</table>

* = significant difference

The results from the content analysis of the interview data supported the quantitative results. Two scales, Family Strengths 1 and 2, were elaborated in the following excerpts from the semistructured interviews.

**Family Strengths 1: Esteem and communication.**

Six dimensions of this scale were assessed during the content analysis of the interview data. These dimensions included: family esteem, communication, mutual assistance, optimism, problem solving ability, and encouragement of autonomy.

The change in the family esteem dimension was evident in the mothers' interviews. One mother who attended the PEP with her husband illustrated this dimension when she expressed:

> It (his participation in the sessions) added to my respect for him. ... I think it can make a big difference to your marriage, to your relationship with your kids. It's made a big difference for us (23, 546).

From the deductive content analysis, a change in the mothers' communication abilities was evident. Empathy,
listening, and verbal communication with spouses, children, family members, and friends were aspects of this dimension that had changed. First, one mother described greater empathy with all persons in her life as she explained:

*Things are flowing a little easier. Instead of being chopped conversations you start with a point, you go through it and then you can go on to the next point. ... Along with empathy and conversation, if somebody's angry or upset about something or having some sort of feelings, I can let them know that I know. Like "you must be feeling angry, that's OK." .... which is something that I never used to do. I never used to put any thought to it (5, 32).*

Another mother described the following change in her understanding of her parents and later in the interview explained similar changes in how she dealt with friends and her brother and sister-in-law.

*It helped me recognize their discomfort, how uncomfortable they are with the situation. And their reactions are their way of coping with it. I didn't realize this. So it helped me be a lot more understanding towards their views. And then I was able to approach it at a much slower rate, I simplified my explanations. Just a few weeks ago they were here. I got a video (viewed at the PEP on seizure disorders) and we went out. ... When we got home, I said "What did you think?" We actually talked for half an hour on the subject (difficult epilepsy) (23, 166).*

A greater ability to listen to others was evident in the mothers' interviews. One mother, who attended the PEP without her husband, expounded:

*He didn't figure out why, but in retrospect, it came up in a discussion in a couple's support group about listening to what the other person is saying and not jumping down their back because they reacted this way, but to acknowledge the way they're feeling. (husband) "Oh, so that's why we're talking so much more is it?" You know, it was like "Oh, that's why." It hadn't lit up his light but obviously he noticed it, subconsciously*
Another mother, who attended with her spouse, described their communications the evening of each session. This sentiment was reiterated by all the other coupled PEP participants.

... Driving home we would find ourselves talking about what we went over that night. It's just him and I. We can listen. We hear what the other one is saying (27, 717).

This same mother went on to talk about her relationship with her able bodied daughter.

I think (daughter) is coming to me more now. I've always hoped I'd be a mom she felt she could come to (27, 1484).

Another mother, who was concerned about her daughter who was a sibling of a spinal injured son, explained the change she has noticed.

(in the sessions) we discussed different ways you can have conversations with people to make them feel like you're listening even if you're not going to agree with what they want. I've been trying to do that with my daughter. It does work but it's not perfect ... I still react when I'm stressed (39, 577).

Altered verbal communication was evident in the interview transcripts. With reference to their spouses, two mothers mentioned:

Our communication is much better. Much, much better (23, 3430).

This course helped us to communicate with each other. We (she and her husband) talk, that is the best thing that we talk, we talk a lot. We show our feelings (38, 707).

In dealing with her disabled son, one mother elaborated on
her communication:

S: I've had to make it clear to (son) that he needs to tell me specifically what he wants and doesn't. He knows what he wants, and I can help him better. ... So I think our communication skills have improved (40, 758).

Improved problem solving dimension of Family Stengths 1 was a common theme throughout the mothers interviews. One mother described her problem solving related to a medical test her daughter, with intractable seizures, was going for:

I don't know anything about this. It's radioactive. So I looked in my manual (PEP). I followed the problem solving steps. What they said to do about gathering information. Who to talk to. I made a list of who I should talk to. And, I did. But that made all the difference in the world. By the time I went in for the test, I was prepared for it. I had no fears. Nothing. I had gotten information from everywhere that I possibly could. There was no written information on it and that was the major problem. But, that (problem solving process) made the difference (23, 654).

Another mother depicted the following situation:

Somebody who is angry in the family, has some frustration and we find out what is the real reason that caused that doubt. There is one thing, if a person needs somebody's help, a person needs to help us, we need to explain, just to ask them to follow the steps, cause there are steps, it seems quite helpful (38, 48).

Only two mothers specifically mentioned that they encouraged greater autonomy. First, one mother explained the following alteration in her spousal relationship.

What has changed is rather than me automatically thinking of the answer, so what do you think, what should we do?" "OK, well I just can't handle this right now, you figure it out, then let me know what you think we should do." ...I think that by me trying to learn to delegate more. Not delegating and giving instructions as well has helped (27, 769).

One mother described the changes she had noticed in her
relationships with her children, her son's attendants, and her spouse.

*What has changed is that if two people in the house are having a disagreement, just letting it be between them and not getting involved. Just saying, "well that's your relationship with that person."* (39, 609).

**Family Strengths 2: Mastery and health**

The second FIRM scale that showed a significant increase (p=.001) post-intervention was Family Strengths 2: mastery and health. This scale had three dimensions which were measured by the FES and were illustrated through the deductive content analysis of the interview data. These dimensions included: mastery over family outcomes; family mutuality; and physical and emotional health. While the interviews were less explicit on these dimensions, several mothers did describe changes that they had noticed after completing the PEP.

One mother spoke about her sense of helplessness before taking the program and subsequent mastery over family outcomes. When interviewed, she said:

*It felt good to be doing something about her because you always feel like the system does this to you, or the seizures do this to you, or the doctors. You don't have a lot of control. So it felt good to be doing something positive about her disability. Even if it was educating myself. So I was looking forward to that too, actually taking some action on something. Otherwise, I just feel like I have no control over anything. So that was part of it. Taking some action* (8, 466).

Similarly, another mother added:

*I felt more in control of the situation. In control of whatever I could be in control of. We don't know what's going to happen, we're not in control of that.*
It doesn't scare me any more (23, 656).

Three aspects of family mutuality were assessed. These aspects encompassed emotional support, togetherness, and cooperation.

First, emotional support was perceived by mothers as important and was altered after taking the PEP. This perception was evident as one mother described the importance to her:

*I really do believe that mothers handle things differently than dads. ... In most situations, I find that the mom is the caregiver, the emotional supporter of the family. ... The moms, a lot of time, just want that emotional support from somebody else for them to cry on their shoulder. To say "why me? Poor us." Yet, whether or not you do anything different might not happen. But just having someone there that might empathize with you. And (husband) is more there for me now (27, 581).*

Another mother elaborated on the change in emotional support that she was aware of:

*Cause he'll, on occasion now, "I think you're pretty stressed out about this.", or whatever. He's actually able to identify. ...he's much better at saying "that really bugged you didn't it." So that I think it's definitely good on both our parts. It's made a big difference on not reaching that boiling point. We realize that it doesn't have to be about (daughter with chronic condition), it can be about other things (23, 891).*

Second, the togetherness aspect of family mutuality was mentioned in the mothers' interviews often. Three mothers elaborated on their spousal relationships.

*So they (her two children) go to separate homes every third weekend and we have the weekend off to do whatever we want to do. Stay home, do nothing, busy ourselves until we're exhausted (5, 824).*

*So he (husband) actually took the initiative to go over*
there (next door) and say "we need to get out and do you sit?" And she's been really good and really available (8, 844).

I'm really beginning to realize that we, as a couple, need to have some time for ourselves too (40, 594).

Another mother talked about her relationship with the sibling of her child with a chronic condition:

I'm trying to find more mom/daughter time. I'm trying to find times to sit there and talk to her just about her books and her school (27, 1394).

Lastly, the cooperation dimension of family mutuality was reported as changed by the mothers. The mothers asked for more cooperation from others after taking the PEP. As the mother of a totally dependent older child was able to express to her husband:

Hey, I'm not the attendant here.", as he was about to leave after getting our son transferred to bed (son's attendant hadn't come in that evening). "We're the parent's together of (child) and you help by doing..." This was something I would never have done, I surprised myself (39, 1764).

