PARENTAL COPING WITH A CHILD'S EPILEPSY:  
A SECONDARY ANALYSIS USING  
THE CANAM ADAPTIVE TASK FRAMEWORK

by

SUSAN ELLEN CATHERINE CALVERT  
B.S.N., The University of British Columbia, 1985

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF  
MASTER OF SCIENCE IN NURSING  
in  
THE FACULTY OF GRADUATE STUDIES  
School of Nursing

We accept this thesis as conforming  
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA  
April 1998

© Susan Ellen Catherine Calvert, 1998
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.

Department of Nursing

The University of British Columbia
Vancouver, Canada

Date April 29, 1998

DE-6 (2/88)
Abstract

This qualitative study is a secondary analysis of an existing data set generated from a descriptive study of parents of children with epilepsy. The conceptual framework that provided a basis for this study was the Canam Adaptive Task Framework (ATF) and the purpose of this study was to apply the ATF to transcribed narrative data from a sample of parents to determine if the adaptive tasks effectively represented their experiences. The ATF is based on the premise that there is a series of eight adaptive tasks common to parents of children with chronic conditions, regardless of the child’s specific medical condition. The ATF is an organizing structure that guides the nurse in not only identifying the common issues, but in determining the knowledge, skills, and resources required for the parent to cope. By determining the representativeness of the ATF with this condition-specific data set, the credibility of the ATF with parents of children with chronic conditions may be increased. In the current study, 12 families were randomly selected from the original, convenience sample of 20 families from the Seizure Clinic at BC’s Children’s Hospital. Data were analyzed using latent content analysis (Morse & Field, 1995) according to the appropriate adaptive task categories. Through the study, the author’s findings demonstrate that the ATF provides the nurse with credible and practical direction to collaborate with parents in identifying the knowledge, skills, and resources needed by parents to cope effectively with their child’s condition. More specifically, these parents had difficulty accessing adequate, useful information about their child’s condition, developing effective working relationships with health care professionals, communicating with their children’s teachers, and promoting normalization in their families’ lives. A major conclusion indicates that by being representative of these parents’ experiences, the ATF is considered to be effective in identifying the difficulties and strengths of parents of children with epilepsy and in facilitating the acquisition of their coping strategies. Implications for nursing practice, education, and research are presented.
TABLE OF CONTENTS

Abstract ii
Table of Contents iii
List of Tables vi
Acknowledgements vii

Chapter One: Introduction 1
  Background to the Problem 1
  Research Question 2
  Definition of Terms 2
  Assumptions 3
  Significance of the Study 4

Chapter Two: Conceptual Framework and Literature Review 5
  Conceptual Framework: Canam Adaptive Task Framework 5
  Impact on Parents and Parental Coping 8
  Nurses’ Role with Families 13
  Summary 17

Chapter Three: Method 18
  Description of the Original Study 18
  Secondary Analysis 19
  Study Sample 19
  Data Analysis 20
    Coding 21
  Rigor 21
  Limitations 23
  Summary 23

Chapter Four: Findings 24
  Accepting the Child’s Condition 24
    Difficulties 24
    Coping Strategies 25
      Comparing to Others 25
      Maintaining a Positive Perspective 26
  Managing the Child’s Condition on a Day-to-Day Basis 27
    Difficulties 27
    Accessing Information About the Child’s Condition 27
    Regulation of Medications and Side Effects 28
    School and Learning Difficulties 30
    Medical Management 32
    Relationships with Health Care Professionals 33
    Coping Strategies 33
      Becoming Informed 33
      Forming Relationships with Health Care Professionals 34
List of Tables

Table 1. Common Parental Adaptive Tasks

...........................................................................................................6
Acknowledgements

I would like to acknowledge and thank the following people for their contributions to the writing of this thesis and the completion of this masters degree:

The families who participated in the original study and gave their time to share their experiences of living with a child with epilepsy

The members of my thesis committee:
Connie Canam, Anne Sutherland-Boal, and Jinny Hayes
For their enthusiasm, encouragement, and expertise
And Connie, for being positive, motivating, and so supportive

Carol Bassingthwaighte, for her assistance with the preliminary data analysis
Lynda Christie, for providing me with her resources, perspectives, and editing

My friends, and my study group Rosella, Mary-Ann, Bev, and Susan for support, encouragement, and stimulating conversation

My family, especially my parents Eddie and Sheila Calvert for support and encouragement

Tony Sadownichik, for the endless support, encouragement, and meaningful, well-needed, pep talks through all my ups and downs; for helping me develop greater clarity in my writing; for editing; and for helping me keep perspective
Chapter One: Introduction

The difficulties in coping that families of children with chronic health problems have are well documented in the research literature. While most of the studies to date have focused on specific chronic conditions such as cystic fibrosis, diabetes, or epilepsy, Canam (1993) examined multiple studies that explored families coping with their child’s chronic condition and found a number of common issues regardless of their child’s specific medical diagnosis. These common issues were conceptualized as eight adaptive tasks and provided an initial framework for nurses working with families with a child with a chronic condition. This Adaptive Task Framework (ATF) suggests that by determining how families are coping with each of the eight adaptive tasks, nurses can identify the knowledge, skills, and resources these families need to cope more effectively.

The purpose of this study was to conduct a secondary analysis with a set of existing data about parental coping with a child’s epilepsy, applying the Canam ATF to determine if the adaptive tasks represent the experiences of the parents who participated in the original study.

Background to the Problem

Three general factors were identified as major influences in the lives of families of children with chronic health conditions: advanced technology; increasing parental responsibility; and the role of nurses in supporting these families. Various sources of literature and statistics suggest that the health needs of chronically ill children and their families are rising. Stein and Jessop (1982) indicated that “a larger relative share of health professionals’ time is being spent on patients with chronic conditions” (p. 354). As a result of advances in medical diagnosis and treatment, the mortality rates of chronically ill children have dropped significantly over the last 100 years with many of these children now surviving into adulthood (Newacheck & Taylor, 1992). This would indicate an increasing need for resources to assist these children and their families in coping with their health needs.
Growing parental responsibility in caring for a child with a chronic condition is related to three societal trends. The first trend involves a shift from acute or hospital care to community or home care, when children are discharged earlier from hospital with higher levels of acuity and parents are required to care for them at home. The second trend is family-centered care, where families are intended to have more collaborative relationships with health care professionals both within the home and hospital. Parents require support in this shared decision-making (Ahmann, 1994a). The third trend involves shifting emphasis from reactive to proactive health care where, within the perspective of prevention, individuals have a greater responsibility in adopting behaviors that promote the maintenance of good health. This reflects an increased focus on parents caring for their child rather than the physician ‘curing’ the child. All three of these trends involve an increasing need for parental education and support.

The role of nursing is to empower and support people in managing their health and health conditions. In order to perform this role, nurses and other health care professionals require a comprehensive knowledge base regarding how people manage and respond to health and health challenges. Therefore, it is important for nurses to understand the factors that influence parents that are coping with a child with a chronic condition, and to develop a knowledge base that assists them to empower and support these families.

**Research Question**

Does the Canam ATF represent the experiences of parents coping with their children’s epilepsy within an existing set of interview data?

**Definition of Terms**

*Parents*: The primary caregivers of a child who are birth, step, or adoptive parents.

*Children*: Four to 16 year old individuals who are birth, step, or adopted dependents of their parents.

*Epilepsy*: An unpredictable, reoccurrence of seizures with no other medical cause. A seizure is
“usually a brief, sudden malfunction of the brain that is attributable to a massive abnormal electrical discharge” (Jan, Ziegler, & Erba, 1991, p. 16).

Petit Mal Seizures: “Nonconvulsive seizures with total loss of consciousness or awareness. Short periods of blinking, staring, or minor movements lasting a few seconds” or “absence seizures” (Wong, 1995, p. 1715).

Grand Mal Seizures: “Total loss of consciousness with convulsions usually lasting 1 to 3 minutes” or “tonic-clonic seizures” (Wong, 1995, p. 1715).

Coping: The cognitive and behavioral efforts made by individuals to deal with the internal and/or external demands of a situation with which they are confronted (Lazarus & Launier as cited in Canam, 1987).

Adaptive Task: A task designed to promote parental coping and deemed important for parents of children with chronic conditions to accomplish in order to cope with the common issues facing them (Canam, 1993).

Canam Adaptive Task Framework: An organizing structure based on a series of eight broad tasks which parents need to address in order to cope with their child’s chronic condition. The framework provides direction for the nurse in promoting parental coping through assessing the parents’ needs and strengths, and supporting them in their acquisition of knowledge, skills, and resources. (Canam, 1993).

Assumptions

One of the main assumptions made in this study is that parents of children with epilepsy share common issues with parents of children with other chronic conditions. Additionally, it is assumed that the parents originally interviewed were honest and open in their responses and that the existing data set continues to accurately represent the experiences of parents.
Significance of the Study

In order for children with long-term health problems to have their well-being maintained and mental health risks minimized, their parents and siblings must also have their needs addressed. This principle is a component in Patterson and Geber’s (1991) framework for promoting mental health in children, which is based on a series of principles to guide prevention. Nurses need to develop a broad-based knowledge of parents' concerns and abilities, and by understanding how parents adapt, provide them with the resources and support required to better assist parents in managing their children's health (Patterson & Geber, 1991).

While the ATF was based on common issues faced by families with children with chronic conditions (Canam, 1993), in this study the ATF will be related to a condition-specific data set of parents of children with epilepsy. By determining if the ATF accounts for the experiences expressed by these parents, the credibility of the framework for assessing and supporting parents of children with various chronic conditions could be further developed. Through recognizing the similarities in the psychosocial responses of parents of children with various chronic conditions, nurses and other health care professionals may apply that knowledge to facilitate the adaptation and empowerment of other families. In Chapter Two, the Canam ATF is presented as the conceptual framework and the literature is reviewed.
Chapter Two: Conceptual Framework and Literature Review

This chapter presents an overview of Canam's Adaptive Task Framework (1993) which provides the basis for this study. This conceptual framework is presented with pertinent, supporting literature. In addition, a review of the literature relevant to parental coping with having a child with a chronic health condition is presented in two sections: the impact of the child's chronic condition on parents and parental coping; and the nurse's role with these families.

Conceptual Framework: Canam Adaptive Task Framework

Canam (1993) identified common themes related to psychosocial issues of family coping with a child's chronic condition from a broad review of research, theory, and clinical-based literature. These issues are not specific to the child's medical diagnosis and became the basis for the Canam Adaptive Task Framework (see Table 1). During development of this framework, Canam discovered that although parents needed to learn various adaptive tasks, there was no source which specifically identified or organized them as a framework for assessing and supporting parental coping.

The ATF is based on a noncategorical perspective which involves perceiving individuals according to functional ability/life challenges as opposed to diagnostic category. Stein and Jessop (1989) articulated the noncategorical approach to chronic childhood health conditions based on the general view that chronically ill children and their families experience many similar challenges regardless of the specific disease process. Findings from their study suggested that using diagnosis to categorize individuals for psychological and social variables was not useful. Although diagnosis was recognized as an important factor in treating the physical components of a child's condition, it did not provide significant information about the lives and concerns of chronically ill children and their families. They suggested that for health professionals, a knowledge of children with various chronic health conditions may help in caring for other children, not necessarily with the same health condition. Through recognizing the similarities
among children with chronic illness and their families, programs can be developed to meet the needs of those with diverse conditions. Walker, Epstein, Taylor, Crocker, and Tuttle (1989) studied whether parents of children with differing chronic health challenges had similar needs. The results of their study indicated that various parental/child health condition groups showed more commonalities than differences when identifying which needs and services were important to them. These findings also supported the use of a noncategorical perspective when dealing with psychosocial responses of those involved with chronic health conditions.

The adaptive tasks are based on difficulties identified by parents within the research literature, however they are stated in positive terms as tasks for parents to address and resolve rather than as problems or difficulties. This format provides direction for nurses when determining if families have unresolved issues that relate to any of the adaptive tasks and in identifying the knowledge, skills, and resources these families need to manage these tasks more effectively.

Table 1: Common Parental Adaptive Tasks

<table>
<thead>
<tr>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Accept the child's condition</td>
</tr>
<tr>
<td>2. Manage the child's condition on a day-to-day basis</td>
</tr>
<tr>
<td>3. Meet the child's normal developmental needs</td>
</tr>
<tr>
<td>4. Meet the developmental needs of other family members</td>
</tr>
<tr>
<td>5. Cope with ongoing stress and periodic crises</td>
</tr>
<tr>
<td>6. Assist family members to manage their feelings</td>
</tr>
<tr>
<td>7. Educate others about the child's condition</td>
</tr>
<tr>
<td>8. Establish a support system</td>
</tr>
</tbody>
</table>

(Canam 1993, p. 46)

The first task of Accepting the Child's Condition refers to parents moving through shock, disbelief, and denial until a realistic view of the child's condition is developed. The parent's acceptance of their child's condition is described as being influenced by their perspective on the child's condition and the meaning they associate with the illness. The task for parents is to attribute personal meaning to their child's illness which contributes to their further acceptance of
the condition. The second task, *Managing the Child's Condition on a Day-to-Day Basis*, relates to parents requiring accurate information and needing to feel some sense of control in the situation. The task for parents is to positively influence the day-to-day management of their child’s condition by becoming well informed about their child’s condition and developing collaborative, working relationships with health care professionals.

The third task, *Meeting the Child’s Normal Developmental Needs* refers to the need for parents to find a balance between meeting the child’s developmental needs and meeting his/her physical health needs related to the chronic condition. Sometimes in the parent’s effort to promote the child’s emotional health, the child’s physical health is at risk or vice versa. The task for parents is to meet the child’s health needs related to the chronic condition within the context of his/her normal developmental needs. The fourth task, *Meeting the Developmental Needs of Other Family Members* is described as creating a balance with family needs and relationships between the parents, the siblings and the child with epilepsy. The task for parents is to protect and nurture family relationships by identifying and addressing the needs of all family members and the family unit. The fifth task, *Coping with Ongoing Stress and Periodic Crises* refers to identifying various sources of stress, such as those associated with the child’s condition and repeated hospitalizations. The task for parents is to identify and reduce or prevent the accumulation of stress that could lead to crisis.

The sixth task, *Assisting Family Members to Manage Their Feelings* relates to recognizing the various emotions, such as anger, guilt, and resentment that family members experience when living with a child with a chronic health condition. Parents, siblings and the child with the chronic condition often have difficulty in sharing and managing their feelings. The task is for parents to learn how to express and manage their feelings and to facilitate their children in sharing and managing theirs. The seventh task, *Educating Others About the Child’s Condition* refers to parental difficulties in communicating with the child with the chronic
condition and family members about the health problem and concerns associated with teaching others about the condition. The task is for parents to develop an in depth understanding of their child’s illness and to educate others about the condition, including the child with the condition and any siblings. The eighth task, *Establishing a Support System* describes how support systems can promote a higher level of family functioning and adjustment to chronic health conditions. Difficulties in developing and maintaining social relationships can negatively influence the development and utilization of support systems. The task is for parents to develop, nurture and be actively involved in a support system in their community that may help them cope with their child’s condition and promote meaningful relationships with others.

Parents are deemed able to accomplish these tasks if they have developed the necessary knowledge, skills, or resources (Canam, 1993). This framework is intended to be useful for nurses and other health professionals to facilitate the identification of issues or tasks that parents may struggle with and to help them acquire the knowledge, skills, and resources necessary to resolve these issues. This framework is intended to guide nurses in assisting parents to effectively manage their child’s condition on a continuing basis.

This framework has been utilized as the basis for a parent education program with the purpose of enhancing parental coping and decreasing parental stress in the ongoing management of a child’s chronic condition (Canam, 1992). This program consists of eight, two hour sessions, with each session focusing on one of the adaptive tasks, and involves a high degree of parental interaction with the various issues parents encounter with the adaptive tasks. This program also involves parents in identifying and acquiring the knowledge, skills, and resources they need to manage their child’s condition on an ongoing basis.