Two other mothers described differences they had experienced:

When somebody else is at home, then I cop out of a lot of things. "Oh, why don't you run upstairs and do that" or you feed the kids and I'll do the laundry." And I don't feel bad (5, 339).

I can't get hyped out and handle 10 of them (tasks). You (husband) can at least take a couple here and figure out what you're going to do. ... But it's working. And so, it's taking one more thing off of me (27, 846).

Another aspect of cooperation mentioned by mothers was that between siblings. As one mother expressed:

I try to make him (child with chronic condition) help
more so she's (sister) not feeling that she has to do everything (27, 325).

The results on the remaining 2 scales supported their null hypotheses at probability levels of >.05 (see Table VIII). These results suggested that any change in the mothers' perceptions of these scales could be attributed to chance.

In contrast to the mothers' FIRM findings, the fathers' results supported the null hypothesis on all five scales at > 5% significance levels (see Table IX). These findings suggested that any alteration in the fathers' perceptions of their family's utilization resources was likely due to chance. This result was upheld throughout the deductive content analysis of the fathers' interviews.

Table IX: Fathers' FIRM Paired t-tests Results

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>SD</th>
<th>SE</th>
<th>T value</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SFS</td>
<td>2.765</td>
<td>.977</td>
<td>-.77</td>
<td>.234</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>3.462</td>
<td>1.224</td>
<td>-1.33</td>
<td>.113</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>5.425</td>
<td>1.918</td>
<td>-.26</td>
<td>.401</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>4.803</td>
<td>1.698</td>
<td>.74</td>
<td>.243</td>
</tr>
<tr>
<td></td>
<td>FIRM</td>
<td>15.737</td>
<td>5.564</td>
<td>-.40</td>
<td>.349</td>
</tr>
</tbody>
</table>

Summary

While mothers increased in their perception of utilization of resources, fathers did not perceive a change in their use of resources after participating in the program.
Program Variables

The following program variables were identified as important by the majority of parents in their interviews: timing of the group in relation to the timing of the child's diagnosis; attending the group as a couple; and composition of the group.

Each of the interview subjects had strong views about the timing of the PEP. One mother of 2 totally dependent youngsters emphatically stated the views expressed by all 9 interview subjects.

*I think it would have helped a lot more if I had known this information 2 years ago, when I really needed some direction of how to do it, how to live it. Up until this course, I was sort of stumbling through and sort of hit and miss. Whereas, if you're ready for something like this early enough, and it's there, to use, I think people could gain an awful lot from it. I think the first months are too overwhelming. People are dealing with their personal feelings like "God, this really sucks, this is my family, it stinks, it's not fair." But if we'd known about it maybe 6 months to a year after (daughter) was diagnosed. It depends on the person. But if it was something that was on-going, like every 6 months you started a new one, like in the Spring and in the Fall, that would give a family the opportunity, when they were ready. I think it should be an ongoing thing in the community so that people can snowball and hopscotch their way through the stages. In that way there are not too many people left forever and ever who could have really used it but it was never there (5, 1208).*

The interviewed parents unanimously expressed the opinion that an appropriate time for taking the PEP was six months to one year after the initial diagnosis of a child's chronic condition. Moreover, all these parents believed that the PEP should be available to all parents who have
received this diagnosis.

A second program variable that was identified by parents as important was attending the program as a couple. The interview subjects who did not attend with their spouse unanimously expounded the opinion that they felt that, if married, spouses should attend the PEP. As one married mother who attended the program without her husband said:

The fact that I took it alone and (husband) didn't. That made a big difference. When I'd come home and say we discussed this and this. He'd go "Yeh, Yeh." He didn't get the full, he was not really involved. I mean, if one parent can't take it, then I'd say it's better than not taking it at all (23, 416).

Two mothers and one father who attended with their spouses expressed the following opinions:

I think you get more than double by having both spouses there because on the way home, you talk about what went on in the class. So, you're getting an extra half hour of discussion on each thing. I think that a big plus is making the time for both spouses to go (8, 1090).

It would be beneficial to make the first two sessions on dealing with aspects of stress and personal feelings compulsory for couples. Then from there you could decide whether you wanted to continue coming. But at least you deal with a couple of sessions together (43, 740).

I think it's good for both people to hear the information. It did me a lot of good to go, but it's not going to necessarily help my relationship if he hadn't heard it. So I think it would be really helpful if the next time it was sort of stressed that it would be really great if you could both go (39, 1514).

A third variable discussed by a number of participants was the composition of the group in relation to the category of disease their child had. While all the interview subjects believed that the non-categorical approach with
regards to the course content was appropriate for them, several of the neurology clinic group parents felt the epilepsy nucleus group suited them best. As one mother expressed:

One of the reasons I decided to go was because it was a focus of seizures. I tried one support group for chronically ill children. I just couldn't relate to them. I've got my own set of problems. They look at you and say "what's your problem?" Even though you're under the umbrella of chronically ill, it's like apples and oranges. I wouldn't have gone with different conditions because it was too diverse. This way you say something and everyone there knows what you're talking about. You mention a drug and everyone knows it. As it turned out, we all had the same neurologist. You don't waste a lot of time explaining things (8, 1123).

In direct contrast to the first mother's opinion, another mother explained:

I think it's nice to have a focus for people that want it and for those who want a general forum to have that. I probably would have, if I had known there was two, would have gone to the general one because my kids are more involved than just epilepsy (5, 1175).

Moreover, one mother from the general pediatric PEP group said:

I liked that everybody was there with different things. Because when your child has, whatever his disability is, you form groups with parents of that same type because of the therapies you're going for. You don't get the overall picture of other people and other disabilities. You may seem to think yours is the worst. It really is an eye-opener for you to see, there's always somebody worse off than you, no matter how bad you think you've got it. So, I think the broad spectrum is better. Not specialized groups (27, 1574).

Summary

This chapter presented the findings of the parents perceptions of coping, family functioning, and utilization
of resources. Mothers' coping, family functioning, and utilization of resources increased significantly following the program. Fathers' coping and family functioning increased post-intervention. In addition, the parents' recommendations included: program participation commence 6 months to one year after receiving their child's diagnosis; couples attend together when possible; and both general and specific diagnostic options be available on an ongoing basis.

The discussion of the study's findings, conclusions, implications for nursing theory, administration, and practice, and recommendations for further research will be the focus of the following chapter.
CHAPTER FIVE

DISCUSSION

Mothers perceived an increase in their coping, family functioning, and utilization of resources after participating in the program and fathers perceived an increase in their coping and family functioning. In addition, the interview subjects recommended that: the PEP participation commence six months to one year after diagnosis; when possible, couples attend together; and both general and specific diagnostic group session options remain available on an ongoing basis to parents of children with chronic conditions. The study's findings are discussed in this chapter followed by conclusions; implications for nursing theory, administration, and practice; recommendations for further research; and this study's concluding remark.

Discussion

The discussion of the results will take place under five major headings. These headings include: sample characteristics, parental coping, family functioning, utilization of resources, and program variables. The results will also be discussed in relation to methodological problems inherent in the study.

Characteristics of the Sample

The characteristics of the sample are discussed in three sections. These sections include: the diagnostic categories, the demographic profile, and knowledge base.
With respect to the broad spectrum of diagnoses within the term chronic conditions described in the literature, this sample was representative of that diverse population (Nelkin, 1987; Rosenbum, 1987; Wegener & Aday, 1989). The study was based on the theoretical premise that the PEP has similar effects on parents' coping, family functioning, and utilization of resources regardless of the specific medical diagnosis of their child. Based on the study results, the noncategorical theoretical premise of the PEP was an appropriate assumption for this study. This premise addressed the non-representativeness of prior evaluative studies including: Canam's (1990) study which excluded parents of children with below average intelligence and the investigations of Rudolph et al. (1991), Moxley-Haegert and Sebin (1983), Hornby et al. (1983), Duffy et al. (1987), and Lewis et al. (1991) that were diagnosis specific studies. Moreover, the wide age range for both children (2 1/2 to 20) and parents (24-60) enhances the representativeness of sample and, consequently, the results can be generalized to the population of parents of children with chronic conditions. The inclusive nature of the PEP and the measured changes in parental coping, family functioning, and utilization of resources demonstrated the suitability of the program as an intervention for parents of children with a wide variety of chronic conditions. In addition, this study's results reaffirmed the validity of the noncategorical premise for
use in nursing theory.