**Impact on Parents and Parental Coping**

Parents can be significantly affected by having a child with a chronic health condition. Areas of impact included difficulties with the child’s normal development (Loebig, 1990;

Various studies reported that parents expressed concerns about their child’s chronic health condition negatively affecting the normal growth and development of their child. In one exploratory, descriptive study, mothers of children with spina bifida were concerned about the social development of their child and promoting independence (Loebig, 1990). Deatrick, Knafl, and Walsh (1988) described how parents had concerns regarding disciplining their child and were overprotective in their need to prevent further injury. Diehl, Moffitt, and Wade (1991) described the parental focus group responses of 80 caregivers of medically complex children. These parents expressed a need for increased information about what was developmentally normal for their child and what to expect in the future.

Through secondary analysis, Sharkey (1995) studied uncertainty in a subset of four families with children with chronic health conditions from a larger study of families receiving home care. These results showed that uncertainty was related to fears of the child dying, stress on the siblings, and concern regarding consistent home care nursing services. In addition, uncertainty was related to financial pressure, and having difficulty in communicating feelings.

Family communications have been a common source of difficulty for families. Canam (1987) studied how families of children with a chronic condition coped with their feelings and found that “over half of the parents ... said they did not talk about their feelings to anyone” (p. 14). Those parents that did communicate their feelings indicated that having others to share their experiences with was very beneficial to coping with their situation. Some parents reported
having conflicts with grandparents regarding discipline and independence issues (Loebig, 1990). In families with a child with osteogenesis imperfecta, nurturing and showing affection resulted in some parents feeling “fearful of causing injury as a result of physical contact” (Deatrick, Knafl, & Walsh, 1988, p. 19). Limitations to functioning spontaneously also affected family lifestyle, when minor outings required extensive coordination (Loebig, 1990; Diehl et al., 1991). Diehl et al. (1991) described how families needed to accept their child’s state of health, deal with other family members’ fears of being responsible for the child, and resolve fears that siblings may develop the same health condition.

Some parents expressed dissatisfaction with interactions involving health care professionals. They felt that health professionals did not listen to nor respect them, and that the parents had to have, specific knowledge in order to understand the health professionals (Diehl et al., 1991). Additionally, these parents felt that their doctors did not give them sufficient time to discuss and understand home care. Sharer and Dixon (1989) described the impact of having a ventilator-dependent child on parents of ten families. Their results included concerns of some parents regarding the lack of respect medical residents’ had for parental knowledge and the unwanted interference of some nurses with their parenting. Robinson (1985a) described how some parents felt they were expected to care for their child at home, yet were not respected for their knowledge during the child’s hospitalization. In addition, they felt that they received conflicting and inconsistent direction from some hospital staff regarding their expected involvement in their child’s care.

Information specifically about the child’s illness was described as a highly rated, major need by parents (Canam, 1987; Diehl, Moffitt, & Wade, 1991). Parents in the Diehl et al. study described feelings of frustration and being overwhelmed when gathering information about their child’s illness because information was either incomprehensible and/or inadequate. One of three broad themes related to coping in parents of children with gastrostomy tubes was “managing the
gastrostomy" (Thorne, Radford, & Armstrong, 1997, p. 47). This theme is based on gaining knowledge of the technology, complications and nutrition, suggesting a strong relationship between effective coping and developing a useful knowledge base. In a study by Coulter and Koester (1985) examining parents’ learning needs, physicians identified medical concerns as having greater significance and psychosocial concerns as having less significance in comparison with ratings of parents of children with epilepsy. This study identified a schism in parents’ and physicians’ perceptions of what constituted important information and likely affected these parents’ dissatisfaction with the quantity and level of information they received.

Diehl, Moffitt, and Wade (1991) described the concerns of parents of technology-dependent children requiring 24 hour care. Major areas identified by the focus groups were family issues regarding breakdown of family structure and fear of caring for the child, the need for useful, illness-specific information and appropriate equipment, and fragmentation of care. The parents in this study felt that to effectively cope, they needed greater organization of the type of information and guidance they required, and the services they received. Although numerous areas of difficulty were identified in this study, ultimately the need for better coordination of information and services was necessary.

Common coping strategies utilized by parents of children with chronic conditions include normalization (Deatrick, Knafl, & Walsh, 1988; Knafl & Deatrick, 1986; Robinson, 1993; Scharer & Dixon, 1989; Sharkey, 1995; Thorne, Radford, & Armstrong, 1997), support (Loebig, 1990; Patterson and Geber 1991; Scharer & Dixon, 1989; Thorne, et al., 1997; Youngblut, Brennan, & Swegart, 1994), and open communication with others (Coulter & Koester, 1985; Murphy, 1991; Thorne, et al., 1997). Indicative of this, 92 percent of parents of children with osteogenesis imperfecta described normalcy as an important goal for both their child and their family life (Deatrick, et al., 1988).

Robinson (1993) described normalization as a significant theme that emerged from two
previous studies of 40 families with a member (but not necessarily a child) with a chronic condition and identified four practices that promoted normalization in family members. The first, ‘covering up,’ related to making visible differences seem less obvious to others by encouraging the child to participate in common attainable activities rather than highlighting limitations. ‘Covering up’ also involved controlling the information shared with others. The second practice, ‘doing normal things’ involved doing activities as the family would if all members were healthy and maintaining a routine, including establishing rules. It also described parents ‘letting go’ and balancing feelings of protection with promoting independence in their child. This second practice also involved family members ‘filling in’ by helping out and participating in the caretaking of the person with the chronic condition. The third practice, ‘desensitization’ related gradually exposing the visible differences of the child to others, for the benefit of both. The fourth practice was ‘making trade-offs’ and involved a family member “giving something up in order to gain something else that was of greater value” (p. 19).

A second coping behavior, seeking social support, was described as the most common resource for promoting competence and preventing mental health problems in children with chronic health conditions (Patterson & Geber, 1991). Butcher (1994), in an examination of the literature, described social support as integral to the care of families. Scharer and Dixon (1989) did a qualitative study of 10 families describing the impact of ventilator-dependent children on parental management styles. Results indicated that having support from outside the home was crucial to the family’s ability to manage. Additionally, parents needed encouragement to develop a support system in their community, especially if they had spent significant time at the hospital and previous supports had not been sustained by the family.

Open communication with others is a third coping strategy used by families (Coulter & Koester, 1985; Murphy, 1991; Thorne, et al., 1997). In an exploratory study on stress and coping in home care, parents described coping with difficulties with the nurses by communicating
directly, having regular meetings between the parents and nurses, and having clearly defined training sessions for the nurses (Murphy, 1991). Thorne, et al. (1997) had similar findings.

This review of the impact on parents of a child with a chronic condition demonstrates the significant difficulties these parents experienced in coping with their child’s condition. This literature further indicates the needs parents have for support and assistance in coping.

**Nurses’ Role with Families**

The role of the nurse is to empower and support parents in managing their child’s chronic health condition. In order to do this, nurses need to understand and value family-centered care and develop skills to work in collaboration with the family. In addition, nurses work with various frameworks that give them direction in thinking about and organizing information when working with families of children with chronic conditions. The philosophy of family-centered care and two different models will be discussed regarding the direction they give to the nurse and how they relate to the ATF.

The philosophy of family-centered care was formally introduced in 1987, when the United States Surgeon General and the Association for the Care of Children’s Health (ACCH) published documents identifying the elements of family-centered care (Ahmann, 1994b). Two of the key elements of family-centered care are “facilitating family/professional collaboration at all levels of health care” and “recognizing family strengths and individuality and respecting different methods of coping” (Johnson, Jeppson, & Redburn, 1992, p. 3). Consistent with family-centered care, and central to the ATF, is the collaboration of the nurse and the parent in the identification of the parents’ difficulties, coping strategies and strengths. This process also assists in the acquisition of the knowledge, skills, and resources needed to effectively resolve the difficulties. Three other elements of family-centered care are; “understanding and incorporating the developmental needs of children into health care;” supportively sharing complete information with parents; and “encouraging and facilitating family-to-family support and networking.” These
three elements relate directly to the adaptive tasks within the ATF which relate to the importance of considering the child’s developmental stage, the parents’ need for information, and the need for support.

Family-centered care, a current trend in health care, allows a greater sense of empowerment to learn specific skills, develop confidence, and increase competence in parents through greater independence in the management of their child’s care (Johnson, Jeppson, & Redburn, 1992). Callery and Smith (1991) indicated that the quality of care for hospitalized children is broadly considered to have been improved by an increase in parental participation. The purpose of utilizing the ATF is that parents will become more empowered with increased knowledge, skills, and resources, thereby being able to cope more effectively.

Within the philosophy of family-centered care, children are seen to exist within the context of their families and therefore ‘family’ should be central in the planning of children’s care (Ahmann, 1994b). As advocates, nurses need to understand the specific needs of families, and to respond to knowledge learned from families (Ahmann, 1994b). Nurses care for and learn from families of children with numerous chronic conditions and apply their knowledge to individual families. Similarly, nurses can learn through using the ATF, which is based on the experiences of many families, and apply this knowledge when interacting with specific families.

Family centered care has become widely recognized for its benefits to: families, children, and health care providers. However, nurses need to reflect upon the nature of their own practice in relation to how they interact with families (Hayes, 1997). The specific role that individual nurses take with parents is significant to the ease and degree with which parents are involved with their child’s care. The nurse has the balance of power in the nurse-patient relationship and therefore has a responsibility not to abuse this power. The nurse is familiar with the physical setting and the field of information, while the parent often experiences uncertainty, anxiety, and stress; has an unwell child; and is adjusting to a changing parenting role (Callery & Smith,
1991). The parent often feels more vulnerable and sometimes helpless in this relationship (Robinson, 1985a). Nurses need to recognize how their own beliefs and values may negatively influence their interactions with families, in order to provide the most effective delivery of family-centered care.

There are a number of frameworks that have been developed to give guidance to nurses working with families of children with chronic conditions. The Social Skill Development Model (SSDM) (Clark, Striefel, Bedlington, & Naiman, 1989) and the Family Power Resources Model (FPRM) (Ferraro & Longo, 1985) are described in addition to the Canam ATF, to provide a comparison. The ATF supports the principles of family-centered care by promoting competence and independence in parents (Canam, 1993). While the authors of the SSDM maintained their model was based on family-centered care, in some situations children alone received skills training, with parents becoming involved based on family need. Although the FPRM is not explicitly based on family-centered care, its ultimate goal of families becoming more able to effect change within themselves, clearly reflects family-centered care philosophy.

The Social Skill Development Model is intended to be used by nurses and other health care professionals in promoting coping and mental health in children with social, emotional, or chronic health conditions. This model is used with parents, or with children accompanied by their parents, and is preventative and remedial in its application. It consists of three major components: Assessment and Tracking Progress involving identifying problems, strengths, and risks; Selection of Skills and Goals which involves teaching interpersonal skills and promoting new emotional responses to be used as coping strategies; and Training and Generalization Methods involving various strategies when teaching new skills to children or their parents. Although these three components of the SSDM are broad, specific direction is given within each which would likely benefit the nurse or other health professionals. The use of this model with families whose children have been admitted to hospital or are visiting clinics broadens its use.
Three aspects of the SSDM contrast with Canam’s ATF. The SSDM is focused on developing social skills to manage various situations, and not directly on common challenges associated with chronic health conditions. In contrast, Canam’s ATF may be more helpful in accessing concerns of families by guiding the nurse to work with families regarding commonly identified issues related to their children’s chronic conditions. Secondly, because the SSDM was developed to promote coping in children, parental needs are not central to the model, except when directly related to the child’s difficulty in coping. The focus for the training is on the child and the parent may not have been in attendance. In contrast, parental involvement is core to Canam’s framework, and additionally acknowledges the needs of all members of the family. Thirdly, this model differs from Canam’s ATF in the numerous tools that were identified as options for assessment. When using the SSDM the nurse would need to make decisions regarding the most appropriate tool(s) for each family situation, while with the ATF, the eight specific tasks more directly guide the nurse to determine family needs in knowledge and skills. This provides direction for the nurse to inquire about general issues without the parents experiences being interpreted within a rigid structure.

The Family Power Resources Model, adapted from Miller’s (1983) Patient Power Resources Model, was used to help families with children with chronic health conditions or with acute medical conditions. The purpose of this model was to give nurses direction in assessment and intervention of these families in relation to their coping with, and adaptation to their health situations. This model refers to seven resources: Belief System, Motivation, Knowledge, Positive Self-Concept, Energy, Psychological Stamina and Support Network, and Physical Strength and Reserve. Nurses apply each of these seven components of the model or ‘power resources’ to a family to determine if they are experiencing powerlessness and in which areas they may need assistance with coping and adapting. Ferraro and Longo claimed that coping strategies, or ‘family power’ are enhanced if one or more of these resources are supported during
a hospitalization.

Similar to Canam’s ATF, the FPRM guides the nurse in regards to its seven resources (content areas) and advocates a positive, empowering approach. However, like the SSDM, the FPRM does not guide the nurse to help the family identify or manage certain common difficulties associated with chronic conditions, such as a sibling requiring more attention, as Canam’s ATF does additionally. The FPRM, unlike the ATF, is limited to use with families when children are hospitalized and was adapted from a model for use by individuals, not from the perspectives of parents or families. However, Ferraro and Longo stated that the use of each of these seven content areas was supported in the literature regarding families coping with children with chronic health conditions.

Summary

The literature clearly demonstrates the significant and challenging impact of a child with a chronic condition on parental coping. Many parents have difficulty accessing adequate information, interacting with health care professionals, normal growth and development, and family communications. Parents developed coping strategies by promoting normalization for their child, seeking support, and communicating with others. By effectively using the philosophy of family-centered care, nurses have the ability to positively influence the empowerment and coping of parents of children with a chronic condition. While the SSDM and the FPRM are identified as providing some guidance to nurses, they are not as comprehensive as Canam’s ATF, which supports the principles of family-centered care by promoting the empowerment of parents through the acquisition of knowledge, skills, and resources.

To demonstrate an in-depth application of this framework, using an existing set of narrative data from parents of children with epilepsy, this study used latent content analysis. The following chapter explains the methods and describes the original study.
Chapter Three: Method

This qualitative study is a secondary analysis of an existing data set generated from a descriptive study of parents of children with epilepsy. This study used the ATF as a guiding framework for analysis of the data from the original research. A description of the original study and secondary analysis is provided, followed by an outline of the procedures, data analysis, ethical considerations, rigor, and limitations.

Description of the Original Study

The purpose of the original study (Canam, 1985) was to describe parents' experiences in coping with a child's epilepsy. McCubbin and Patterson's (1983) Double ABCX Model of Adjustment and Adaptation was the conceptual framework utilized for this original study. An exploratory, descriptive research design was used to answer the following research questions: 1. What are the perceived needs of parents coping with a child's seizure disorder? 2. What resources do parents identify as meeting their needs? A semi-structured interview guide was used to collect data regarding parents' perceived needs and the resources to meet those needs. Parents from 20 families were interviewed within their homes with interviews lasting approximately one hour. Interviews were audiotaped and transcribed verbatim and the data were analyzed using manifest and latent content analysis (Morse & Field, 1995).

The sample from the original study of 20 families, all from Greater Vancouver, consisted of parents of children with epilepsy who were contacted through the Seizure Clinic at the British Columbia's Children's Hospital (BCCH). After obtaining agreement from clinic physicians (Appendix A), potential families were first contacted by the nurse from the Seizure Clinic who briefly explained the study and asked if they would be interested in receiving more information. The interested parents were given greater details in a letter (Appendix B), with those willing to participate giving their name to a clinic nurse who passed it on to the researcher. These parents were then contacted by phone and an appointment was made for an interview and to obtain
written informed consent (Appendix C).

Selection criteria for the study included:

1. The parents were able to speak and communicate in the English language.
2. The child had been diagnosed one year or longer.
3. The child was not currently admitted as an inpatient in the hospital.
4. The child was of average intelligence.

Ethical approval was received from the University of British Columbia and the BCCH Ethics Committees. The confidentiality of participating families was maintained by coding the interviews without using names, and by the researcher exclusively transcribing the interview tapes before destroying them.

**Secondary Analysis**

Secondary analysis is appropriate for this study because both research questions are concerned with the experiences of parents coping with a child’s epilepsy, and therefore the topic of the secondary inquiry is represented in the data set (Thorne, 1994). The technique of secondary analysis allows previous research to be further developed with the intention of increasing the breadth of understanding in a particular field and increasing opportunities to apply the findings (Thorne, 1994). Secondary analysis provides for the efficient and effective use of “hard-earned, costly, and valuable human data” (Thorne, 1994, p. 269) through an “appreciation for the inevitable progress for knowledge beyond the time frame of our discrete research endeavors” (Thorne, 1994, p. 267).

**Study Sample**

For this secondary analysis study, 12 families were randomly selected from the original study participants. Interview participation within the 12 families was: both mother and father in seven of the families; only the mother in four families; and only the father in one family. There were eleven two-parent families and one single parent family while 11 families had at least one
additional child other than their child with epilepsy. The children's ages ranged from four to 16 years with a mean age of 10 years, and the majority had grand mal seizures.

**Data Analysis**

Content analysis is based on analyzing the data according to topic and then dividing each interview into categories by these topics (Morse & Field, 1995). Content analysis is intended to classify words from interviews into select categories identified because of their theoretical importance (Burns & Grove, 1993). Content analysis is comprised of two types, manifest and latent. Manifest content analysis involves dividing the interview text into words, phrases, or units of meaning, which are central to the research, then using descriptive statistics to quantify and analyze (Burns & Grove, 1993; Morse & Field, 1995). This study consisted of examining the data using latent content analysis, in which ideas and meanings were identified within paragraphs or sections and interpreted in relation to the whole interview (Morse & Field, 1995). This form of content analysis is most commonly used with qualitative research and provides greater access to the richness in the data (Morse & Field, 1995). Additionally, latent content analysis promoted the categorization of the interview data into the adaptive tasks and further into subcategories, when relevant.

Prior to analysis, a category guide was developed in order to further promote familiarity with the ATF and to facilitate the consistent allocation of data to each appropriate task category. This guide was divided into the eight ATF categories, with point form content which was generated from the difficulties and coping strategies of each task (Appendix D). The specific analysis process involved initially reading all 12 transcripts to develop a general sense of all the data (Creswell, 1994), while the ATF was not considered to promote as complete a comprehension of the intended meanings as possible. Focusing on the ATF in this initial analysis period could have been a distraction that biased interpretations. The interviews were then reviewed individually for 'underlying meaning' in the responses, and themes related to the
appropriate adaptive task were written alongside the data segment (Creswell, 1994, p. 154).

In the process of analyzing the data, the increasing familiarity with the data allowed for greater clarity in allocating data to each adaptive task. Interviews analyzed early in the process were reviewed and if appropriate, data was reallocated to a different adaptive task category.

**Coding**

Creswell (1994) encourages the researcher to "be comfortable ... making comparisons and contrasts ... and be open to possibilities and see contrary or alternative explanations for the findings" (p. 153) in data analysis. It was considered that some data may not have corresponded to any of the adaptive tasks, and would require re-examination together for patterns or relationships throughout the analysis process, but this was not the case. Data that did not relate to difficulties, coping strategies, nor the parents' experiences, but was more introductory to the interview process and the structure of the family, was considered for its usefulness and then discarded. The process of organizing the data set into the appropriate adaptive task was accomplished by using a color-coding system.

**Rigor**

Sandelowski (1986) described a criticism of qualitative research as inadequately providing for validity and reliability. Rigor may be promoted through *auditability* in qualitative research as a parallel to reliability in quantitative research, and through *credibility* in qualitative research as a parallel to validity in quantitative research (Guba and Lincoln, 1981. *Auditability*, or reliability (stability and dependability) builds consistency within a study and is based on the researcher presenting a clear decision trail that allows another researcher to understand the logical progression of events. *Credibility* is based on presenting accurate descriptions of the human experience "so the people having that experience would immediately recognize it from those descriptions or interpretations as their own" (Sandelowski, 1986, p. 30). Guba and Lincoln (1981) indicate that credibility builds truth value.
In this study, auditability was maintained by specifically implementing the process as planned for the data analysis, while discussion with thesis committee members helped to promote a logical progression throughout the process. Additionally, the category guide developed prior to the commencement of the analysis promoted the consistent assignment of interview data to the appropriate ATF categories. A journal was maintained in order to track thoughts, difficulties, and methodological notes, and provided a rationale for decisions made regarding analysis and assignment of interview data. This allowed for later reflection on issues requiring a consistent approach for the remainder of the analysis process (Creswell, 1994).

Sandelowski described a threat to truth value, termed "holistic fallacy" (1986, p.32), in which data are made to fit certain categories or are made to look more regular than they are. This risk of inaccurate data categorization was managed by having a content expert and the researcher independently categorize two transcripts, with any differences discussed and resolved. This risk was also managed by purposefully attempting to discount conclusions determined from the data, in relation to the ATF, and by working closely with the thesis committee (Sandelowski, 1986). Additionally, typical and atypical elements of the data regarding participants’ experiences, were included in the descriptions or explanations made regarding the data (Sandelowski, 1986). The researcher recognized that when presented with absent or incomplete participant responses, that assumptions could not be made to predict intentions or explain motivations. For example, because some parents did not comment on a certain issue, such as marital conflict, this did not discount the possibility that they had related thoughts or feelings. However, only existing data, as opposed to assumptions about data were utilized in this study.

The purpose of this study fell within the larger purpose of the original study and therefore was included within the scope of the written consent previously received from the participants. The data set transcripts were carefully managed by utilizing a secured filing system with numerical identification to preserve the confidentiality of the participants from the original study.
**Limitations**

The parents who consented to participate in this study were involved with the Seizure Clinic as a resource at the time of the original data collection, which may have differentiated them from average parents of children with epilepsy. Because parents who have support and resources function and cope more effectively than those who do not, it is likely that the population of parents not studied had greater difficulty managing in general, than the sample of parents who were studied.

**Summary**

A secondary analysis was done on a data set of 12 interviews of parents with a child with epilepsy attending a metropolitan hospital seizure clinic to determine if the ATF accounted for the experiences of those parents. This sample was selected from an existing data set in a descriptive study analyzing the needs and resources of these parents. The interview data were coded according to the ATF and analyzed using latent content analysis. Additionally, ethics and rigor were considered and discussed. The findings of this study are presented in Chapter Four in relation to the Canam ATF.
Chapter Four: Findings

The Canam Adaptive Task Framework (1993) has provided a means for describing the experiences of the study parents and has logically encompassed the interview responses. The difficulties experienced and the coping strategies employed by the study parents in coping with a child’s epilepsy will be summarized within each of the eight adaptive task categories. The summaries are divided into subcategories intended to capture the meanings expressed by the parent sample group and to organize the data. Discussion of the findings will be separately presented in the following chapter.

A number of responses contained in the transcribed interviews fit logically in two or more task categories. For example, the coping strategy of attaining support from the clinic nurse could be represented by the adaptive task “Managing the Child’s Condition on a Day-to-Day Basis” or “Establishing a Support System.” For the purposes of data organization and consistency, only one task category was usually selected, except in relevant situations which are specified in the report that follows.

All comments described in this chapter are based on the perspectives of the parents interviewed, and are not intended to be statements of fact expressed by the writer.

Accepting the Child’s Condition

The adaptive task Accepting the Child’s Condition relates to how the parent perceives or “comes to terms with” (Canam, 1993, p. 47) his/her child’s condition. Parents struggle with denial and disbelief yet also find ways of coping such as ascribing meaning to their child’s situation (Canam, 1993).

Difficulties

The comments made by parents regarding difficulties in accepting the child’s condition related to accepting the diagnosis. Some parents denied their child’s condition of epilepsy by not recognizing and acting on signs of seizures. One parent perceived her spouse as not accepting
their child’s condition when he disciplined their child after misinterpreting seizure activity as inappropriate behavior. This mother made the following statement in reference to her spouse:

He felt that he [child] was just spoiled ... this is a way of not accepting it. It would be far easier to say he’s spoiled than to say that he has something that you have no control over. So, here’s his dad, when he had a seizure, he would try to shake him to make him stop.

One parent found it difficult to accept that his child’s seizure condition was worsening, and felt a sense of loss over his expectations for his child. Numerous factors, including inadequate emotional and information support, combined with an irritable and frustrated child, negatively influenced this parent’s ability to accept his situation:

There are many times I’ve had to rush out in the middle of the night to get her an injection from the hospital to stop the seizures and I can handle her, but at the emotional end of it I’m not very good at it. I find it difficult to accept that she isn’t the cute little person that she was as an infant. She’s very difficult to teach anything to ... I happen to be a teacher, so I find that frustrating.

A few families had extended family members who based their perspectives of the child’s condition on misinformation about the meaning of epilepsy such as its relationship to mental illness or being ‘possessed’. Another parent blamed an adult extended family member, who had epilepsy, for his child having the condition. This may have been an attempt by this parent to find a cause or to ascribe meaning to the epilepsy.

Coping Strategies

A common coping strategy recognized as promoting acceptance of the child’s condition was comparing ones’ own experience to that of another family. Parents also benefited from having a positive outlook toward their family’s situation.

Comparing to others.

A number of families knew people with epilepsy and compared their own experience to that of the other person and/or family. Parents found their coping was promoted, and their perceptions and acceptance about their own situations were improved, when other families’
situations seemed worse than theirs. For example, in support group gatherings, some parents liked to talk to others who had children with more difficulties as it made these parents feel better about their own families’ lives. Various parents found comfort and understanding when meeting other families with a member with epilepsy. A child’s uncle who had a positive experience with epilepsy was able to reassure the family, including the child, thereby helping them to accept the condition. Another family was encouraged by the positive attitude toward epilepsy of this parent’s colleague, whose family member had the condition.

**Maintaining a positive perspective.**

Various families expressed that maintaining a positive attitude promoted success in coping with their child’s condition. They reinforced a positive perspective by discussing epilepsy freely within the family. One family described how their child’s epilepsy diagnosis occurred concurrently with another diagnosis in the same child, yet they felt comfortable and indicated they had the situation under control. In another household, the attitude of family members was that taking medications was a normal, accepted, and nondisruptive part of their daily routine. In another family, one child with epilepsy decided she would minimize the invasiveness of her medication regimen and side effects on her daily activities by taking control and changing her attitude. One mother described how she felt proud in watching a teaching video made with her child, and it helped her gain a sense of control, which facilitated her acceptance of the epilepsy.

The difficulties that parents’ experienced in *Accepting the Child’s Condition* related to not having enough information or emotional support and not feeling in control. Coping strategies they found useful in accepting the child’s condition were: comparing their own childrens’ conditions to those of other children in a worse condition; and maintaining a positive outlook regarding their child’s condition.
Managing the Child’s Condition on a Day-to-Day Basis

The adaptive task Managing the Child’s Condition on a Day-to-Day Basis relates to the ongoing provision of care for the child. Having accurate and complete information and developing collaborative relationships with health care professionals are paramount to managing the child’s condition effectively (Canam, 1993). Because of the numerous difficulties and coping strategies identified by the parents in managing a child’s condition on a daily basis, this task accounted for more data than any of the others.

Difficulties

Many of the parents had difficulty accessing and understanding current, accurate information about their child’s condition and regulating medications and side effects. In addition, parents expressed difficulties with their child’s schooling and learning, effective medical management, and forming helpful relationships with health care professionals.

Accessing information about the child’s condition.

Most parents identified areas in which they did not have enough information to adequately manage their child’s condition. These parents first realized they were receiving inadequate information at the time of their child’s diagnosis and this continued for years after the child was diagnosed. They also reported being poorly informed about the side effects of their childrens’ medications and of having to make decisions before they felt prepared.

Parents had significant concerns about their difficulty in getting information about the nature of their child’s illness. In hospitals other than the major pediatric healthcare facility in British Columbia, parents perceived physicians as unable to provide a medical diagnosis within what they deemed was a reasonable time. Some parents experienced fear that their child had a very serious, acute health problem, such as a subdural hematoma, because they had not received adequate information from which to build a comprehensive understanding. Some children were hospitalized from four to seven days without their parents feeling they had received a good
explanation of their child’s condition. Parents were concerned that even after their child was administered anticonvulsant medication, they were not told the child’s condition was a seizure disorder or epilepsy. Parents had many questions that, when not answered, created greater anxiety. When trying to find out the results of her daughter’s electroencephalogram (EEG), one mother said “I had an awful lot of fishing to do with doctors to find out anything.”

Most parents needed more information regarding medication side effects, in some cases, to better differentiate those side effects from inherent learning disorders. In one family, when a dosage was decreased, the parents said they were not informed that the child was at a greater risk of seizuring, and were surprised and upset when seizuring occurred. The parents in these families felt that they had been inadequately informed about how to manage their childrens’ medication side effects.

Some parents were concerned about having to rely on themselves and manage situations they felt unqualifed to manage. These situations were usually related to not having enough information or not having access to resources at the time of need.

Like the other day when she’d forgotten her pills from the morning, she had already taken her afternoon pills. And I wasn’t sure whether she should then proceed to take another dose. Whether it was too close because she’d be having an evening dose. Or to leave it out or just exactly what to do. And I couldn’t reach anybody in neurology because everybody goes home at four thirty in the afternoon. It’s kind of frustrating to not be able to reach people.

Parents felt inadequately informed, but compelled to make certain decisions.

I look at as recently as this spring and the medication over-dosing that was taking place where we finally had come to a decision at nine o’clock at night or something, standing in our kitchen because we could not get any answer one way or the other to do it [adjust medication dosage].

**Regulation of medications and side effects.**

The children experienced numerous unpleasant effects from their medications, including increased seizure activity if their medications were not regulated. In the process of having the
appropriate medication and dose regulated, children required testing, which involved enduring invasive procedures. In addition to the difficulty of managing the various effects, this process was unpredictable and resulted in various safety concerns for the parents.

The most common medication-induced side effects were nausea, vomiting, and fatigue. One parent thought her child had the flu, then was informed that high serum drug levels likely caused these symptoms. Some parents were concerned that when their child vomited, the medications would not be absorbed and that seizure activity could occur. Children who had side effects affecting their physical stability, such as stumbling, dizziness, and lack of coordination, caused parents concern regarding possible injury. Children had side effects affecting cognitive functioning, such as difficulty concentrating, being slow to respond, and feeling 'dopey,' which in turn affected their ability to learn and participate in activities. They experienced mood changes including depression and crying spells, as well as changes to their appetite in relation to certain medications. Some children became increasingly temperamental and had greater difficulty in managing their own behavior. For example, one child on medication became destructive, while another child became irritable and had temper tantrums. Some of the children experienced headaches.

In general, parents found the process of regulating their children's seizures with medications very frustrating and time consuming. Blood levels, side effects, and seizure effects were monitored in order to detect the effectiveness of various medications and dosages. This process often involved weekly visits to the clinic/hospital, frequent changes in the medications, and re-filling prescriptions. For some children, this resulted in years of unpleasant side effects and seizure activity, and became a discouraging and difficult experience for their parents as well. Most families were frustrated at how long it took for their child to become regulated while trying one drug after another, as many drugs did not work. In the following quotation, the parent
describes his frustration with the lack of success in his child becoming regulated with her medications:

Now as far as I’m concerned none of them work and various times I’ve been tempted to take them off them all together. I’ve been convinced by medical people that the downside of that, of course, is that they could die during the night in their sleep and there is too big a risk to do that. But as far as I’m concerned none of them work.