This study's sample included: Caucasian (74%), Christian (68%), married (93%), highly educated (7% had < grade 12), moderate to high income (59% > 41,000), and urban dwelling individuals. This socio-cultural profile of the subjects reduced the representativeness of the sample with respect to ethnicity, and marital and socioeconomic status. Further to this limitation, while the small sample size (n=28) was appropriate for a group clinical intervention, it was small as far as a research study is concerned. This sample decreased the generalizability of the results to the population. However, with the exception of Lewis et al. (1991) cross-national program evaluation, it was representative of parents who have participated in the reviewed evaluative studies of parent education programs.

Due to the self-selection bias of this convenience sample, the subjects' baseline readings on each of the 3 questionnaires were at or above the midrange for each variable. Therefore, these baseline readings indicated that the sample may be different than the population. These differences further limited the generalizability of the results.

In summary, the study's sample was representative of the population with respect to the wide spectrum of children's diagnoses and the wide variance in parent's and child's ages. However, this sample's representativeness was limited by the self-selected convenience sample with regard
to their socio-cultural and economic profiles, and their baseline levels of coping, family functioning, and utilization of resources.

**Parental Coping**

While the study results demonstrated an increase in mothers' and fathers' parental coping after program participation and that change was maintained 4-5 months post-intervention, they differed in the coping patterns in which this change occurred. Three researchers reported differences between mothers' and fathers' coping in their study results. First, this disparity by gender was noted by Damrosch et al. (1989) in their investigations regarding how parents cope with their child's chronic condition. In this study, fathers described adjustment as a gradual steady recovery and mothers reported periodic peaks and valley crises patterns. Second, Lewis et al. (1991) reported that during pre- and post-test fathers rated lower anxiety levels than mothers. Third, Duffy et al. (1987) found that parental perceptions of confidence in dealing with their child's asthma increased but at differing rates. Although the results of the studies were not measured with this study's tools, they do confirm this study's findings that mothers and fathers differ in their reactions to and abilities to cope with their child's chronic condition.

All of the interviewed fathers described a change in their outlook on family life as being more involved in the
family and helping to alleviate some of their spouse's responsibility. Although Canam (1990) did not differentiate between mothers and fathers in her testing of this dimension of the coping variable, the results revealed a significant increase. The remaining literature does not discern between the family, support, and medical dimensions of coping.

Mothers described a change toward sharing the burden or "responsibility" of their child with the chronic condition with others. Although Venters (1981) identified sharing the burden of illness as a major coping strategy, this response to program participation was not described in the reviewed evaluative studies. Furthermore, in the CHIP questionnaire, one out of the 19 questions was related to letting go or sharing the burden. This question was "getting other members of the family to help with chores and tasks at home" (McCubbin & Thompson, 1987, p.177). Therefore, the instrument may have lacked sensitivity to the type of change, in the FAMILY pattern, experienced by the study's mothers. Moreover, Lewis et al. (1984) found that mothers assume the major responsibility of caring for the chronically ill child. This study's mothers' willingness and ability to share the burden could be related to fathers assuming a role in and responsibility for their child's care. Conversely, as fathers participation increased the mothers may have been able to let go of some of their responsibilities. To determine the relationship between these two divergent but
not dissimilar changes in the FAMILY pattern of coping, this study's marital dyads data should be reworked and/or a correlational study should be designed and implemented.

The mothers' perceptions of the SUPPORT pattern of parental coping significantly increased after the PEP. This change in the support variable had three facets. First, the interviewed mothers' reported that they received social support from the group and expressed a need for an ongoing support group. Second, these mothers described being more involved in activities that increased their self-esteem. Finally, the mothers delineated strategies that they now use to manage their psychological tensions. These strategies included: acknowledging the stress, hobbies, relaxation techniques, and humor.

The results from Meyerowitz et al.'s (1967) study revealed a parental sense of social isolation due to perceived negative attitudes from the community and their lack of time for involvement. This observed isolation was disclosed by the study subjects. Based on the results of three studies, parental involvement in support groups with parents in similar situations provided much needed social support (McCubbin, 1984; Van Cleve, 1989; Walker, 1989) and, consequently, support groups were lauded as an invaluable service for parents (Diehl, 1991). As a result of the subjects' program participation, they reported feeling less alone. Furthermore, the positive change in support was
described by several parent education program investigators. While these studies did not differentiate by gender, they confirmed this study's finding. Hornby et al. (1983) documented that most parents commented that they appreciated the opportunity of sharing problems and feelings with other parents that understood them. This finding was reiterated by the evaluative studies of Rudoph (1981) and Lewis (1991). Clearly, this coping pattern was positively influenced by program participation. Given that these mothers assumed the main caretaker role for their children, the improved ability to cope on this dimension reduced their sense of social isolation, increased their self-esteem, and enabled them to effectively manage their psychological tensions.

Both mothers' and fathers' Medical coping pattern significantly increased after participating in the PEP. Each of the study subjects described possessing more knowledge about their child's chronic condition and recounted the mastering of care for this child at home through communication with other parents of children with chronic conditions and with health care professionals.

According to Shulman et al. (1983), families that coped well had trusting relationships with health care professionals. Further, the results of McCubbin et al.'s (1982) study indicated that consulting with the medical team was all-important. The reviewed evaluative studies confirm this study's finding on this medical dimension. Rudoph et al.
(1981) found that fathers appreciated the opportunity to learn about the medical aspect of their child's condition and all subjects felt they had gained from communicating with other parents. In Hornby et al's (1983) study, parents commented on the increased knowledge which they had gained. Further support was evident in Gaudet et al's (1989) study. These researchers concluded that parents' knowledge about coping with pediatric chronic illness and their coping skills changed from the beginning of the program. Similarly, Duffy et al. (1987) found that parent's understanding of asthma had changed. This study's result, which showed an increased perceived parental ability to cope with a child's medical condition, corroborated Canam's (1990) results.

In summary, even though the subjects' coping pattern results varied by gender, overall parental coping increased after taking the PEP. These findings are verified and supported by the literature. This increased parental coping embodies vital components required for parental adjustment to the enduring stressors related to having a child with a chronic health condition. Therefore, the PEP was an effective clinical intervention which facilitated parental coping.

Family Functioning

Canam (1990) found that her study's interview subjects perceived a change in family functioning as a result of participating in the PEP. Therefore, this researcher's
study replicated Canam's study and used the FES tool to assess changes in family functioning that resulted post-program. Again, mothers and fathers differed on the sub-scales in which change was noticed. This change was apparent in family cohesion, expressiveness, independence, and active recreational orientation.

The mothers' and fathers' perception of the cohesion subscale of family functioning increased as a result of their program participation. From the interviews, this cohesion was described as a "strengthened commitment of staying together" and "keeping the family as a unit", "being more unified", and "spending time together". In the literature on family functioning, two divergent views were evident. Gath (1977) contended that parents of chronically ill children had significantly poorer marital relationships and Tew et al. (1974) revealed that marital harmony decreased in couples with spina-bifida. On the other hand, Koocher et al. (1981) reported that the childhood illness had brought them closer. McCubbin et al. (1982) suggested that keeping the family together was essential for positive outcomes and Van Cleve (1989) determined that there was a significant positive relationship between coping and a strong marital relationship. Moreover, the Royal Commission (1991) and Shelton et al. (1987) asserted that an intact family was the most important influence on the child. Based on the study results of increased cohesion between the study's marital
dyads, the PEP represents an important intervention which ameliorates family functioning and, in turn, optimizes the child's environment.