One parent felt that she had to rely on her own knowledge to know what to ask for regarding problems with the medications, and was concerned that if certain adjustments were not requested, adequate care might not have been provided. Some parents feared making decisions about regulating medications when balancing the side effects of the medication versus their child’s unstable condition, even with guidance from their physician.

Often in the process of regulating the medications, parents had to face and manage unpredictable and difficult situations such as adjusting to changing patterns of seizure activity (i.e. frequency and type). For example, parents described how seizure activity would occur throughout the day, cease for a varying amount of days, and then recur. The parents were disappointed when this happened because it challenged their hope that the seizures may not recur. Another parent described how his/her family had to adjust to varying types of seizures such as petit mal and grand mal.

**School and learning difficulties.**

The difficulties described in this section commonly resulted from the children’s medications and seizures not being regulated, and affecting their schooling and learning. In addition to some parents having concerns about the effects of medications and epilepsy on their children’s progress in school, they often did not know if their child had this difficulty because of epilepsy, medications, an unrelated learning disability, or poor working habits.

Seizure activity was thought to affect coordination and participation in gym class, cause general irritability, and affect a child’s memory, including the ability to spell his/her own name.
But in periods where she’s seizuring a lot, we’ll have more problems, like with um, letter reversals. And I’ll assume that’s just because there’s more disturbance ... like her spelling her name. When she’s not feeling well, she’ll do things like spell her name wrong. There’ll be an extra ‘r’ in there or she’ll forget the ‘e,’ that kind of thing. Which, you know, normally would never happen.

Some parents thought their child had difficulty concentrating and had to work harder than other children who did not have epilepsy. These parents noted that after medication adjustments were made, their child developed some difficulties at school. After further adjustments, such as increasing the dosage or discontinuing certain medications, their child’s behavior and ability to concentrate significantly improved.

We reduced it [the medication] to three pills and all through the school year we had trouble, but we didn’t relate it to the medication because the doctor had said his seizures were under control and we should be able to start reducing it, and gradually take him off now. We didn’t relate it to that. We thought it was, he was having trouble concentrating at school, getting his work done and moody...would cry easily. If you try to help him with his homework and he’d start crying and he would have a really hard time getting it done himself; you would have to stay right on top of him. So I put him on four pills a day and the difference in just two days was just remarkable and his attitude and reactions to things, just within about two days.

The child’s teacher said “You wouldn’t believe the change in him in this last month.” She said “he just tries and works so hard.”

Parents from two families had major concerns regarding the educational content their respective children were missing when having seizures during class. In one incident, a child had a seizure, unbeknownst to the teacher, and when he emerged not able to respond to the teacher, he was punished. Another child needed to repeat a school year due to difficulty with medication regulation, including accidental overdosing, difficulty with concentration, being very drowsy, and being physically unbalanced. One family indicated their child who was tired and depressed, had decreased grades during a difficult period. This family, like others, did not know whether this was as a result of their child’s epilepsy or another unknown physical or emotional cause. In another situation when the parents also did not know the cause of their child’s learning difficulties, academic expectations were lowered by the parents for fear of upsetting her or...
causing a seizure. They eventually believed her schooling difficulties were related to poor work habits and inadequate encouragement.

A few parents had challenging situations to manage with school staff. Not knowing the source of their child’s learning difficulty created uncertainty for the parents in determining how much they expected teachers to encourage their children. One parent felt their school psychologist’s opinion that her child did not have a learning disability was inaccurate. Another parent felt that her public health nurse was slow at getting pertinent information about epilepsy to the teachers. Parents were not only managing their child’s condition, but were also trying to coordinate their child’s care with other professionals.

**Medical management.**

Nearly half of the parents commented that their child’s care was not well managed by their physicians, resulting in a trial and error approach to managing their child’s condition, such as changing medications. Parents believed this was due to their physicians generally being poorly trained in diagnosing and treating epilepsy, and especially being uninformed about alternate medications, treatments, and available resources.

Some parents indicated that no one physician took responsibility for managing their child’s care and that it sometimes took perseverance to be seen, managed, or to have their questions answered. One father said “the doctors are putting out fires rather than trying to do preventative medicine. This should have been a preventative medicine type of thing, it should have been something that is monitored on a regular basis, seeing a doctor.” These parents became dissatisfied with the medical care they received, such as in the use of medical jargon and the failure of physicians to do expected blood tests and adjust medication dosages, when there were clear indications that these were required. One parent found it frustrating that the neurologist would use trial and error rather than initially using a more careful approach. This parent’s concern was based on her belief that the neurologist was inadequately informed about
the optimal treatment regimens for epilepsy.

**Relationships with health care professionals.**

Almost half the parents were troubled by the quality of their parent-physician relationships. Their concerns were related to the perceived indifference of their physicians to their questions and fears. Some of these parents reported that their physicians rushed them through office visits, often did not listen to their concerns, and did not elicit their perspective. Instead these parents felt their physicians were more interested in whether the medications were working and in test results. One parent stated, “the whole problem to me really was the fact that he didn’t seem to care. And from that I got the feeling he didn’t know what he was doing.” Communicating with a physician who did not seem to care reduced this parent’s ability to trust his physician.

**Coping Strategies**

The significant strategies that were recognized as promoting family coping in day-to-day management included parents becoming more informed about epilepsy and making decisions regarding their child’s care. Other strategies included techniques in medication administration.

**Becoming informed.**

Many parents expressed how beneficial it was to learn more about their child’s condition. They found it easier to cope with their child’s condition when they had enough useful information to help them make informed decisions. In order to gather this information, parents used various sources such as books, pamphlets for children and parents, staff in the seizure clinic, and a television documentary. One parent stated, “I think Dr. J.’s book was really helpful. It was a lot to read all that stuff. That, I think, is probably excellent for the new parents.” One father felt he had access to drug information which was very beneficial only because his wife was a pharmacist, while another father recognized that he could have had better information with a more diligent search and therefore coped better with his child’s condition.
Another coping strategy used by parents and related to becoming informed was ‘taking the initiative’ to make decisions. Parents sometimes found that just making a decision, even before they felt ready, made them feel like they were moving forward with a problem. Some parents found they had to first search for resources to become informed in order to make decisions about their situation. On some occasions, when side effects became excessive, bloodwork and blood test results were requested and medication dosages were adjusted by parents, without direction from a physician. In these circumstances, parents used their past experiences and newly acquired knowledge to adjust their child’s dosages. Some parents commented that they appreciated interactions where physicians included them in making decisions involving their child’s treatment and care.

Various other coping strategies were learned by study parents in the process of managing their child’s condition. One family devised a medication cup labeling system that safely allowed their child to independently take her own pills. In another family, the father administered the medications as he coped better than the mother with difficulties their child had when taking her pills.

Other parents booked clinic appointments at the first available time in the day to avoid waiting; another used a private tutor for a child who required extra time and support when learning. In addition, one parent revealed that when he was at work, he could be around people and have a rejuvenating break from the unique stresses of having a child with epilepsy at home. Another parent said that the passage of time helped the most when trying to absorb the large volume of new information to which he had been exposed.

**Forming relationships with health care professionals.**

In general, parents indicated that forming interactive and productive relationships with the health care professionals at the seizure clinic was a very useful coping strategy in promoting day-to-day management. Parents developed positive relationships with the nurse and appreciated
when the physician acknowledged and included their child. An important variable to the parents was that the staff were willing to help with questions and concerns. One parent expressed that the willingness of everyone to help was more important than the actual information received.

Most parents described their interactions with the seizure clinic nurse as very positive in relation to the emotional and informational support they received. Most parents strongly expressed that the nurse was very supportive, reassuring, helpful, and available. Some parents said that she provided a greater degree of comfort to them than anything else. In addition to this emotional support, most parents appreciated the information support the nurse provided. Parents recognized that clear and thoughtful explanations to them and their children by health care professionals were very important in promoting understanding of the seizure disorder and its management.

The majority of positive comments that parents made about their relationships with physicians related to how the physician related to their child. Some of the parents found some of the doctors to be very helpful and supportive in communicating information to themselves and their child about their child’s condition. “He really takes an interest in C. [child]. Like C. isn’t just this little girl that we’re bringing in ... you know, she has a conversation with him too. And that’s really important.”

In summary, through the adaptive task Managing the Child’s Condition on a Day-to-Day Basis, numerous parental difficulties and coping strategies were identified in the data analyzed. The most significant difficulties described were the need for useful, comprehensive information, and the regulation of medications and side effects. Other expressed difficulties were related to their child’s schooling and learning needs, maintaining quality medical management, and relationships with health care professionals. Significant coping strategies included becoming more informed about their child’s condition, making decisions, and developing interactive and productive relationships with health care professionals.
Meeting the Child’s Normal Developmental Needs

According to Canam (1993), the adaptive task Meeting the Child’s Normal Developmental Needs relates to the effect of the health condition on the child’s normal development. The task for parents is to meet the child’s normal developmental needs within the context of the chronic condition, balancing the needs related to the child’s health with the needs to be a normal child (Canam, 1993). All of the parents discussed concerns they had in meeting their child’s developmental needs.

Difficulties

The majority of the parents expressed difficulty in balancing the risk of their child’s physical health with their child’s emotional health. Almost half the sets of parents had concerns about the effect of the epilepsy and the activity limitations on the child’s normal development. Most parents in the study described how they needed to set limits on their children’s activities in order to protect them from injury. However, parents had difficulty establishing these limitations because they also wanted their child to have ‘normal’ childhood experiences.

Limitations were applied to children’s activities such as biking, camping, skiing, football, boxing, horse-back riding, and driving. In one case, a mother limited her child from skiing until the doctor suggested skiing would be safe. At that time, the mother was concerned about the child’s emotional health as the child expressed a sense of loss over missing the years of skiing. Another set of parents were concerned and considered limiting their light-sensitive child from going to movies for fear that a seizure may be triggered. A few parents did not want their child doing certain activities unsupervised; they wanted specific details of their children’s activities. Another parent described not wanting the child to know she was watching her closely. A few parents started to limit their child’s activity when the child developed an interest in higher risk activities or sports, and reduced limitations at times when the child’s condition became under control.
Sometimes the limitations parents established involved conditions under which their child could participate in certain activities. If the conditions were not met, then the child would be prohibited from the activity. For example, in one situation an adolescent was unable to meet her father’s criteria of informing those swimming with her that she had epilepsy. Her father respected that she had difficulty in accepting her health condition and let her make the decision about informing her friends of her epilepsy versus not swimming.

In addition to imposing limitations on their children’s activities, half of the parents in the sample described feeling overprotective. They felt they were more protective and cautious than they would be had their child not had epilepsy. Two sets of parents had differences between the mother and the father in their degree of overprotective behavior and expectations of their child. One of these fathers thought the mother was too overprotective and he felt a need to overcompensate and have higher expectations of their child. Another set of parents described not knowing if they were overprotective of their child because she was an adolescent or because she had epilepsy. Other parents described feeling more overprotective and worried since their child had fallen while seizuring.

Some parents identified specific areas in which they had concerns about their child’s development, such as maintaining good friendships and feeling good about themselves. Various parents described their children as feeling insecure because of teasing at school. For example, one child limited her own participation in activities because of a fear of seizing and another child had greater needs to be close to his mother than other 10 year old children. Various parents described how their children wanted to be like other children.

**Coping Strategies**

Parents identified coping strategies, most of which related to normalization, which guided them in helping their children with epilepsy to meet their developmental needs. Most parents wanted to promote typical activities and a relatively normal environment for their child with
epilepsy. These parents wanted to focus on their child’s abilities, even if they also needed to limit some potentially dangerous activities for their child.

Although comparing ones’ situation to other individuals was a parental coping strategy discussed as promoting acceptance of the child’s condition, it is described here for a slightly different purpose. In order to promote normalization, parents compared their child to other children with epilepsy. In doing this, parents helped their children feel better about themselves and to understand how their experience was likely better than that of others. A mother described how this occurred:

She said to me ... that she wished she didn’t have all these problems. And I said to her, ‘Well, really you know, you don’t have very big problems.’ And I reminded her of a little girl that we’d seen in the neurology clinic one time, who obviously had something like cerebral palsy as well as seizures. She was wearing a helmet and braces on her legs. ‘Why does that little girl have to wear a helmet?’ And I said ‘Probably so that she won’t hurt herself every time she falls down.’ ‘Why does she fall down?’ ‘Because she cannot hold herself up. She has braces on her legs, so obviously her muscles are not as strong as your muscles.’ ‘Oh.’ ‘At least I don’t have to wear a helmet’ she’ll say. So obviously it did sink in.

Two sets of parents wanted their children to meet and be exposed to other children with epilepsy functioning with at least the appearance of normalcy, so they would cope with their own situation better. One of these parents described how the nurse at the child’s camp acknowledged diverse health conditions and promoted a normal environment by distributing the pills to the various children.

An effective means of coping that numerous parents spoke about was making a concerted effort to treat all their children (with and without epilepsy) in a similar way and to have similar expectations of each child. In addition to the purpose of promoting the child’s normalcy, these parents believed that if they had reduced expectations of their children because of their health problem (being treated differently), they may act differently and develop behavioral or learning difficulties. The value of treating their children similarly was sometimes recognized by parents after they became aware of these implications, as in the following parent’s words:
I think maybe, make a special effort to treat them the same way as you treat the other kids. You know, I think this is possibly in school, where we’ve fallen down a bit. You know, we’ve had to correct ourselves. Uh, it’s just something that, a way you fall into naturally. You don’t realize you’re doing it until you start getting bad results or bad feedback, you know. Then you say ‘hey, maybe we should be, you know, coming down a little harder and checking ourselves.’

This parent’s spouse had some insight into the effect of peoples’ attitudes and actions on the normal development of a child with epilepsy when she said “I think people around children can handicap them more than the actual disease itself.” Her husband added “Than the actual handicap.”

By having an understanding of common social expectations for their children’s age group, a third of the parents were more able to anticipate their children’s needs and interpret their behavior. Some of these parents acknowledged when their child required privacy at home after a seizure due to embarrassment, or with the physician regarding a discussion. Other parents recognized how their child’s age would influence their understanding of explanations regarding the progress of their condition. In the following quotation, this mother wanted to promote safety for her child, yet recognized his need to explore and develop. “When he goes skating, he always wears a helmet ... I guess that’s about the only restriction, but we don’t want to restrict any activity because he’s still a growing boy. He has a lot to learn.”

Within the task of Meeting the Child’s Normal Developmental Needs, the study parents found it difficult to find a balance between limiting their child’s activity for safety reasons and being overprotective, and allowing their children to be involved in common childhood experiences. Normalizing the childrens’ experience by focusing on their abilities, comparing them to other children and treating each sibling in the family similarly were effective strategies toward meeting the children’s developmental needs.

Meeting the Developmental Needs of Other Family Members

The adaptive task Meeting the Developmental Needs of Other Family Members represents
the developmental needs of family members other than the child with epilepsy, including those of the siblings, the couple, and the family unit (Canam, 1993).

**Difficulties**

Some parents spoke about difficulties of the siblings of the child with epilepsy and a few parents commented on difficulties in meeting their own needs. All children with epilepsy except one only child, had between one and three siblings. Parents had concerns about neglecting the needs of their children without epilepsy, as the children with epilepsy often required much of these parents’ time. As these parents were busy with clinic appointments, diagnostic testing, and sometimes hospitalizations for their child with epilepsy, nearly half of these siblings were reported to have revealed their need for more attention in various ways. One of these siblings was a four year old boy who did not directly seek attention, but had other ways of getting the attention he needed, as described by his mother: “He’s a very cheerful little guy and he’s not a whiner. He will just start getting into things. He will decide to ‘fix’ something that should not be fixed.” Some of these children were jealous of the attention their siblings with epilepsy received, such as two siblings being jealous that they did not get to go to BC’s Children’s Hospital and miss school. Although some siblings in other families seemed to cope well and did not demonstrate a need for more attention, these parents also wanted to divide their time more evenly among their children.