The fathers' expressiveness subscale showed a significant increase after the PEP. The interviewed fathers portrayed themselves as being more ready to discuss things and attempting to listen more. Moreover, two of the interviewed mothers disclosed that during and since the program, their husbands "expressed their feelings" and "talked about issues". Turk's (1964) study revealed that family stress levels increased as a result of communication problems. In the reviewed evaluative studies, one researcher documented a similar increase in father's expressiveness after taking an education program which affirms the above study findings. Rudoph et al. (1981) reported that changes in communication patterns between husbands and wives occurred in some families and several wives described their husbands as "opening-up" for the first time. Researchers have identified communication problems as a stressor on families. Since the fathers' who participated in the PEP were more able to communicate their feelings and issues, their family functioning improved.

The change in the mothers' and fathers' FES subscale of active-recreational orientation was statistically non-significant. However, the deductive content analysis contradicted this result. Eight of the nine interviewed subjects
observed changes in the extent of participation in social and recreational activities. These subjects described the maintenance of their regular weekly spousal outings and vacationing together. Five of the parents reported that they participated in more frequent family outings. Moreover, these parents maximized their child's opportunities to participate in new activities. While a change in spousal or family orientation to recreational activity was not an evident parental outcome in the reviewed evaluative studies, one researcher's findings supported the need for children's activities. Horner et al. (1987) conducted a parental survey of perceived needs and found that one of the three major parental needs was recreation for their child. This ancillary outcome of increased spousal, family, and child active-recreational orientation enhanced the quality of life for these families which enabled them to function more fully after program participation.

Overall, family functioning had increased post-intervention. The facets of this enhanced function differed by gender. Both mothers and fathers perceived more cohesion within their marital dyad and were more recreational active. Moreover, the study's fathers had become increasingly expressive and independent.

**Utilization of Resources**

Canam (1990) established from her subjects' interviews that utilization of resources increased following program
participation. Consequently, this researcher replicated Canam's study and used the FIRM questionnaire to determine these changes quantitatively. Once again, the mothers' and fathers' were dissimilar in their perceptions of utilization of resources. Fathers' perceptions on this variable showed a non-significant increase. This non-significant result could be attributed to the following factors. Given that mother's assumed the role of primary caretaker, father's may not perceive a need to increase their knowledge and skills regarding resources. Another possible reason for this absence of results could be attributed to the small sample (n=8) of fathers. It was more difficult to show significant levels of change with small n's and the chance of making a Type II statistical error was increased.

On the other hand, mothers' perceptions of utilization of resources increased on the esteem and communication scale, the mastery and health scale, and their total repertoire of resources. Mothers' disclosed an increase in their family esteem in the interviews. This esteem was verbally depicted as "adding to their respect" for their spouses, children, and extended families. Esteem was not explicitly evident in the reviewed evaluative studies.

The mothers' noted a prevalent change post-intervention with respect to three aspects of communication. First, mothers expressed an increase in their empathy for spouses, children, parents, other family members, and friends.
Second, the mothers described an enhanced listening ability. This listening skill pertained to their spouses, and the child with the chronic condition and their siblings. Third, the mothers articulated an heightened ability to communicate verbally with their spouse and their child with a chronic condition. As mothers' competence in communication increased post-intervention, they reported having established more meaningful and closer relationships with their spouses, ill children and their siblings, extended family, and friends. Similarly, Rudolph et al.'s (1981) study demonstrated changes in the communication patterns between husbands and wives and these results confirm this study's positive change in communication patterns as a result of an education program.

While several mothers talked about increased spousal involvement, others talked about the interrelationships between their child with the chronic condition and her/his siblings, extended family members, friends, health care providers, and community members involved in activities with disabled persons. These interrelationships were integral parts of this mutual assistance experienced post-intervention. Another common theme throughout the mothers' interviews was their increased problem solving ability. This problem solving was used in dealing with health care providers and family members. According to Shulman (1983) and Venters (1981) studies, a support network was needed to help
families cope with the complexities created by their child's chronic condition. Although Canam (1990) recommended the use of measures to determine utilization of resources, this was not quantitatively measured in that study. Furthermore, the remaining reviewed evaluative studies did not address the involvement of other people in the care of the child with the chronic condition or the use of problem solving strategies in their daily life.

In the interviews, mothers expressed having felt a sense of helplessness or lack of control prior to program participation. This sense of helplessness had origins in the chronic condition, the health care professionals, and the health care system. During the five month post-intervention interviews, the mothers felt that taking the action of participating in the PEP enhanced their sense of control and, consequently, mastery over family outcomes. As one mother explained, "I felt more in control of the situation. In control of whatever I could be in control of. ... It doesn't scare me anymore." Although Walker et al.'s (1989) survey revealed that parents need parent education on rights and entitlements, help in getting needed services, and information on community resources, the reviewed evaluative studies did not consider the parent's mastery or sense of control over family outcomes. Moreover, according to Frey et al. (1989), parental beliefs are the single most powerful correlate of parent outcomes. The present study's results
concur with Walker et al.'s survey and demonstrates the effectiveness of parent education.

When interviewed, the mothers reported improvement in three aspects that were encompassed in the dimension of family mutuality. First, mothers had noticed increased spousal emotional support. They described feeling that their husbands were "more there" for them and were more attentive to their emotional needs. Second, a common theme throughout the mothers' interviews was increased togetherness. This togetherness was evidenced by spending more time alone with their spouses and the siblings of their child with the chronic condition. Many mothers reported that, prior to taking the PEP, the child with the chronic condition absorbed an inordinate amount of their attention, time, and energy. Consequently, they expressed positive views on these alternate focuses of attention. In addition, they described improved relationships with their children with the chronic conditions. Third, the mothers had noticed an increased sense of cooperation from others. After participating in the PEP, the majority of the interviewed mothers said that they expected and asked for help from their spouses and special care workers. Moreover, they were able to ask for cooperation without feeling guilty. In addition, several mothers had observed increased cooperation between siblings post-intervention. Shulman (1983) described that families that coped well shared the following common charac-
cteristics: good quality of marital and familial relationships; and a good support system. Similarly, Venters (1981) identified parents ability to share the burden of illness, both with family members and with someone outside the family as a strategy that helped families to manage the hardships of the child's illness over time. With the exception of Cama's (1990) study, the reviewed evaluative studies did not consider these outcomes. Since the program increased the mothers' perception of spousal support; family togetherness between and among spouses, and the child(ren) with the chronic condition and their sibling(s); and cooperation from others, the program was an effective strategy that improved the mothers' overall ability to manage the enduring stressors embodied in their child's chronic condition.

The Double ABCX Model (McCubbin et al., 1983) predicted that families possessing a larger repertoire of resources manage more effectively and adapt better to stressful situations inherent in having a child with a chronic condition. This study demonstrated that program participation increased mothers' repertoire of resources, parental coping, and overall family functioning. Using McCubbin's prediction, families who participate in PEP will effectively manage and will better adapt to the stress of having a child with a chronic condition. Therefore, the PEP represents an effective clinical intervention for these parents. This study's 9 interviews determined that the subjects had maintained
these changes up to the 4-5 months post-intervention.

Program Variables

The interviewed parents unanimously recommended that the appropriate timing for the PEP was six months to one year after the initial diagnosis was made. This recommendation fits with McCollom & Gibson's (1970) suggestion that parents' adaptation to their child's diagnosis was a process and that readiness is important to learning. A further recommendation was that this program be available to all parents when their child's diagnosis has been conferred. This recommendation concurs with the reviewed literature's (Austin, 1990; Haladay, 1978; Klein et al., 1979) views that parents of children with chronic conditions require specialized parenting knowledge and skills. Moreover, the interviewed parents expressed the view that, when possible and if applicable, marital partners ought to both participate in the PEP. In Canam's (1990) inclusion criteria, only the primary caregiving parent could attend, thus eliminating marital dyads. However, based on this parental recommendation, couples' participation ought to be strongly advocated. Although there were two opposing views about whether or not the PEP ought to be offered in diagnosis specific groups, the consensus of parental opinion was that both options ought to be available on an ongoing basis.
Conclusions

The findings of this study document an increase in parental coping, family functioning, and utilization of resources for parents who participated in the program. Furthermore, parents made 3 recommendations that provide direction for future program presentations. Since the sample size was small and self-selected, the results of this study have limited generalizability.

The major conclusions of this study are as follows:

1. Program participation increased parental coping in the following manner:
   a) Fathers had a more positive outlook on their family life and their child's illness.
   b) Mothers and fathers possessed more knowledge about their child's chronic condition and increased in mastering the care required for the child at home.
   c) Mothers were more willing to share the burden of their child's condition.
   d) Mothers' personal sense of well being increased.

2. Program participation increased family functioning the following ways:
   a) Mothers and fathers strengthened the degree of their commitment, help, and support for family members.
   b) Mothers and fathers participated in more social and recreational activities with each other and with their child who had the chronic condition and her/his sibling. The
child with the chronic condition was involved in more activities.

c) Fathers expressed themselves more openly and directly.

d) Fathers increased in their sense of independence.

3. Program participation increased the mothers' utilization of resources in the following manner:

a) Mothers' sense of family esteem was enhanced.

b) Mothers' communication skills improved.

c) Mothers expanded their problem solving ability.

d) Mothers encouraged spouses and the child with the chronic condition and her/his sibling to become increasingly autonomous.

e) Mothers' sense of control and mastery over family outcomes increased.

f) Mothers perceived an increase in family mutuality which includes emotional support, togetherness, and cooperation.

Implications

The findings of this study have a number of implications for nursing theory, administration, and nursing practice. The following section delineates these implications.

Implications for Nursing Theory

The study results validated the following nursing theories used within the study. These theories were the Double ABCX model (McCubbin et al, 1983), the noncate-
gorical approach to chronic conditions (Stein et al. 1989), and the common adaptive task framework (Canam, 1993).

The conceptual framework chosen for this study was the Double ABCX model developed by McCubbin et al. (1983). This model provided direction for the literature review and for the selection of the quantitative data collection tools. Furthermore, it was useful, during the data analysis, for understanding the interrelationships between coping, family functioning, and utilization of resources as they related parental management and adaptation to the ongoing and unremitting stress of having a child with a chronic condition.

The theoretical premise of the program and an assumption of this study was that the PEP would have similar effects on parents' coping, family functioning, and utilization of resources regardless of the specific medical diagnosis of their child (Canam, 1990). Given that the study involved 2 general and 2 specific diagnostic groups and given that the program proved effective for all groups of participants, this non-categorical postulate was supported by this study.

The common adaptive task framework (Canam, 1993) provided the program's theory base and structure. Given that the PEP increased parental coping, family functioning, and utilization of resources, this framework was a useful conceptualization for understanding and supporting the parents' process of adaptation to their child's condition.
Implication for Nursing Administration

Given the Royal Commission's (1991) guidelines for determining government expenditures, the positive outcomes for program participants, and the parental endorsement of this program, hospital and community health unit administrators must actively lobby for program funding to ensure regular and ongoing program presentations.

Implications for Nursing Practice

1. The parent education program is one effective method of supporting parents whose child has a chronic condition by helping them to learn the necessary knowledge and skills to accomplish the common adaptive tasks. The program should be offered on an ongoing basis by pediatric nurses and nurse clinicians as a health promotion and prevention strategy. The inclusive nature of the program and the measured changes in parental coping, family functioning, and utilization of resources demonstrated the suitability of the PEP as a group clinical intervention for parents of children with a wide variety of chronic conditions.

2. Future nursing program planners responsible for recruitment and screening should be cognizant of the recommended 6 month to 1 year post-diagnosis time frame.

3. Future nursing program planners responsible for recruiting participants should strongly advocate, in their program promotions, that couples attend together if at all possible.
4. Future nursing program planners responsible for organizing sessions should offer general and specific diagnostic group options depending on the assessed needs of the population.

**Recommendations for Further Research**

This study's findings suggested a number of areas for further research to evaluate the effectiveness of a parent education program. These suggestions include:

1. The PEP should be offered and evaluated in several smaller outlying communities. This research project would have a more representative sample in terms of its socio-economic and cultural profiles than the existing study. The control group should be equivalent to the experimental group in terms of size, specific or general diagnostic options, and demographic characteristics. The proposed project could replicate this study's quasi-experimental research design.

2. Future studies that evaluate the PEP should employ a more sensitive quantitative and/or qualitative instrument to more accurately assess the mothers' perceived change in coping.

3. In order to reduce the chance of Type II statistical errors, future studies should include larger numbers of fathers in their samples.

4. Longitudinal qualitative studies should be conducted, using past participants, at 1, 2, and 5 year post-intervention times.
5. The interview schedules in future qualitative studies of the PEP should include a question pertaining to perceived negative program outcomes.

Concluding Remarks

In conclusion, the PEP represents a health promotion strategy for nurses caring for children with chronic conditions and their families both hospital and community settings. This strategy enhances the family's ability to manage and adapt to the persistent stress embodied in caring for a child with a chronic health problem or disability.
REFERENCES


Litman, T.J. (1974). The family as the basic unit in health and medical care: a social-behavioral overview. Social Science Medicine, 8, 495-519.


Moos, R.H. & Moos, B.S. (1986). Family environment scale


Nursing, 7(4-5), 165-176.


APPENDICES

Appendix A

Participant Information Letter

Dear Parents or Guardians,

I am a registered nurse presently working towards a Master's degree in Nursing at the University of British Columbia. As part of this degree, I am evaluating the effectiveness of a parent education program.

The program is being offered to parents who have a child with a long term health problem or disability. The purpose of this program is to help parents cope with the tasks of raising a child with a chronic condition by teaching them the knowledge and skills they need to complete the tasks.

The program will cover the following: obtaining information about your child's health condition, helping your family cope with ongoing stress, meeting your child's developmental needs, meeting other family members' needs including your own, managing your feelings and helping other family members to manage theirs, talking about the health condition within the family and explaining the condition to others, and developing and using resources to meet your child's and family's needs. Parents who participate in the program will have an opportunity to share, learn, and practice skills to enhance their ability to cope with their child's chronic condition.

The program will be held one evening a week for eight weeks, starting in October of 1992, and each evening's session will be two hours in length. Parents who have a child with any chronic health problem or disability are invited to attend. There is no cost involved but parents will be asked to respond to three questionnaires, one week prior to the program and one week after program completion, as part of this research study to evaluate the program. Filling out the questionnaires will take approximately one hour to complete. Parents will also be asked, upon completion of the program, to volunteer to be interviewed three to four months after the program has finished. The purpose of the interview will be to talk about the effects the program has had on your coping and family life and will take approximately one hour.
If you are interested in participating in the program or would like more information please contact:

Ethel McLean        XXX-XXXX
Connie Canam        XXX-XXXX
Appendix B

Notice to Parents:

An Education Program for Parents of Children with Chronic Conditions.

A parent education program is being offered by the School Liaison Program of the Public Health Department for parents who have a child with a long term health problem or disability. The purpose of this program is to help parents cope with the tasks of raising a child with a chronic condition by teaching them the knowledge and skills they need to complete the tasks.

The program will cover the following: obtaining information about your child's health condition, helping your family cope with ongoing stress, meeting your child's developmental needs, meeting other family members' needs including your own, managing your feelings and helping other family members to manage theirs, talking about the health condition within the family and explaining the condition to others, and developing and using resources to meet your child's and family's needs. Parents who participate in the program will have an opportunity to share, learn, and practice skills to enhance their ability to cope with their child's chronic condition.

The program will be held one evening a week for eight weeks, starting in October of 1992, and each evening's session will be two hours in length. Parents who have a child with any chronic health problem or disability are invited to attend. There is no cost involved but parents will be asked to respond to three questionnaires one week prior to and one week after completion of the program as part of an ongoing research study to evaluate the program.