Regarding parents’ roles, one third of the mothers were identified as responsible for the clinic appointments of the child with epilepsy and most communications with health professionals and teachers. It was difficult for the fathers to attend appointments because of other responsibilities, such as work or caring for other children. One of these mothers expressed concern about her husband feeling uninvolved in their child’s care. Home and family related responsibilities were shared more equally between one couple when the father was not working and had more time. A few sets of parents talked about having differing perspectives regarding
care for their child, yet did not address the implications on their relationship or lifestyle.

**Coping Strategies**

In meeting the developmental needs of the siblings, most parents found value in providing them with more attention and in helping them build an understanding of the condition of the child with epilepsy. Coping strategies used by some of the parents of siblings seeking more attention, included listening to and discussing the siblings' concerns and experiences, and spending more time with all of their children together, for example, reading or bicycling. One sibling needing more attention and likely experiencing jealousy, wished he was the child with epilepsy. His mother tried to comfort him, as illustrated in the following quote: “He [child with epilepsy] would do anything in the world to trade places with you ... he'd be very happy if you would want instead to be going to the doctor’s all the time and taking his medication.” This parent was helping the sibling more realistically understand the experience of the child with epilepsy. Some parents involved their siblings in the experiences of their child with epilepsy and in a few cases this meant having the whole family, including both parents, attend clinic appointments. This enabled these siblings to better understand the experiences of the child with epilepsy.

The developmental needs of siblings were also met when they adopted particular responsibilities in caring for the child with epilepsy. In four families, siblings were involved and protective, encouraged their brother or sister to take medications at the correct time, and informed their parents when a seizure was occurring or impending.

In meeting their own needs, one third of the parents made comments about communicating with and supporting each other. Problems and issues were discussed between these parents and different coping strategies resulted. Some of these families developed coping strategies where parents shared responsibilities. In one of these families, the father became responsible for the administration of the child’s medications as he was more successful with this
task than the mother, while another father participated more in managing the care when he had
time off from work.

To summarize, in the adaptive task *Meeting the Developmental Needs of Other Family Members*, parents identified some difficulties in parenting, but predominantly identified concerns about how the siblings were affected by having a child with epilepsy as a brother or sister. In their coping strategies, these parents paid attention to the needs of their children without epilepsy and they described how they managed those concerns through interactions with all their children.

**Coping with Ongoing Stress and Periodic Crises**

This adaptive task relates to the ongoing stress and crises that parents experience when caring for a child with epilepsy. Demands associated with the illness, hospitalizations, the child’s vulnerability, and the unpredictable nature of the disease are some of the sources of the stress and crises (Canam, 1993).

**Difficulties**

Most of the parents in this study experienced ongoing stress, and for some, it was reinforced by the intermittent crises that occurred. Parents were stressed by the unpredictable nature of epilepsy, and by hospitalizations.

**Unpredictability.**

Although the unpredictability these parents experienced is a significant result of their children with epilepsy being unregulated with their medications (which was discussed within the task regarding managing on a day-to-day basis), it is described here because of the effect on the ongoing stress in these parents’ lives. Some were more distressed about the child being injured during the period of unconsciousness and physical movement of the seizure, than the seizure itself. One of these mothers described how she felt:

The seizures don’t really bother me that much. It’s when ... if she’s going to hurt herself if she has one. Well, she had one in the bath and really banged her head a good one, you know. I worried that she was ... half dead or what? Cause she’d hurt herself. The seizure
was over in a matter of, you know, minutes.

The father responded to the mother's comments with the following:

I'm always more concerned about what happens if she's crossing the middle of the road and has a seizure. This kind of thing. Rather than the seizures themselves. They don't bother me, they don't scare me.

Two separate families had unpredictable and stressful crisis situations arise after their respective children had started on new medications. Both of these families were out of town when continuous seizure activity commenced. These were frightening experiences for the families as their usual healthcare resources were unavailable. In one situation, an excess of medication administered by the physician to control the seizure activity caused the child's breathing to temporarily stop. In another situation, the family recounted an experience during their vacation:

We'd started our holiday ... she went haywire. Lost all control, 20 a day. She had grand mal seizures, virtually all night, all day, she was just a gel. Especially during the night. I didn't know what to do and we were camping. We came back home and I phoned up ... She was just a jelly. She couldn't walk, she couldn't do anything. Because we were away, it wasn't so easy to just bring her back into hospital, really. We were frantic of her falling, falling down. Ya, it was constant 24 hour monitoring really, we didn't sleep for three days because she was, ... every hour.

Parents had additional safety concerns based on incidents where individual children had: fallen while walking and banged his/her head; collapsed; burned a hand accidentally; or been found 'sleep walking'. One family felt they could not trust anyone else to care for their child as her condition was not improving and there was a concern of her falling. Another family had identified that their child being stressed was a precursor to a seizure, so they felt compelled to protect her from stressful situations. The anticipation of these types of situations provided parents with ongoing stress and fear of potential problems.

Hospitalization.

Children from all of these families had visited the hospital for diagnostic testing or for treatment in an emergency situation. These tests included Electroencephalogram, Computerized
Tomography Scan, and sometimes Angiogram or Lumbar Puncture, which are all potentially isolating and/or invasive procedures. Many of these children experienced significant stress regarding these tests, as expressed by this parent:

You made that appointment for her in late November? It was before C.'s [sibling] birthday, in December. And that's when she started crying about it. It wasn't until May that she was to have it. That's the sort of terror she had about that appointment.

Another parent recalled her child’s response to repeated diagnostic testing:

Although I noticed this last little while, I think she's pretty well tested out, as far as you know, tests go. I don't know if anything she'd ever do would ever be accurate when she has to go for a test or, she's in a big knot. We went to get her eyes tested the other day and she started acting up a bit in the morning.

Being turned away from hospitals because the physician did not know how to treat the child provided a tremendous amount of stress for two sets of parents. One child had some distressing tests done in hospital when her parent was not allowed to accompany her and when she did not understand what was happening. Generally the children and parents’ experiences in hospital were stressful and frightening.

**Additional stressors.**

Parenting some of these children was considered stressful for different reasons, such as when one set of parents was criticized for their parenting skills and their child’s health problems by the child’s grandparents. This intensified an already stressful and difficult situation for the parents of this child. Another father described how hard it was to concentrate at work when difficulties were occurring with his child’s health condition. A few of the parents in the study had children, both of whom had chronic conditions; these conditions provided additional demands and stress for parents.

**Coping Strategies**

Strategies identified by parents to promote their coping with unpredictable situations were predominantly to reduce the frequency and risk of situations they feared. As discussed in
previous sections, promoting the regulation of the child’s medications and putting limitations on the child’s activities involved parents controlling and preventing some traumatic events from occurring. Relying on others as support systems, (which will be discussed in the last section entitled “Establishing a Support System”) helped reduce stress. Additionally, to cope with stressful situations, parents identified strategies to promote their coping which included being at the hospital and diagnostic tests with their child in order to provide support.

In summary, within the task *Coping with Ongoing Stress and Periodic Crises*, parents found there were many unpredictable events associated with having a child with epilepsy, most of which created ongoing stress. Hospitalization and diagnostic testing were also major sources of stress. Parents coped with these stresses by trying to prevent situations which would be difficult for their child or the parent to manage and by seeking and providing support.

**Assisting Family Members To Manage Their Feelings**

This adaptive task, *Assisting Family Members to Manage their Feelings* relates to parents working through their own feelings related to their child’s chronic condition, thereby becoming able to help their family members manage their feelings (Canam, 1993).

**Difficulties**

Various family members had difficulties managing their feelings including the parents, the child, and the siblings. The parents described a range of feelings in relation to having a child with epilepsy including fear, concern, frustration, disappointment, and guilt. The fear experienced by these parents was most commonly associated with uncertainty. As described in the previous section, some of these parents were more concerned about the unexpected nature of injuries to their child occurring during, but not caused by, seizure activity. At the time of diagnosis, several sets of parents were fearful about what the cause was or about how the condition would progress. Some other parents feared their child dying in their sleep and another parent worried when her child came home late. The component of not knowing what to expect
was the greatest source of fear for these parents.

Parents in a third of the families in this analysis had fears about their children’s futures. Some feared their children’s career choices being limited and the long-term effects of medication therapy. Other parents feared that epilepsy would affect future family members as they had an extended family member with the condition. In addition, some parents feared what may happen with their child in the future as the medications were not effectively controlling the condition.

A couple of the fathers expressed feeling frustration and disappointment associated with the loss of how they had previously communicated and interacted with their children. One father commented on finding it very frustrating to manage his own emotions regarding the condition of his child. Some parents felt guilty that they were not able to prevent the epilepsy before the child was born and others felt guilty that they did not detect the seizure activity earlier, as illustrated by the following statement:

My guilt was that I didn’t do something sooner. That I didn’t realize what was going on. And that still bothers me. It bothers me today because ... I think now if we could start this thing all over again and had discovered this when she was three, would she be any different today?

The parents in this study described a greater range of feelings in their children with epilepsy than they did for themselves. The children’s feelings identified were anger, resentment, depression, worry, stupidity, guilt, and as with the parents, most commonly, fear. Some of the children experienced fear in having their peers aware of their condition, which was usually identified as a fear of not being accepted. One of these children refused to tell her peers and was resistant to informing her teachers that she had epilepsy. Another of these children felt fatigued more often than her friends, which made her feel different and less recognized. A third child with this fear expressed that she was required by her peers to show her physical ability in order to play with them.

Parents described how a couple of the children with chronic conditions expressed fears
that something bad or harmful might happen to them. Because one of these children did not understand his condition, nor why others would not talk about it, he assumed he would not grow up and was likely dying. Another child feared that she would become like another child she had met who was mentally retarded.

Several children were described by their parents as angry and resentful and additionally, all these children had experienced a difficulty in accepting their condition. One 13 year old girl was frustrated that she must endure her seizure condition and struggled to manage independently following each seizure. Another of these children, who was seven years old, was angry about also having allergies, which increased her frequency of blood tests and medical appointments.

The parents in this study described a number of their children who had difficulty expressing their feelings, and some that additionally expressed feeling depressed. Talking about their feelings was difficult for some children because they could not explain what was happening.

Parents from two families described traumatic experiences of their children without epilepsy. In one of these families, when a sister learned more about her brother's epilepsy and after observing him seizing, believed that he was going to die. In the other family, the parents had been very concerned about their child with epilepsy and felt the sibling was reacting, at least in part, to their concern. A third sibling had felt disadvantaged because the family vacation had been canceled at a time when his sister's seizure activity was uncontrolled.

Coping Strategies

Parents found that strategies such as expressing feelings and changing their perspective of their child’s condition promoted their coping. The most common coping strategy parents used as a couple and as a family was expressing their feelings. Some parents encouraged their children to talk about their fears and concerns and one set of parents in particular took turns having time in the evening with their child to talk about how she felt and was managing. Some of these
parents also encouraged their children to talk to close friends, their doctor, or their nurse.

The parents described other coping strategies that broadened their perspective of the impact of the child’s health condition on their life. One set of parents said that ‘time’ itself was a major factor in coping, as was the awareness that the condition was not life-threatening. Another set of parents commented that being ‘depressed’ about their child’s epilepsy was unfair to the sibling and one additional set of parents said they coped by knowing there was a realistic chance their child’s epilepsy would subside. Other parental coping strategies involved reassuring themselves about the abilities of their child, and on a practical level, one family wired their home with intercoms so they could hear if one of their children called for help. A child who had difficulties expressing his feelings, isolated himself by reading and became more intensely involved in his schoolwork, which was portrayed as a negative coping strategy by his parents.

In summary, in the task *Assisting Family Members to Manage Their Feelings*, the parents commented on how both they and their children most commonly experienced fear. The parents’ fears predominantly related to uncertainty and their children’s futures, and the children’s fears related to causes such as others becoming aware of their condition and ‘feeling different.’ Parents and the children with epilepsy also experienced other feelings such as frustration, anger, and depression. The children with epilepsy had trouble expressing their feelings, and parents encouraged them to talk about their fears and concerns. Parents themselves coped by expressing their feelings.

**Educating Others About the Child’s Condition**

This adaptive task, *Educating Others About the Child’s Condition*, relates to parents talking to their children with epilepsy and other people such as the siblings, extended family members, friends, neighbors, and teachers about their child’s condition. It involves discussing others’ perceptions, answering questions, and providing information in order to promote others’ acceptance and understanding and to promote coping for the child (Canam, 1993).
Difficulties

Parents described significant concerns about discussing their children’s condition with other people, especially the children’s teachers. In addition, communication with extended family and some friends was reported as difficult.

Discussing with teacher.

Most parents were frustrated by the lack of understanding or desire for understanding of teachers in the schools. These parents provided varying degrees of information such as books, pamphlets, and films and often spoke with individual teachers at the beginning of the school year about their children’s condition. Some of these parents met with the teacher during the school year to understand the effect of the seizure activity on the child’s learning and how their child was managing. In these cases, teachers could only occasionally detect changes in the child’s behavior, which parents related to their lack of knowledge. One parent, whose child experienced petit mal seizures, which involved periods of unconsciousness that looked like the child was daydreaming, described her frustration:

Well, when she first started school, I went to the kindergarten class and I spent about an hour with the teacher, explaining to her and I brought a couple of pamphlets with me. And uh, explained to her what was happening and what we were trying to do. At that time we were trying to regulate her. And I also offered to bring some film into the school if they wanted to. But she wasn’t too interested in that. And uh, two months later I went back to see how L. [child] was doing, and she said well, ‘She’s doing great,’ she said. ‘But she seems to have periods where she daydreams.’ She just didn’t seem interested in what I was telling her.

One parent was hesitant to tell her child’s teachers and staff at school that her child had epilepsy. This parent, among several other parents, felt that although some teachers were very supportive when aware of the child’s condition, they were concerned that some of the teachers became overprotective, and did not give the child the firm encouragement they required. Specifically, this parent felt that by inaccurately relating a writing difficulty the child had to his epilepsy, the teacher was labeling her child as different from other children. Another parent
expressed some insight into the response of teachers in the following quotation: “I don’t think they know what it is, they don’t know how to handle it. So they’re kind of afraid to get too close in case something might happen.”

This parent also expressed:

Well, the biggest problem is with the school. With parents that have children going to schools, to try and educate the teachers. You go and you tell them and they’re not listening to what you’re saying. They’re probably devastated by the word epileptic and, you know, they’re thinking about that while you’re trying to, you know, explain farther [sic] to them.

Another parent had difficulty discussing her child’s condition with the school staff and on the advice of her family physician, did not inform them of her child’s epilepsy. The teachers, school nurse, and the principal questioned this parent about the child’s behavior and she struggled in withholding the information. The added concern for this parent was in how her son felt fearful and different and did not understand why others were uninformed of his condition. When this parent was finally able to discuss her child’s condition with the school staff, she found them supportive and helpful. Unlike other parents comments, this parent’s source of difficulty was in the directions she accepted from her physician. A couple of parents felt their children’s teachers had been proactive in understanding the childrens’ situations and responsive to the parents’ concerns.

**Discussing with extended family, friends, and others.**

Nearly one half of the grandparents had difficulty understanding the child’s epilepsy and one quarter of the grandparents believed the children had psychological problems, or were mentally retarded. One parent did not believe there was any stigma connected with epilepsy in his family, although his parents associated it with some form of mental retardation and his sister did not understand the condition. These parents felt that regarding their child’s epilepsy, communications with, and useful support from these family members was difficult.

Some of the children with epilepsy were not comfortable in telling their friends about
their seizures and/or why they took medications. Generally the children who had greater
difficulty were older, predominantly in their early teen age years. A couple of the children were
 teased when their peers became aware of their epilepsy. Although sharing common experiences
and approaches with other parents promoted comfort for some study parents, some people made
inaccurate comments, which the study parents needed to respond to and clarify.

**Coping Strategies**

Effective coping strategies included talking to the child with epilepsy, the siblings, and
friends about the child's condition.

**Discussing with child.**

Parents took a variety of approaches to teaching and communicating with their children
about their epilepsy. Most parents commented that they told their children about their epilepsy,
and responded to specific concerns of the children, although they were not aware of their
children's understanding of their conditions. These parents believed their children were only
comfortable managing information directly related to their own concerns. Several parents were
proactive regarding discussing the epilepsy by informing their children, encouraging them to ask
questions, seeking their understanding, and having discussions with the whole family. Several
parents said that as their children have grown older, their questions and need to understand
developed, and other parents anticipated that as their children grow, they will require additional
information and support.

**Discussing with family.**

The parents in this study discussed the child's epilepsy with other members of the
immediate and extended family to varying depths. In general, they talked about topics such as
the actual seizures, medications, difficulties at school, the child's future, diagnostic testing, and
sought answers from various resources such as brochures, books, and films.

Most parents commented on talking about the child's epilepsy with siblings who had
varying degrees of curiosity and interest. Siblings were taught about epilepsy through discussions, by having questions answered pertaining to a seizure they witnessed, a clinic appointment, a hospital visit or test that was done, medication routines, and activity limitations. The little interest and few questions of some siblings, along with parents not exploring the siblings’ understanding, led these parents to feel unaware of the siblings’ understanding. Some parents felt their unaffected children accepted the epilepsy and engaged in ordinary conversation about epilepsy within the family or with others. In the following quotation, the parent describes a four year old sibling’s playful response to his sister’s seizures:

They were just going to bed and she said ‘I have this really awful taste in my mouth.’ And I said, ‘well go downstairs and get a drink of water and see if that helps’. And [sibling] says, ‘well how come she has that bad taste in her mouth?’ And I said ‘[sibling], that’s a kind of seizure. It’s like sometimes when [child with epilepsy] face moves. Sometime [sic] she gets a bad taste in her mouth or a bad um, a bad smell.’ And um he says ‘Dad, I think I smell a seizure. It smells like a seizure salad.’ I couldn’t believe he’d say that. ‘A seizure salad.’

**Discussing with friends and others.**

Parents described how some of the children with epilepsy told their friends about their seizures and/or why they took medications, and some parents encouraged this communication strategy. Some children had ways of talking about their condition that made it easier, such as by demonstrating a seizure. Parents believed their children’s understanding was promoted when they encouraged them to participate in discussion with their physicians about their conditions. Some parents encouraged the child to speak with the physician independently and others participated in the discussion.

Some parents spoke to their children’s friends and parents about the condition and several parents of children with epilepsy asked the friends to watch the child (their friend) with epilepsy in order to anticipate and protect them from injury. For the parents, this was a means of coping and feeling more comfortable about the safety of their child, although it may have caused feelings of responsibility or stress with the friends. When discussing their family’s experience of
epilepsy with friends and colleagues, parents found that others also had experiences with epilepsy which were comforting.

In summary, in the adaptive task, *Educating Others About the Child’s Condition*, talking to teachers and extended family members were the major difficulties identified. Discussing epilepsy with the child with the condition, the siblings, and selected friends was beneficial for parents in promoting their own coping.

**Establishing a Support System**

This final adaptive task, *Establishing a Support System* refers to parents developing support networks and using available resources in order to maintain well-being, esteem and adjustment of the family to having a child with a chronic condition (Canam, 1993).

**Difficulties**

Parents experienced difficulty in receiving adequate support from other people and difficulty in accessing the services they needed. Some of the parents had difficulties in either finding the support they required, or in accessing the services once they determined what they needed. In addition, some parents felt they would have benefited from having someone else to talk with, such as a health care professional or another parent with a similar experience. These parents sought reassurance, support, and information, although one set of parents were unable to ask other family members to provide help as they were unreliable or uninterested.

One third of the parents had difficulty getting to support group meetings. This was due to excessive distance to travel, working schedules, and having other children at home. In the early stages of their childrens’ epilepsy, some parents were not aware of the Seizure Clinic and one parent in particular felt he should have been informed earlier about this valuable resource.

**Coping Strategies**

The coping strategies identified by these parents included emotional and informational support that they sought from support groups, which they acknowledged was time-specific.
Parents also sought support from friends, family, and various other resources. Informational and emotional support was derived from the clinic nurse, as previously described within the second adaptive task regarding forming relationships with health care professionals.

**Support groups.**

Most parents described how much they benefited from attending parent support group meetings at the Seizure Clinic. They described how listening to other parents was a useful way to learn about caring for their children and manage the condition at a time when they very much needed the support. Not only did parents find comfort in being among others with similar difficulties, but they also found the group to be a valuable source of information regarding the facts and alternatives to their medical care.

A lot of it was speakers and that was interesting and helpful. And it was nice to hear and talk with the other parents on a one-to-one. And it was nice to know that other mothers didn’t feel they were ... you know, other mothers were not sleeping at night. The first year I don’t think I did. Because C. [child] was seizuring a lot at night. You know, I just was ... I was getting up every fifteen, twenty minutes and checking her. And there was [sic] other moms that were doing the same thing. They were in exactly the same position and I think that really helped. I think probably that’s about three quarters of the reason why the mothers go ... the new mothers go, is for that ten minutes coffee time in between when you can talk to another mom or listen to another mom. And there was always mothers who had kids who were ten times sicker than my child ever was. And you think well, on the way home, this could be a heck of a lot worse than it’s ever been. I could have, you know, a little girl who can’t walk and so on ... and, so I think that really helped me too.

Parents gained knowledge (informational support) and emotional support from attending parent support groups. In addition, the aforementioned parent described how comparing her child to other children with more challenging conditions was beneficial in putting her own child’s condition in perspective. A comparison, in this case helped contextualize the problem because it related to how the parent perceived the child and how the parent perceived troubles she had in the care of her child.

Parent support groups were sought out and were useful particularly when the family was still adjusting to the child’s epilepsy, in other words, near the time the diagnosis was made.
However, once their child became regulated with their medications and seizure effects, most parents felt they no longer benefited from the support and information from the group and it became more difficult to prioritize the time required to attend. Additionally, by this time, parents wanted to concentrate on re-establishing the lives of their families, as described by this mother:

At the beginning, I did find it very helpful to talk with different parents that have children with epilepsy. And to hear their problems. And we’d have people...groups coming in and talking about different things. But as time went on and L. [child] was regulated, I found that it was...I’d rather concentrate on getting into a normal stream of life. You know, I found that listening to people that had all these problems all the time wasn’t really helping me. I wanted to get into the swing of our life and get it going.

This child’s mother also felt that the support group was for parents whose children’s conditions were more severe and that her child’s condition was not acute enough. In this previous quotation, the mother described her transition from receiving support and knowledge from the groups, to ‘getting on’ with normalizing family life.

**Friends and family.**

The parents in this study found that various family members and friends were available to provide support. Siblings and friends of the children with epilepsy helped to watch for seizure activity or associated problems. Although some extended family members were not supportive, others were understanding, accepting, and trustworthy in caring for the child with epilepsy.

**Utilizing resources.**

In addition to the support groups and the Seizure Clinic staff which were both used by all 12 families (as previously described under Managing the Child’s Condition on a Day-to-Day Basis), parents utilized various other resources. Films, books, brochures, booklets, and a newsletter provided useful information to parents as well as the school nurse, community health nurse, and some school staff. Brochures included information for parents, children, and friends of children with epilepsy. Some parents found the Neurological Center a useful source of information and one parent organized a new support group in her own community. Some parents
did not access resources that were available to them such as two parents from different families that on hindsight thought they perhaps could have benefited from participating in support groups. One father thought it might have promoted an improved perspective of his child’s condition.

In summary of the task *Establishing a Support System*, some parents had difficulties finding the support they needed or in being able to participate in available resources. Most parents found support groups invaluable and a major source of support for a limited period of time. Parents also sought and received support from friends, family, and numerous other resources.

**Summary**

In this chapter, a description was presented of parental coping with a child’s epilepsy using the Canam ATF to organize parents’ accounts from the 12 family data set. The ATF focuses on difficulties parents encounter in accomplishing a number of tasks associated with their child’s chronic condition and the coping strategies parents’ employ and find useful in resolving these difficulties. All interview data was incorporated into the findings except introductory data relating to the interview process and family structure. In Chapter Five, the major findings will be discussed in relation to the ATF and related literature about parents of children with chronic conditions.
Chapter Five: Discussion and Application

The purpose of this study was to determine if the adaptive tasks from the Canam ATF represented the experiences of 12 sets of the parents of children with epilepsy who participated in the original study. All experiences described by parents were appropriately represented by one or more of the adaptive tasks and will be explored according to the ATF, with a further discussion of the ATF to follow.

Adaptive Task Framework and Parents' Experiences

The process of determining how representative the ATF was of the parents' experiences in this study is similar to using the ATF for clinical assessment of parents in a hospital or community setting. In the clinical context, once parents' experiences have been categorized according to the adaptive tasks, the nurse collaboratively identifies the knowledge, skills, and resources required in relation to the parents' strengths and difficulties, in accomplishing each task. According to each corresponding adaptive task, the major findings (of difficulties and coping strategies) from this study are discussed, with the integration of relevant, supporting literature and the knowledge, skills, and resources needed by the parents.

Managing the Child's Condition on a Day-to-Day Basis

One of the adaptive tasks replete with data was 'Managing the Child’s Condition on a Day-to-Day Basis.' Issues such as inadequate information, the regulation of medications, and relationships with the health care professionals were described by the parents. As the parents in this study cared for their children at home, they were responsible for all of their children's needs and therefore required a good understanding of the child’s diagnosis and ongoing condition. They had significant concerns over the lack of information they received, which caused stress and anxiety beyond the concerns related to the condition itself. Diehl, Moffitt, and Wade (1991) described the caregivers of medically complex children as overwhelmed with the frustration of gathering information about their child’s condition, which was the second of 12 areas identified.
as major needs for these parents. Needing information about managing at home and expectations for the future were concerns frequently repeated. Either inadequate information was provided or the medical jargon used inhibited parents from understanding. Ahmann (1994b) has suggested that in the practice of family-centered care, that families are viewed as the center of care, and in this position, they require knowledge and understanding of their child’s condition.

The majority of parents found the process of having the medications regulated very difficult as it involved numerous unpleasant effects and seizure activity. The day-to-day lives of these parents and children were disrupted with effects from the medications such as nausea, fatigue, lack of coordination, and depression. The children’s abilities to participate in peer and family activities and progress in school was sometimes limited. Families were unable to function in their usual manner, or as they perceived others managing. The difficulty associated with medication regulation related to events in their lives being unpredictable and hard if not impossible to control, the perception of not having choices, and the sense of unfairness for the child having to endure the related effects which affected their ability to function in life. In a qualitative study of ten families, Jerrett (1994) described the parents’ experience in caring for their children with juvenile arthritis with “the child’s therapy became an indelible and inescapable part of the parents’ reality” (p. 1053). The unregulated medication ‘therapy’ for these children with epilepsy was a burden for the parents on an ongoing basis. Diehl et al. (1991) reported parents comments of feeling responsible to make decisions about medication administration between different physicians’ advice, while respecting the daily functioning of their child.

Although the study parents commented on how positive their interactions were with the Seizure Clinic nurse and physician in terms of providing information and support, they felt that other physicians did not listen to, nor seem interested in their concerns. Diehl et al., (1991) had similar findings, as parents felt the physicians had a different purpose in their children’s care than
their own, and that the parents needed to be well informed when discussing issues with the physicians. Leff and Walizer (1992) described the difference between the ‘Professional View’ and the ‘Parental View’ regarding conflicting approaches and expectations of healthcare partnerships and decision-making. Darling (1983) described the socialization of parenting as having a powerful influence on how parents view child development and parental behavior. Physicians and other health care professionals develop their views from their education, professional experience, and nonprofessional life experience. Various reasons were identified for the differing ‘world view’ of these two groups of people such as social stigma, professional dominance, bureaucratic context, and blaming the victim (Darling, 1983). In spite of these variables, the potential for core human contact between parent and professional may promote a strength and cohesion to the relationship (Leff & Walizer, 1992). Family-centered care provides a philosophy from which healthcare professionals and families may understand the differing realities of those involved in the care of the child.

Robinson and Thorne (1984) described three stages of health care relationships as Naive Trusting, Disenchantment, and Guarded Alliance, the first two of which are recognized in this situation. Naive trusting occurs when the family, often uninformed, believes health care professionals will provide necessary and appropriate care. Patient/parental expectations of health care to be received may not be realized because their illness-management perspective is different from the disease-focus of the health care professional. This situation may create discomfort and conflict, hence the second stage of ‘disenchantment.’ The parents in this secondary analysis study described when they attended appointments, how the physicians often dealt with issues of their own concern, rather than of parent need.

The parents in this study had strong needs to be heard and to have their concerns addressed. Parents’ needs are more likely to be acknowledged and addressed through the application of Canam’s ATF as it is situated within the domain of the parent (Canam, 1993).
Knowledge needed by the study parents in order to accomplish the task, ‘Managing the Child’s Condition on a Day-to-Day Basis’ was diverse. In order to understand and make decisions about their child’s day-to-day care, the parents needed information on epilepsy; what it meant, its cause, the difference between seizuring and epilepsy, and common medical terminology. Of great importance, this information was needed early upon becoming involved with the health care system, so parents could begin to manage their lives, and so fears based on the unknown could be minimized. They needed information on the long-term effects of epilepsy and the medications, and the child’s future ability to function generally in life. Knowledge the parents required regarding medications included information about the medications, time between starting a new drug and the effect, development of tolerance to medications, and common side effects and their management. They required knowledge that medications had varying effects on different people and may or may not be effective with their child, that drugs and dosages may require adjustment and that this may take time. Parents also required information on normal growth and development of children.

Skills needed by these parents in order to accomplish this task included assertiveness (in asking questions, in asking for clarification, in seeking information until they were satisfied), communication, and decision-making. Parents needed to know how to monitor medications, doses, side effects, seizure activity, along with triggers to seizures. They required the ability to recognize the difference between medication actions and side effects, which involved an understanding of their child’s normal behavior.

Resources needed by parents included current, non-technical books and literature, information resources in waiting rooms, clinics, and medical offices, and counseling services for school problems, study habits, and general concerns. These parents needed services in outlying communities, and an awareness of the BCCH Seizure Clinic. Although during the time of the study all parents lived in the Lower Mainland, some had previously lived in outlying areas and
were very aware of the lack of resources.

**Meeting the Child’s Normal Developmental Needs**

Another Adaptive Task replete with data was ‘Meeting the Child’s Normal Developmental Needs.’ Many parents protected their child from injury by setting activity limitations as they feared injury to their child. In addition, these parents were overprotective by not encouraging their children in activities or schoolwork. These parents feared having unrealistically high or unfair scholastic and athletic expectations of their child with epilepsy versus their other children. Some parents feared their expectations could be interpreted by the child as ‘pressure’ and could cause a stress-induced seizure.

It is not uncommon for parents, teachers, or others to discourage active participation by children with special needs in normal life experiences due to fears about the child’s safety and the ridicule or stigma that may come from insensitive peers or adults. (Patterson & Geber, 1991, p. 152)

Parents in this study commented on limiting their child’s activities in order to prevent further injury rather than to reduce chance of ridicule, although this may have also been a motivating factor.