If you are interested in participating in the program or would like more information please contact:

Deborah Ryan, West Main Health Unit, XXX-XXXX.
Appendix C

Participation Consent Form

Title of Study: Evaluation of an Education Program for Parents of Children with Chronic Health Conditions.

Investigator: Ethel McLean, BScN., RN. XXX-XXXX

Thesis Committee: Connie Canam, M.S.N., RN. (Chair) XXX-XXXX
Tom Sork, Ph.D. XXX-XXXX

Dear Parents:

You have been given information about an education program that is being offered for parents of children with chronic health conditions.

The program was developed to provide parents with an opportunity to share, learn, and practice skills to enhance their ability to cope with their child's chronic condition. The following topics will be covered: obtaining information about your child's health condition; helping your family cope with ongoing stress; meeting your child's developmental needs; meeting other family members' needs including your own; managing your feelings and helping other family members to manage their feelings; talking about the health condition within the family and explaining the condition to others; and developing and using resources to meet you child and family's needs. The program is sixteen hours in length with two hour sessions held one evening a week for eight weeks. The program will commence in the fall of 1992.

Your participation in the program will involve attending the eight sessions and completing three questionnaires one week prior to the program beginning and one week after it is completed. The questionnaires will cover such things as your perceptions about what helps you cope with your child's condition, what your family is like, and what resources you have to help you manage family life. Filling out the questionnaires involves making a selection from a number of choices and ticking them off. They will take approximately one hour to complete and you are free to refuse to answer any questions you do not want to answer. Although you may find the questions personal, substantial discomfort is not expected.

Parents will also be asked upon completion of the program, to volunteer to be interviewed three to four months after the program has finished. The purpose of the interview will be to talk about the effects the program has had
on your coping and family life and it will take approximately one hour. Interviews will be tape recorded and will be shared only with the members of the thesis committee. The tapes will be erased immediately following completion of the study. The information gained from the questionnaires and the interviews will help to evaluate the helpfulness of the program for parents.

All information that you share on the questionnaires and in the interviews will be kept confidential. No names will appear on the questionnaires or interviews; they will be identified by a code number only. Only the researchers will have access to the information and only group data will be used in a project report.

Participation in the study is entirely voluntary and should you decide to participate, you have the right to withdraw from the study at any time. Your refusal to participate will not affect the present or future medical care of your child. If you would like to talk with us about any aspect of this study, please call the numbers listed above.

Date _________  Signature of Investigator ________________

The program and study described above have been explained to me, and I have had an opportunity to ask questions and understand that future questions I may have about the study or my rights will be answered by the investigator. A copy of the consent form will be given to me. I consent to participate in the study.

Date _________  Signature of Parent(s) ________________
Appendix D

CODE NUMBER

DEMOGRAPHIC QUESTIONNAIRE

1. What is the name(s) of your child's chronic condition(s)?
2. What is the age of your child with the chronic condition?
3. List the gender and age of other children in the family in your family.

PLEASE CIRCLE THE ANSWER WHICH IS MOST APPROPRIATE.

4. Please indicate your relationship to this child?
   i) mother
   ii) father
   iii) stepmother
   iv) stepfather
   v) foster mother
   vi) foster father
   vii) guardian
   viii) other (specify)

5. Does anyone else in your family have the same type of health condition?
   YES
   NO
   If yes, who?
   i) you
   ii) spouse/significant other
   iii) child's brother(s)/sister(s)
   iv) grandparent(s)
   v) other (specify) _______________________

6. What is your ethnic background?
   i) Caucasian/White
   ii) Oriental (Chinese/Japanese)
   iii) Asian (East Indian)
   iv) Spanish
   v) Italian
   vi) Greek
   vii) First Nation
   viii) Other (specify) _______________________

7. What is your religious background?
   i) Catholic
   ii) Jewish
iii) Protestant
iv) Other (Specify) __________________________
v) No religion

8. What is your marital status?
   i) single
   ii) married
   iii) common-law
   iv) widowed
   v) divorced or separated
   vi) remarried
   vii) other (specify) __________________________

9. How long have you been married/living together?

10. Are you currently employed? YES NO

   If yes, what do you do? __________________________

   Do you work a) full-time, or b) part-time?

11. What is the occupation of your spouse/significant other?

   Does he/she work a) full-time, or b) part-time?

12. What is the total amount of income in your household, all sources combined?
   i) less than $10,000
   ii) $11,000 - $20,000
   iii) $21,000 - $40,000
   iv) $41,000 - $60,000
   v) over $60,000

13. What level of education have you completed?
   i) 9th grade or less
   ii) 10th grade
   iii) 11th grade
   iv) 12th grade
   v) some college or university
   vi) college or university graduate
   vii) master's degree
   viii) doctoral degree

14. How has your general health been in the past year?
   i) excellent
   ii) very good
   iii) good
   iv) fair
   v) poor
Appendix E

Interview Guide for Parent Interviews

I. Looking back, what would you say is the single most important thing you got from the program.

II. Since you have taken the program, what changes have you noticed in yourself? in the way you think about things? in the way you feel about things? in the way you do things?

If there were things you wanted to work on, how have you done this?

III. By way of comparison, in what ways has your parenting changed since taking the program?

Tell me about the sources of stress that seem to have changed?

In what ways do you react differently to daily hassles?

IV. Since the program ended, has your family experienced a crisis situation such as a readmission to hospital?

If yes, in what ways did you deal with the situation differently?

V. Is your family situation any different now than before you took the course? Describe those differences.

Describe differences you have noticed in the way you relate to your spouse? your child with the chronic condition? your other children? your parents? your neighbours?

What differences have you noticed in the way they relate with you?

VI. Since taking the program, are you aware of resources or
supports in the community that you weren't aware of before?

Describe additional personal, family, medical, and community resources you are now aware of?

Which of these additional resources are you making use of? What changes have you noticed about the way you relate with your doctor? other health care professionals?

What changes have you noticed when you talk to your friends, your neighbours about your child's chronic condition? What brought about these changes (program contact, ideas of other parents) for you?

What contacts, if any, have you made with the other parents in the group? with other support groups?

VII. In closing, what other comments would your like to make with regards to changes you have noticed while and since taking the program?

VIII. Would you recommend the program for other parents of children with chronic conditions? If so, why? If no, then why not?
Appendix F

The Interview Categorizing Scheme

<table>
<thead>
<tr>
<th>#</th>
<th>Category</th>
<th>Criteria for assigning content to a Category</th>
<th>Sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Coping</td>
<td>1. Parental outlook on life and illness.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Maintaining sense of own well-being through:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>a) social relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>b) Involvement in activities that increase self-esteem</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>c) managing psychol. tensions (anxiety, stress)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Mastering information needed to care for child at home through:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>a) Commun. with other parents</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>b) Commun. with HCP</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Family Functioning</td>
<td>1. Cohesion (commitment)</td>
<td>Relationship Dimension</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Expressiveness (openness)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Conflict (disagreement)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Independence</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Achievement Orientation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Intellectual-Cultural Orientation (groups)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Active Recreational Orientation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8. Moral Religious Emphasis</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. Organization (formality)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>10. Control (hierarchy)</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>Resources</td>
<td>1. Family Esteem</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Mutual Assistance</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Optimism</td>
<td>Esteem &amp; Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Problem Solving Ability</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Encouragement of Autonomy</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Mastery over family events and outcomes</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>8. Family mutuality</td>
<td>Mastery &amp; Health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>a) emotional support</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>b) togetherness</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>c) co-operation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>9. Physical and emotional health</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>10. Extended family social support</td>
<td></td>
</tr>
</tbody>
</table>
IV. Program Variables