In contrast, many parents wanted to provide normalcy to their child’s life to promote his/her development, where normalcy is defined as conforming to a standard or pattern as perceived by the definer. The use of normalization by families as a coping strategy for children with chronic conditions is well described in the literature (Burkhart, 1993; Deatrick, et al., 1988; Knafl & Deatrick, 1986; Robinson, 1993; Scharer & Dixon, 1989; Sharkey, 1995; Thorne, Radford, & Armstrong, 1997). Having normal life experiences promotes self esteem, development of identity, and a sense of accomplishment (Patterson & Geber, 1991). The technique of normalization may be behavioral, as described by Knafl and Deatrick (1986), or it may be related to an attitude or way of thinking (Robinson, 1993).

In a concept analysis, Knafl and Deatrick (1986) described five parental behaviors
associated with normalization, the first of which is engaging in ‘usual parenting activities.’ Parents in this secondary analysis study demonstrated this behavior by focusing on their child’s abilities, having similar expectations of all their children, and experiencing activities together as a family. Another parental behavior, ‘controlling information’ (Knafl & Deatrick, 1986) was used by these parents to normalize the child (to be discussed within the context of educating other people about the medical condition). A third parental behavior, ‘limiting contacts with similarly situated others’ (Knafl & Deatrick, 1986), was used to normalize the family (to be discussed within the context of establishing a support system). A normalization strategy that was used by the study parents and not encompassed by Knafl and Deatrick’s normalization behaviors was comparing their child to other less fortunate children and to children who had similar conditions, which resulted in parents feeling more positive or accepting of their child’s condition (to be addressed later in this chapter).

Based on the type and frequency of parental comments, the desire and need for normalization was a central theme with the parents in this study. Social acceptance for one’s child or family is one purpose for normalization and a strong motivating factor. Apart from the study participants, many people in general have a need to feel and be perceived as being similar to others. In school age children and adolescents, there is a developmental need and desire to conform to a peer group (Wong, 1995), and to some degree, for many people this need and desire tends to last throughout a lifetime.

Feeling a sense of control over one’s life because of the ability to create ‘normal’ is another purpose for normalization. The representation of normalization is a societal construct and is based on what is most common in a given context as opposed to any particular standard. There is no single, defined representation of normal. Through experiences with other people, even strangers, or one person, individuals can develop the ability to reframe the context of their lives and significantly alter their perceptions. Robinson (1993) described the process of
reframing as shifting the focus of how one perceives a situation. In this process, one adopts or creates reference points from which to situate one's own experience.

A third purpose to normalization is to create personal meaning in family life because how people see normalization is based on personal interpretation. Jerrett (1994) described how parents perceived an understanding of their experience in caring for their child through their own frame of reference, which became their new reality, and made their experience more meaningful. The interpretation of circumstances, others' perspectives, and what constitutes 'normal' are processed through people's own selves and experiences. This 'filter' through which people perceive what is 'normal,' influences their attempts to process and define normalcy. Parents believing at a conscious or subconscious level that their child is fundamentally different from other children, and therefore not 'normal,' will influence their acceptance of their child's condition. It will also influence their ability to 'normalize' their family, and ultimately affect their child's ability to feel normal and develop a healthy self-image.

The various purposes for normalization which have been identified as social acceptance, the need for control, and creating personal meaning (Jerrett, 1994), can all increase the ability to cope with one's life. What is important is not so much how one defines normalization, but the ability to satisfy a need for it through an individual's personal experiences. The use of normalization as a coping strategy is significant for parents of children with epilepsy because of the lack of control parents can experience with poorly regulated medications and living with uncertainty. The ability of people to create change in their perception of reality, acknowledges the tremendous power people potentially have in controlling their experiences.

Parents tried to both protect their child and to promote normalcy, but they found this balance difficult because they perceived both 'protecting' and 'normalcy' as different, yet equally important to their child's well-being. The sense of responsibility associated with making these decisions about their child's activities and the degree of protecting or encouraging them,
was remarkable. The responsibilities of caring for children with special needs go well beyond the usual responsibilities of supporting healthy children. When making decisions about caring for one’s child, imposing too many activity limitations or inadequate encouragement, risked the child feeling incapable or different from others. There was also the risk of imposing inadequate activity limitations or ‘pushing’ the child beyond his/her ability which could respectively result in physical injury or excessive emotional stress to the child.

Children’s sense of self is influenced not only by their parents’ behavior, but also by how they interpret their parent’s beliefs and attitudes (Wong, 1995), as discussed earlier in this chapter. In this study, a few of the children who parents reported as either feeling different from their peers or having difficulty accepting their condition also had parents or grandparents who either did not accept, or did not understand epilepsy. The decisions parents were making had significant implications for their children’s lives. Some parents acknowledged this responsibility in their expressions of difficulty in finding this balance. Others commented on limitations, or feeling overprotective, yet their experience in making these decisions and their perception of this responsibility was not expressed. It is possible that either these parents had struggled over the decisions without expressing the struggle, or they were unaware of the implications of their decisions. Youngblut, Brennan, and Swegart (1994) did a study with a convenience sample of ten families who described decisions and problems they faced in caring for medically fragile children. The parents identified decisions involving the competing demands of a child’s condition with their normal developmental needs, such as between “a nap and therapy, sending the child to day camp, and deciding whether to move the child to a youth bed or to modify the child’s crib” (p. 465-466). The parents in the Young et al. study described similar difficulties with decision-making and finding a balance in the lives of their children, as the parents in this study.

The knowledge needed by the secondary analysis study parents in order to accomplish the
task ‘Meeting the Child’s Normal Developmental Needs’ included growth and developmental norms (e. g. need for independence) and an understanding of the importance of normalization. Parents also needed information regarding the risks of injury associated with the child’s seizure type, and how well regulated their child’s condition was. In addition, parents needed knowledge to recognize early that their child’s learning difficulty may or may not have been related to medications.

Skills needed by parents involved managing their own feelings regarding their acceptance of the child’s condition and seeking clarity on their rationales for setting limits on their child’s activity between logical risks and their own fears. In addition, parents needed the ability to reframe (Robinson, 1993) how they saw their child’s condition and they required the skill of decision-making and sharing that decision-making. Resources included access to family members for support in making decisions and access to parent support group so parents could talk regarding their own perspective of family life.

Establishing a Support System

Within the adaptive task ‘Establishing a Support System,’ the study parents described how much they valued the social support they received from the clinic nurse and the support groups. Diehl et al. (1991) described support groups as an invaluable service, and as one of the strong, recurrent themes in their study of parents of children with medically complex needs. They suggested that parents who have managed emotional issues better than other parents were often members of support groups. These families “defined their needs more specifically, worked on problem solving, and were able to put away personal guilt and anger” (p. 178). Patterson and Geber (1991) suggested that social support promoted competence and positive mental health. They also identified three categories of support including ‘emotional support,’ which represented the feeling that we are connected with another person and are cared about. ‘Informational support’ represented help in solving problems and finding resources, and ‘instrumental support’
which represented functional help with various jobs, as performing errands, shopping, and completing chores. The families in the secondary analysis study commented on receiving valuable emotional and informational support from the clinic nurse. Some parents felt they needed more support, yet were unaware of resources or were unable to access the services.

Parents attended support groups for emotional support: to relate to and connect with other parents in similar situations; and share ideas about how to manage their child’s condition. A second purpose was for informational support, and a third purpose for attending the groups was so parents could compare their own life situations to those of others in more challenging situations. This improved the parents’ ability to perceive their own situation as more manageable. Although this coping behavior of ‘comparing’ occurs at support groups, a paradox occurs between the first and third purposes. The paradox is the need of the parent to connect with others in a similar situation, yet to also distance him/her self from those in ‘worse’ situations. In order to gain a sense of the ability to manage by talking with or observing others with children with greater health challenges, a detachment or disconnection occurs. This attitude or behavior is therapeutic and exists in lieu of the feeling of closeness that would usually accompany ‘support’ as described by Patterson and Geber (1991). Disassociating oneself from another to make another seem different to oneself and situation, may involve perceiving the other as not normal.

At the time when parents were feeling more comfortable in managing their child’s condition, they decreased and/or terminated their involvement with the support group. Knafl and Deatrick (1986) in their description of parental behaviors associated with normalization, described this as ‘limiting contacts with similarly situated others.’ The main reason parents both compared themselves to others in more challenging situations and reduced their support group involvement was to promote normalcy to their own lives. The process of normalization helps to define who we are, and are not, and helps to define what is normal, and what is not. As
described above, through this process, parents gain control and become empowered, and their life situations may become more meaningful.

Knowledge needed by the study parents in order to accomplish this task of establishing support included information regarding the benefits and availability of parent support groups. Skills required included the ability to independently access available resources and to seek social interaction. Resources needed included their own family, friends, or teachers, other parents with similar situations or those who lived nearby, trustworthy people who were willing to help, support groups in outlying communities, and written materials and newsletters.

Coping with Ongoing Stress and Periodic Crises and Assisting Family Members to Manage their Feelings

Uncertainty was the greatest source of stress for parents and was based on fear, the most common feeling experienced by parents. The uncertainty was about what may happen to the parents’ children during a seizure, and the childrens’ future. These data were documented in the adaptive tasks ‘Coping with Ongoing Stress and Periodic Crises’ and ‘Assisting Family Members to Manage their Feelings’. Sharkey (1995) described uncertainty about a chronically ill child’s future as possibly being “the single most difficult stressor for which parents must learn to cope” (1995, p. 38). According to Sharkey, uncertainty begins with the diagnosis of the child’s condition and the parents not understanding the implications of the condition, nor the expectation for the future. It affects how the family functions as a unit and plans for family activities. In a study describing the feelings of parents with children with chronic health conditions, Canam (1987) also described fear as the most frequently expressed feeling. Factors influencing these parents’ experiences of fear were the severity of the child’s condition, the amount of control the parents perceived they had, and their perception of the adequacy of their understanding of the child’s condition. Uncertainty is based on doubt, hesitancy, indeterminacy, indefiniteness, and unpredictability (Webster, 1989), and could clearly result in feelings of lack
of control.

Knowledge was needed by the study parents in order to accomplish the tasks, ‘Cope with Ongoing Stress and Periodic Crises’ and ‘Assisting Family Members to Manage their Feelings.’ That knowledge included anticipating crises and being prepared, and teaching siblings how to react to seizure activity. Parents needed information on preparing their child for hospitalization and diagnostic testing, and confirming in advance that parents may accompany the child. Parents needed information on developing positive associations to the hospital and diagnostic testing areas with their child. Skills needed included learning to manage with uncertainty, to be able to encourage their children to talk about their feelings, and to be able to teach the child how to talk to others about their condition (Canam, 1987). Resources include books and teaching materials regarding hospitalization as well as talking with others with positive hospitalization experiences.

Educating Others About the Child’s Condition

Parents’ greatest concern identified from the adaptive task ‘Educating Others About the Child’s Condition’ was their perception that the teachers were not well informed or interested to know more about the child’s condition. The reason for the teachers’ lack of interest may have been related to their life experiences based on exposure to misinformation and stigmatization of those with chronic conditions or conditions not understood. On the other hand, their disinterest could be based on excessive workload, or may have been a perception of the parent, but not the perception of the teacher. This area requires further study.

As another concern, although some parents wanted the teachers to know about their child’s epilepsy, some parents did not want to inform the teachers or others for fear of their child being labeled, treated differently, or stigmatized. Knafl and Deatrick (1986) described the normalization behavior ‘controlling information’ which gave parents some choice in their child’s exposure to potentially stigmatizing responses of others.

Parents also had difficulties in talking to extended family members, particularly
grandparents about the child’s condition because of the family members’ lack of understanding of epilepsy. Loebig (1990) did an exploratory study about mothers’ assessments of the impact on the family of a child with spina bifida. She reported conflicts between the parents and the grandparents regarding discipline and child independence. In this secondary analysis study, some of the grandparents had beliefs about epilepsy which were founded in misinformation, and reflected the lack of knowledge of epilepsy from a previous era. It is likely that the grandparents described in the Loebig study were influenced by their generation and their own parenting experiences as well. Nevertheless, the grandparents were a potential source of support not available to many of the families in this secondary analysis.

Knowledge needed by the study parents in order to accomplish this task about educating others was a thorough understanding of epilepsy, its treatment (medications), and the normal developmental needs of the child. The teacher is an important potential ally in determining how the child’s learning is affected by medication/seizures and efforts to promote the child’s learning.

Skills included communicating with the teacher about the child’s epilepsy in order to broaden the teachers’ understanding of the child. Articulating what epilepsy was, and being comfortable dispelling myths about epilepsy were also important skills. Part of normalizing epilepsy within the family, involved talking freely among the child with epilepsy, the siblings, and the parents about feelings, concerns, questions, and daily routines. Resources included accessing teaching materials (pamphlets, books, videos) to share with extended family members, teachers, friends or others to promote their understanding of epilepsy.

Adaptive Task Framework

The eight adaptive tasks of the Canam ATF were useful categories from which to examine the interview data to identify common difficulties and coping strategies used by parents in coping with their child’s epilepsy. Some adaptive tasks were replete with data regarding parents’ experiences and other adaptive tasks included less data.
In addition to each adaptive task representing a particular focus, there were similarities between the eight task categories, indicating that the tasks are not mutually exclusive. Some of the difficulties expressed by parents were relevant for more than one adaptive task and two examples will be identified. The first example is the coping strategy of normalization which had relevance within the tasks of ‘Accepting the Child’s Condition,’ ‘Meeting the Child’s Normal Developmental Needs,’ ‘Meeting the Developmental Needs of Family Members,’ ‘Educating Others,’ and ‘Establishing Support Systems.’ It arose in both the context of normalizing the family’s experience, and normalizing the child with epilepsy or the siblings’ experience. The second example is how parents’ experiences with unpredictable events and feelings of uncertainty had relevance for the adaptive tasks of ‘Coping with Ongoing Stress and Crises’, and ‘Assisting Family Members to Manage their Feelings.’ The varying contexts from which these issues have been addressed highlight the impact they had with the parents. A disadvantage to the ATF, is that the overlap of the focus of each task may create difficulty in the organization of data and may cause inconsistencies between those applying the ATF. However, as previously indicated, the ATF provided a means to effectively organize this study data, and also provided a means from which the aforementioned, specific issues have been identified and discussed.

An important point regarding the application of the ATF is that the nurse involves the parents implicitly in determining which adaptive tasks are unmet and the knowledge, skills, and resources required in order to complete the task. The framework provides a basis from which questions and conversation may occur between the parent and nurse on an ongoing basis. Because the framework is based on parental tasks, described as important by the study parents and the literature, the recognition of the parents’ issues are promoted, as opposed to issues deemed important by the nurse. A limitation of the ATF would be if the nurse used this framework without full consideration of the parents’ perspective regarding difficulties and needs.

The purpose of the ATF is to assist the nurse in his/her practice in caring for families with
a child with a chronic condition. The role of the nurse with families is to empower and support them in managing their child’s chronic health condition. Through a philosophy of family-centered care, nurses recognize how they may interact with parents to teach and support them so they may learn to become empowered, and in control of their lives; this was important to the study parents. In addition, nurses use the ATF in order to structure their thinking about how to help families with a chronic condition. Parents have their strengths recognized, their needs identified, and may be assisted in acquiring the knowledge skills, and resources to meet their needs through the application of the ATF. This increases their confidence and competence thereby being consistent with the philosophy of family-centered care. Parents develop greater independence in the management of their child’s care, and learn skills in caring for their children (Johnson, Jeppson, & Redburn, 1992).

This framework gives practical and credible direction to the nurse in that the difficulties commonly associated with caring for a child with a chronic condition are part of the nurse’s knowledge base, as are the coping strategies that parents find helpful in resolving those difficulties. This is a benefit in comparison to two models (Clark, Striefel, Bedlington, & Naiman, 1989; Ferraro & Longo, 1985) which have a general purpose of promoting coping in families. In these models, however, direction is not given to identify or manage common difficulties associated with chronic conditions.