1. Timing of PEP
2. Composition of PEP
   a) couples
   b) diagnosis
Appendix G

Control Group's Paired t-test Pre/Pre-Test Mean Scores for CHIP, FES, and FIRM

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pattern/Subscale</th>
<th>Pre/Pre-test</th>
<th>Pre-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>34.6</td>
<td>32.8</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td>31.4</td>
<td>28.4</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td>17.0</td>
<td>16.6</td>
</tr>
<tr>
<td>FES</td>
<td>C</td>
<td>7.4</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>5.6</td>
<td>5.2</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>4.0</td>
<td>4.2</td>
</tr>
<tr>
<td></td>
<td>IND</td>
<td>6.6</td>
<td>6.6</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>4.6</td>
<td>5.0</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>7.4</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>4.6</td>
<td>4.6</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>4.0</td>
<td>4.0</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>5.4</td>
<td>4.6</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>2.6</td>
<td>3.4</td>
</tr>
<tr>
<td>FIRM</td>
<td>SFS</td>
<td>5.4</td>
<td>5.4</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>20.6</td>
<td>18.0</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>20.6</td>
<td>20.0</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>26.4</td>
<td>26.0</td>
</tr>
<tr>
<td></td>
<td>FIRM</td>
<td>95.0</td>
<td>91.2</td>
</tr>
</tbody>
</table>
## Appendix H

### Female Experimental Groups' ANOVA

Sum of Squares and Mean Squares for CHIP, FES, and FIRM

<table>
<thead>
<tr>
<th>Tool</th>
<th>Subscale</th>
<th>Pattern/ Trivial</th>
<th>Residual Sum of Squares</th>
<th>Total Sum of Squares</th>
<th>Residual Mean Square</th>
<th>Total Mean Square</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td></td>
<td>383.983</td>
<td>444.55</td>
<td>23.999</td>
<td>23.397</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td></td>
<td>848.133</td>
<td>934.95</td>
<td>53.008</td>
<td>49.208</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td></td>
<td>184.750</td>
<td>186.55</td>
<td>11.547</td>
<td>9.818</td>
</tr>
</tbody>
</table>

| FES    | C        |                  | 28.883                   | 32.80                | 1.805                | 1.726             |
|        | EX       |                  | 39.700                   | 60.80                | 2.481                | 3.200             |
|        | CON      |                  | 54.933                   | 62.00                | 3.433                | 3.263             |
|        | IND      |                  | 27.583                   | 34.55                | 1.724                | 1.818             |
|        | AO       |                  | 23.583                   | 30.20                | 1.474                | 1.589             |
|        | ICO      |                  | 27.033                   | 34.55                | 1.690                | 1.818             |
|        | ARO      |                  | 26.083                   | 32.95                | 1.630                | 1.734             |
|        | MRE      |                  | 30.633                   | 31.80                | 1.915                | 1.674             |
|        | ORG      |                  | 24.833                   | 25.75                | 1.552                | 1.355             |
|        | CTL      |                  | 40.383                   | 40.95                | 2.524                | 2.155             |

| FIRM   | SFS      |                  | 58.033                   | 64.637               | 3.627                | 3.402             |
|        | RS       |                  | 119.500                  | 141.80               | 7.469                | 7.463             |
|        | FS       |                  | 170.783                  | 187.80               | 10.674               | 9.884             |
|        | SS       |                  | 96.783                   | 104.20               | 6.049                | 5.484             |
|        | FIRM     |                  | 749.300                  | 799.30               | 46.831               | 42.053            |
# Appendix I

Experimental Groups' Paired t-test
Pre/Post-Test Mean Scores for CHIP, FES, and FIRM

<table>
<thead>
<tr>
<th>Tool</th>
<th>Pattern/Subscale</th>
<th>Mothers' Pre-test</th>
<th>Mothers' Post-test</th>
<th>Fathers' Pre-test</th>
<th>Fathers' Post-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHIP</td>
<td>FAM</td>
<td>39.0</td>
<td>40.15</td>
<td>41.5</td>
<td>46.5</td>
</tr>
<tr>
<td></td>
<td>SUPP</td>
<td>33.55</td>
<td>37.1</td>
<td>33.125</td>
<td>33.25</td>
</tr>
<tr>
<td></td>
<td>MED</td>
<td>17.0</td>
<td>18.65</td>
<td>18.375</td>
<td>20.125</td>
</tr>
<tr>
<td>FES</td>
<td>C</td>
<td>6.8</td>
<td>7.4</td>
<td>6.5</td>
<td>7.375</td>
</tr>
<tr>
<td></td>
<td>EX</td>
<td>4.9</td>
<td>5.55</td>
<td>4.875</td>
<td>6.125</td>
</tr>
<tr>
<td></td>
<td>CON</td>
<td>4.2</td>
<td>4.2</td>
<td>4.0</td>
<td>3.625</td>
</tr>
<tr>
<td></td>
<td>IND</td>
<td>5.85</td>
<td>6.0</td>
<td>4.875</td>
<td>6.0</td>
</tr>
<tr>
<td></td>
<td>AO</td>
<td>4.75</td>
<td>5.05</td>
<td>4.375</td>
<td>4.0</td>
</tr>
<tr>
<td></td>
<td>ICO</td>
<td>6.3</td>
<td>6.45</td>
<td>4.625</td>
<td>5.0</td>
</tr>
<tr>
<td></td>
<td>ARO</td>
<td>4.6</td>
<td>5.05</td>
<td>4.625</td>
<td>4.625</td>
</tr>
<tr>
<td></td>
<td>MRE</td>
<td>4.9</td>
<td>4.8</td>
<td>5.5</td>
<td>5.75</td>
</tr>
<tr>
<td></td>
<td>ORG</td>
<td>5.35</td>
<td>5.6</td>
<td>6.25</td>
<td>6.5</td>
</tr>
<tr>
<td></td>
<td>CTL</td>
<td>4.75</td>
<td>4.8</td>
<td>4.875</td>
<td>4.375</td>
</tr>
<tr>
<td>FIRM</td>
<td>SFS</td>
<td>5.55</td>
<td>2.8</td>
<td>6.625</td>
<td>7.375</td>
</tr>
<tr>
<td></td>
<td>RS</td>
<td>19.8</td>
<td>21.9</td>
<td>19.0</td>
<td>20.625</td>
</tr>
<tr>
<td></td>
<td>FS</td>
<td>20.4</td>
<td>22.3</td>
<td>21.5</td>
<td>22.0</td>
</tr>
<tr>
<td></td>
<td>SS</td>
<td>26.65</td>
<td>27.35</td>
<td>23.625</td>
<td>22.375</td>
</tr>
<tr>
<td></td>
<td>FIRM</td>
<td>97.0</td>
<td>101.5</td>
<td>91.625</td>
<td>93.875</td>
</tr>
</tbody>
</table>
Appendix J

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

DIRECTIONS
• To complete this inventory you are asked to read the list of “Coping behaviors” below, one at a time.
• For each coping behavior you used, please record how helpful it was.
  HOW HELPFUL was this COPING BEHAVIOR to you and/or your family: Circle ONE number
  3 = Extremely Helpful
  2 = Moderately Helpful
  1 = Minimally Helpful
  0 = Not Helpful
• For each Coping Behavior you did Not use please record your “Reason.”
  Please RECORD this by Checking one of the reasons:
    Chose not to use it  Not Possible
    □ or □

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

1. Trying to maintain family stability
2. Engaging in relationships and friendships which help me to feel important and appreciated
3. Trusting my spouse (or former spouse) to help support me and my children
4. Sleeping
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center
6. Believing that my child(ren) will get better
7. Working, outside employment
8. Showing that I am strong
9. Purchasing gifts for myself and/or other family members
10. Talking with other individuals/parents in my same situation
11. Taking good care of all the medical equipment at home
12. Eating
13. Getting other members of the family to help with chores and tasks at home
14. Getting away by myself
15. Talking with the doctor about my concerns about my child(ren) with the medical condition
16. Believing that the medical center/hospital has my family's best interest in mind
17. Building close relationships with people
18. Believing in God
19. Developing myself as a person
20. Talking with other parents in the same type of situation and learning about their experiences
21. Doing things together as a family (involving all members of the family)
22. Investing time and energy in my job
23. Believing that my child is getting the best medical care possible
24. Entertaining friends in our home
25. Reading about how other persons in my situation handle things
26. Doing things with family relatives
27. Becoming more self-reliant and independent
28. Telling myself that I have many things I should be thankful for
29. Concentrating on hobbies (art, music, jogging, etc.)
30. Explaining our family situation to friends and neighbors so they will understand us
31. Encouraging child(ren) with medical condition to be more independent
32. Keeping myself in shape and well groomed
33. Involvement in social activities (parties, etc.) with friends
34. Going out with my spouse on a regular basis
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis
36. Building a closer relationship with my spouse
37. Allowing myself to get angry
38. Investing myself in my child(ren)
39. Talking to someone (not professional counselor/doctor) about how I feel
40. Reading more about the medical problem which concerns me
41. Talking over personal feelings and concerns with spouse
42. Being able to get away from the home care tasks and responsibilities for some relief
43. Having my child with the medical condition seen at the clinic/hospital on a regular basis
44. Believing that things will always work out
45. Doing things with my children

### I do not cope this way because.

- [ ] Extremely Helpful
- [ ] Moderately Helpful
- [ ] Minimally Helpful
- [ ] Not Helpful

**PLEASE Check all 45 items to be sure you have either circled a number or checked a box for each one. This is important.**
INSTRUCTIONS

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

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

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

CONSULTING PSYCHOLOGISTS PRESS, INC.
577 College Ave., Palo Alto, California 94306

Copyright 1974 by Consulting Psychologists Press, Palo Alto, CA 94306. All rights reserved. This test, or parts thereof, may not be reproduced in any form without permission of the publisher.
36. We are not that interested in cultural activities.
37. We often go to movies, sports events, camping, etc.
38. We don't believe in heaven or hell.
39. Being on time is very important in our family.
40. There are set ways of doing things at home.
41. We rarely volunteer when something has to be done at home.
42. If we feel like doing something on the spur of the moment we often just pick up and go.
43. Family members often criticize each other.
44. There is very little privacy in our family.
45. We always strive to do things just a little better the next time.
46. We rarely have intellectual discussions.
47. Everyone in our family has a hobby or two.
48. Family members have strict ideas about what is right and wrong.
49. People change their minds often in our family.
50. There is a strong emphasis on following rules in our family.
51. Family members really back each other up.
52. Someone usually gets upset if you complain in our family.
53. Family members sometimes hit each other.
54. Family members almost always rely on themselves when a problem comes up.
55. Family members rarely worry about job promotions, school grades, etc.
56. Someone in our family plays a musical instrument.
57. Family members are not very involved in recreational activities outside work or school.
58. We believe there are some things you just have to take on faith.
59. Family members make sure their rooms are neat.
60. Everyone has an equal say in family decisions.
61. There is very little group spirit in our family.
62. Money and paying bills is openly talked about in our family.
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
64. Family members strongly encourage each other to stand up for their rights.
65. In our family, we don't try that hard to succeed.
66. Family members often go to the library.
67. Family members sometimes attend courses or take lessons for some hobby or interest.
68. In our family each person has different ideas about what is right and wrong.
69. Each person's duties are clearly defined in our family.
70. We can do whatever we want to in our family.
71. We really get along well with each other.
72. We are usually careful about what we say to each other.
73. Family members often try to one-up or out-do each other.
74. It's hard to be by yourself without hurting someone's feelings in our household.
75. "Work before play" is the rule in our family.
76. Watching T.V. is more important than reading in our family.
77. Family members go out a lot.
78. The Bible is a very important book in our home.
79. Money is not handled very carefully in our family.
80. Rules are pretty inflexible in our household.
81. There is plenty of time and attention for everyone in our family.
82. There are a lot of spontaneous discussions in our family.
83. In our family, we believe you don't ever get anywhere by raising your voice.
84. We are not really encouraged to speak up for ourselves in our family.
85. Family members are often compared with others as to how well they are doing at work or school.
86. Family members really like music, art and literature.
87. Our main form of entertainment is watching T.V. or listening to the radio.
88. Family members believe that if you sin you will be punished.
89. Dishes are usually done immediately after eating.
90. You can't get away with much in our family.
FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

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

PURPOSE

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

DIRECTIONS

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

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

Then make your decision by circling one of the following:

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

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

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

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

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

COMPUTER CODES:  IID  GID  FAMID
<table>
<thead>
<tr>
<th>FAMILY STATEMENTS</th>
<th>Not at all</th>
<th>Minimally</th>
<th>Moderately</th>
<th>Very Well</th>
<th>For Computer Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. We have money coming in from our investments (such as rental property, stocks,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SFS RS SD</td>
</tr>
<tr>
<td>bonds, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Being physically tired much of the time is a problem in our family</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. We have to nag each other to get things done</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. We do the plan too far ahead because many things turn out to be a matter of</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>good or bad luck anyway</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Our family is as well adjusted as any family in this world can be</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Having only one person in the family earning money is (or would be) a problem</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>in our family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. It seems that members of our family take each other for granted</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Sometimes we feel we don't have enough control over the direction our lives</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>are taking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Certain members of our family do all the giving, while others do all the giving</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. We depend almost entirely upon financial support from welfare or other</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>public assistance programs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. We seem to put off making decisions</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Family members understand each other completely</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Our family is under a lot of emotional stress</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Many things seem to interfere with family members being able to share</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Most of the money decisions are made by only one person in our family</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. There are times when family members do things that make other members unhappy</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. It seems that we have more illness (colds, flu, etc.) in our family than</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>other people do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. In our family some members have many responsibilities while others don't</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>have enough</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. No one could be happier than our family when we are together</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. It is upsetting to our family when things don't work out as planned</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. We depend almost entirely on income from alimony and/or child support</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Being sad or &quot;down&quot; is a problem in our family</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. It is hard to get family members to cooperate with each other</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. If our family has any faults, we are not aware of them</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. We depend almost entirely on social security retirement income</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Many times we feel we have little influence over the things that happen to us</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. We have the same problems over and over—we don't seem to learn from past</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mistakes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. One or more working members of our family are presently unemployed</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. There are things that we need to do that are don't seem to get done</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. We feel our family is a perfect success</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. We own land or property besides our place of residence</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. We seem to be so involved with work and/or school activities that we don't</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>spend enough time together as a family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. We own (are buying) a home (single family, condominium, townhouse, etc.)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. There are times when we do not feel a great deal of love and affection for</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>each other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FAMILY STATEMENTS</td>
<td>Describes Our Family:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If a close relative were having financial problems we feel we could afford to help them out</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends seem to enjoy coming to our house for visits</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel we have a good retirement income program</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When we make plans we are almost certain we can make them work</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In our family we understand what help we can expect from each other</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We seem to have little or no problem paying our bills on time</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our relatives seem to take from us, but give little in return</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We would have no problem getting a loan at a bank if we wanted one</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel we have enough money on hand to cover small unexpected expenses (under $100)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When we face a problem, we look at the good and bad of each possible solution</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The members who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No matter what happens to us, we try to look at the bright side of things</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel we are able to go out to eat occasionally without hurting our budget</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We try to keep in touch with our relatives as much as possible</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It seems that we need more life insurance than we have</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In our family it is &quot;okay&quot; for members to show our positive feelings about each other</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel we are able to make financial contributions to a good cause (needy people, church, etc.)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We seem to be happier with our lives than many families we know</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is &quot;okay&quot; for family members to express sadness by crying, even in front of others</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When we need something that can't be postponed, we have money in savings to cover it</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We discuss our decisions with other family members before carrying them out</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our relative(s) are willing to listen to our problems</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We worry about how we would cover a large unexpected bill (for home, auto repairs, etc. for about $100)</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We get great satisfaction when we can help one another in our family</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In our family we feel it is important to save for the future</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The working members of our family seem to be respected by their co-workers</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We have written checks knowing there wasn't enough money in the account to cover it</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The members of our family respect one another</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We save our extra spending money for special things</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel confident that if our main breadwinner lost his/her job, (s)he could find another one</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members of our family are encouraged to have their own interests and abilities</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our relatives do and say things to make us feel appreciated</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The members of our family are known to be good citizens and neighbors</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We make an effort to help our relatives when we can</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We feel we are financially better off now than we were 6 years ago</td>
<td>0 1 2 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>