A factor in the usefulness of the ATF is that the nurse needs to have developed knowledge and understanding of the framework in order to use it effectively. Without this knowledge, the nurse would have less ability to identify difficulties and coping strategies, and less ability to help parents identify required knowledge, skills, and resources.

As described throughout the discussion in relation to the interview data and the literature, the issues identified by these study parents have also been identified by parents of children with various other chronic conditions. Therefore, since the ATF represents the experiences of the
parents of children with epilepsy, it is concluded that this framework is credible when applied to parents of children with other chronic conditions. The underlying notion that families of children with chronic conditions face common issues regardless of their medical diagnosis is supported in the literature (Canam, 1993; Stein & Jessop, 1989; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989).

Summary

The ATF and the literature were utilized to describe and explain the major findings relating to the experiences of the parents in this secondary analysis study. By being representative of these parents' experiences, the ATF is considered to be credible in assessing the parents of a child with epilepsy and other chronic conditions. The ATF provides direction to the nurse in identifying the needs for knowledge, skills, and resources of parents so the nurse may support and empower the parents in accomplishing each task. In this study, the ATF provided direction for the identification of the knowledge, skills, and resources needed by the study parents.

Similarities were identified between the tasks in relation to this study data. The role of the nurse was described in relation to family-centered care through the ATF: of significance in the use of the framework, is parental involvement. The ATF provides practical direction through the knowledge base afforded the nurse regarding the identification of difficulties and coping strategies. This research study will be summarized in the following chapter, along with final conclusions and implications for nursing practice, education, and research.
Chapter Six: Summary, Conclusions, and Implications

Summary

It is well documented that the impact of a child’s chronic health condition on the family is significant. In order for children with long-term health problems to have their well-being maintained and mental health risks minimized, their parents and siblings must also have their needs addressed. By understanding how parents adapt, and providing them with resources and support, nurses are better able to assist parents in managing their children’s health.

This qualitative study is a secondary analysis of an existing data set generated from a descriptive study of parents of children with epilepsy. The conceptual framework that provided a basis for this study was the Canam Adaptive Task Framework (ATF) and the purpose of this study was to apply the ATF to a sample of narrative data derived from these parents to determine if the adaptive tasks effectively represented their experiences. The ATF is based on the premise that there is a series of eight adaptive tasks common to parents of children with chronic conditions, regardless of the specific medical condition. The ATF is an organizing structure that guides the nurse in not only identifying the common issues, but in determining the knowledge, skills, and resources required for the parent to cope. In determining the representativeness of the ATF with this condition-specific data set, the credibility of the ATF with parents of children with chronic conditions was increased. Therefore, the research question was: Does the Canam ATF fully accommodate the experience of parental coping with a child’s epilepsy within an existing set of interview data?

In the current study, 12 families were randomly selected from the original, convenience sample of 20 families from the Seizure Clinic at BC’s Children’s Hospital. Data were analyzed using latent content analysis (Morse & Field, 1995) according to the appropriate adaptive task categories. Reliability included having an assistant and the researcher co-analyze two transcripts at the beginning of the analysis process.
The findings demonstrate that the ATF is a credible means of providing the nurse with practical direction to collaborate with parents in identifying the parents' difficulties and coping strategies. More specifically, the parents had difficulty accessing adequate, useful information about their child's condition, developing effective working relationships with health care professionals, communicating with their children's teachers, and promoting normal family life.

The Canam ATF provided a means for describing and organizing the findings, and fully accommodated the experience of parental coping with a child's epilepsy. The major findings of the parents' experiences were explored and supported through the literature and the assessment and identification of parental needs for knowledge, skills, and resources were described from the direction given by the ATF. In addition, the ATF was discussed in the context of family-centered care, and of parents with children with various chronic conditions, in addition to epilepsy. A major conclusion is that by being representative of these parents' experiences, the evidence is strengthened that the ATF is effective in identifying the capabilities and difficulties of parents of a child with epilepsy, and in facilitating the acquisition of parental coping strategies.

As nurses become more knowledgeable regarding adaptive tasks and parental coping, they need to utilize and share that knowledge. This study has contributed to the knowledge base associated with the use of the Canam ATF in empowering and supporting families to better cope with a child with a chronic health condition. Conclusions and implications for nursing practice, education, and research are presented in the balance of this chapter.

**Study Conclusions**

The following are the major conclusions of this study:

1. Parents require information about epilepsy as close to the time they become involved with the healthcare system as possible. They also require information about: the medications; communicating with healthcare professionals, teachers, and friends; and normal childhood
development.

2. Parents of a child with epilepsy and healthcare professionals need to work together more consistently and effectively towards similar goals.

3. Parents of children with epilepsy are concerned about the need to normalize their children’s and family’s lives.

4. Parents have more fear and stress about the unpredictability of events occurring during or following seizure activity than the seizure itself.

5. Extended family members were often not able to listen to and be supportive of the parents.

6. Teachers were often not able to listen to and be supportive of the parents or integrate understanding of epilepsy into helping children learn and socialize at school.

7. The Canam ATF represented the experience of parental coping with a child’s epilepsy within the study sample originally drawn to investigate the needs of these parents in coping, and their resources utilized.

8. The Canam ATF gives credible and practical direction in assessing and supporting parents of children with epilepsy.

9. A contribution has been made to the knowledge concerning the use of Canam’s ATF with families of children with chronic conditions.

**Implications for Nursing Practice**

When the nurse applies the ATF in practice, parental strengths and difficulties would first be identified collaboratively with the parent to determine if (s)he was accomplishing each task. This acknowledgement of successful coping reinforces the effectiveness of their abilities and promotes self-reliance in parents. Also in collaboration with parents, the nurse promotes parents’ acquisition of required knowledge, skills, and resources to facilitate their accomplishment of incomplete tasks. Important information may involve different types of seizures, medications, and common growth and developmental needs of children. Skills that parents require may
include decision-making, priority setting, values clarification, communication skills, and the ability to develop effective partnerships with healthcare providers. Resources needed by parents may be support from the school system, direction from nurses regarding effective communication strategies with teachers, and the development of satisfying working relationships. In order to better support parents, nurses could provide resources for schools and teachers with condition-specific information regarding ‘What Teachers Need to Know’ about epilepsy. This question sheet could direct teachers to ask parents relevant, useful information regarding the type of seizure and how it manifests, and management issues for the classroom and outings. Further ideas include whether the seizures are regulated, concerns regarding learning, and how the child feels following a seizure, such as having a need for sleep.

**Implications for Nursing Education**

Baccalaureate nursing students need to develop a basic understanding of the parental experience of coping with a child’s chronic health condition and may do so by learning about family-centered care, how guiding frameworks may be useful, and the concerns of parents of children with epilepsy. Developing an understanding of the philosophy of family-centered care provides a strong base for empowering interactions of students and future nurses with parents of children with chronic conditions. Students also require knowledge about the concerns of parents of children with epilepsy, such as the need for information about the condition, information regarding the medications, relationships with health care professionals, and communicating with the teachers.

Using the ATF and other frameworks for assessing and supporting families of children with chronic conditions familiarizes students with various approaches to nursing assessment and care. Students should be assisted in exploring the underlying assumptions of such frameworks, particularly in the ways in which they promote or detract from family-centered care. There is current debate in nursing regarding the use of prescriptive frameworks in comparison to an
unstructured, nonlinear approach to nursing, described as a tension between the natural science paradigm and the health promotion paradigm, respectively (Lindsay & Hartrick, 1996). Students should examine positive and negative features of these paradigms but also recognize that critical to the practice of nursing is the need for familiarity of practice-based research and a strong knowledge base. The ATF can be promoted as a way for nurses to organize their knowledge about family coping with a child's condition with the focus on parents' experiences, perceptions, and needs, as opposed to those of health care professionals (Canam, 1993).

**Implications for Nursing Research**

The ATF could be utilized as a format for interviews to identify the issues of parents of children with chronic conditions not well understood in terms of the experience of the family. Other studies could explore responses of teachers to children with epilepsy, or more generally to children with chronic conditions, to determine why they are not perceived as supportive to parents. Additionally, future studies could focus on nurses and physicians' perceptions of their roles regarding supportive behaviors towards families. It is interesting to note that while we know a lot about difficulties parents have with their children's chronic conditions, and coping strategies that are effective in addressing those difficulties, the literature indicates that parents continue to report similar difficulties, as parents did in this study. It would be useful to determine what nurses do that helps families cope. In other words, we need to switch from studying parents, to studying other members of the health care team to elicit their perceptions of issues and strategies for helping families manage their own or a family members' chronic condition.

**Conclusion**

In order for children with chronic health conditions to experience positive emotional health, they, as well as with their parents and siblings, must have their needs addressed (Patterson and Geber, 1991). The credibility of the Canam ATF, to guide the nurse in empowering families
to effectively cope with their children with a chronic health condition, is bolstered by effectively representing the experiences of parents coping with their children’s epilepsy. Nurses as advocates for their patients, are responsible to understand and respond to the needs of families (Ahmann, 1994b). The quality of life for these families is enhanced when nurses practicing family-centered care through the ATF, empower families by promoting confidence, competence, and independence.
References


Stein, R. E. K., & Jessop, D. J. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. Social Science in Medicine, 29(6), 769-778.


Appendix A: Letter to Physicians

The University of British Columbia
School of Nursing
206 - 2211 Wesbrook Mall
Vancouver, BC

I am a faculty member in the School of Nursing at the University of British Columbia and I am writing to request your cooperation in a research project. I need to contact parents who have a child with epilepsy and I would like to do this through the seizure clinic.

The research is a descriptive study of parents who have a child with epilepsy. The study is concerned with how parents cope with their child’s epilepsy on a day-to-day basis, what their needs are and what is helpful to them in coping. The purpose of the study is to obtain a better understanding of how nurses can be helpful to these families.

Your cooperation is requested in accessing parents who may be interested in participating in the study. Selection criteria for the study include: parents have a good command of the English language, the child with epilepsy has been diagnosed one year or longer, the child is of average intelligence and the child is not currently in hospital.

Attached is an information letter to parents describing the nature of the study and their participation in it. I would appreciate it if the letter could be given to parents who are attending the clinic. If, after reading the letter, they are interested in participating in the study they can contact me at the number given in the letter. Alternatively they can leave their name and phone number at the clinic and request that I contact them. Either way I expect this request to require very little time on the part of the clinic staff.

Thank you for your consideration of this request. I look forward to hearing from you.

Yours sincerely,

Connie Canam, RN, MSN
Assistant Professor
Appendix C: Consent Form

Parental Coping with a Child’s Epilepsy

I have read the information letter and have had the opportunity to discuss the study. I understand that the study is about how parents cope with their child’s epilepsy and what helps them cope, for the purpose of obtaining a better understanding of how nurses can be helpful to families who have a child with epilepsy.

I understand that by agreeing to participate in the study:

I will be asked to participate in an interview which will take approximately one hour and the interview will be taped.

I will be asked to talk about how I cope with my child’s epilepsy and what I find helpful. I may refuse to answer any question at any time during the interview.

Any information identifying myself or my family as a participant in the study will remain strictly confidential and will be destroyed at the end of the study.

My participation in the study is voluntary and I may withdraw at any time which will in no way affect the care my child is receiving currently or in the future.

I consent to participate in the study as explained.

Mother ___________________
Father ___________________
Witness ___________________
Date ___________________

Connie Canam, RN, MSN
Assistant Professor
School of Nursing, UBC

Developed July 1997.

The purpose of this guide is to provide a description of each of the 8 categories of the Canam ATF in order to facilitate the allocation of interview data to these categories.

| 1. Accept the child’s condition |  
|---------------------------------|---|
| **Difficulties**                | **Coping Strategies** |
| "shock and disbelief"           | "denial"        |
| "feeling unable to manage"      | "defining situation within own philosophy of life" |
| "uncomfortable touching/holding child" | "ascribing meaning to situation" |
|                                 | "optimistic interpretation of situation" |
|                                 | "perceiving situation as challenge, gaining sense of control over outcome" |
|                                 | "comparing to others in similar situation & perhaps improving parents’ perceptions" |

| 2. Manage the child’s condition on a day-to-day basis |  
|---------------------------------|---|
| **Difficulties**                | **Coping Strategies** |
| "inadequate information"        | "developing positive relationships with health professionals" |
| "inadequate communication with health care professionals" | "become knowledgeable" |
|                                 | "become socialized into the health care system" |

| 3. Meet the child’s normal developmental needs |  
|---------------------------------|---|
| **Difficulties**                | **Coping Strategies** |
| "determining risk of physical health vs. benefit to emotional health re: activities" | "normalization: focus on the child, not the illness...this parental approach helps child’s acceptance of situation & independence" |
| "focus on disability to exclusion of developmental needs" | "do usual parenting activities" |
| "overprotectiveness & lowered expectations of child" | "relate to all children similarly" |
| "need information re: normal development" | "focus on what child can do" |
|                                 | "setting limits & disciplining to promote sense of security in child" |
|                                 | "know developmental ‘normals’" |
|                                 | "recognize effects of health condition on development" |

| 4. Meet the developmental needs of other family members |  
|---------------------------------|---|
| **Difficulties**                | **Coping Strategies** |
| "neglecting needs of individual family members" | "find balance in time given for child, self, family members, and family as a whole" |
| "strain to marital relationship" | "needs, interests, lives of self and spouse, siblings, other family" |
| "siblings requiring attention"  | "promoting self-esteem of all family members" |
| "unwilling to discuss illness"  | "open communication between parents" |
|                                 | "meet sibling’s needs for support" |
|                                 | "share responsibilities within family" |
|                                 | "family members modify their roles" |
### 5. Cope with ongoing stress and periodic crises

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Coping Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ hospitalizations</td>
<td>◦ problem-solving to make tasks manageable</td>
</tr>
<tr>
<td>◦ demands of illness</td>
<td>◦ decrease intensity of emotional reactions</td>
</tr>
<tr>
<td>◦ stressors not related to illness</td>
<td>◦ anticipation of crisis times</td>
</tr>
<tr>
<td>◦ child’s vulnerability</td>
<td></td>
</tr>
<tr>
<td>◦ unpredictability of disease</td>
<td></td>
</tr>
</tbody>
</table>

### 6. Assist family members to manage their feelings

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Coping Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ feelings of anxiety, guilt, fear, resentment, anger, and depression</td>
<td>◦ finding support person(s) spouse: other family, friends, health professional, other parents in similar situation</td>
</tr>
<tr>
<td>◦ managing feelings</td>
<td>◦ communication</td>
</tr>
<tr>
<td>◦ helping children manage their feelings</td>
<td>◦ expressing feelings</td>
</tr>
<tr>
<td>◦ have no one to discuss feelings with</td>
<td></td>
</tr>
<tr>
<td>◦ responses to events /not getting enough attention</td>
<td></td>
</tr>
</tbody>
</table>

### 7. Educate others about the child’s condition

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Coping Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ discussing the illness with the child</td>
<td>◦ answering child’s questions honestly</td>
</tr>
<tr>
<td>◦ discussing the child’s condition within family</td>
<td>◦ family discussions re: facts of disease</td>
</tr>
<tr>
<td>◦ discussing child’s illness and condition outside the family</td>
<td>◦ teach child how to discuss with others</td>
</tr>
<tr>
<td>◦ fear of impact on child of others’ knowing about illness</td>
<td>◦ communicating with others with facts and honesty</td>
</tr>
<tr>
<td>◦ child’s exposure to teasing and discrimination</td>
<td></td>
</tr>
</tbody>
</table>

### 8. Establish a support system

<table>
<thead>
<tr>
<th>Difficulties</th>
<th>Coping Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>◦ developing support networks</td>
<td>◦ develop new support systems</td>
</tr>
<tr>
<td>◦ using available resources</td>
<td>◦ utilize current support systems</td>
</tr>
<tr>
<td>◦ difficulty with above 2 points due to inadequate time and energy</td>
<td>◦ utilize available resources</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>