MOTHERS' VIEWS OF THE ROLE OF NURSING RESPITE IN MANAGING THE STRESS AND COPING RELATED TO THE HOME CARE OF THEIR CHILDREN WITH MEDICALLY FRAGILE OR COMPLEX CONDITIONS

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTERS 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

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ABSTRACT

This study used grounded theory to elicit mothers' views of the role of nursing respite in managing their stress and coping with children who are being cared for at home with medically fragile or complex health conditions. Respite services are required to provide families (in this case mothers) with a break from the condition, its management, and caregiving. This research was part of a larger quantitative and qualitative study designed to evaluate British Columbia's Nursing Respite Program through exploration of families' responses to beginning and continuing to receive pediatric respite care at home.

This research used a subset of data from 10 families to discover theory related to the process of adapting to respite—from mothers' perspectives. Data collection involved in-depth unstructured interviews and observations in the families' homes at three set time periods: prior to the commencement of nursing respite and six and 12 months during the delivery of services. Data were coded from transcribed interviews and field notes and the constant comparative method of data collection and analysis.

Mothers' experiences of caring for their special children and adjusting to respite were conceptualized as evolving through a four-stage social process of Learning to Manage the System: Taking In; Losing Control; Taking Charge; and Manage Effectively within the Constraints of Inflexible Rules. Influencing factors included whether services were in place at the time of their children's initial discharge from hospital, and the presence of significant degrees of uncertainty. Mothers simultaneously moved through four phases in their relationships with the health care professionals: Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships and Establishing a Working Relationship.

This report includes implications for ways nursing practice can be refocused to facilitate mothers' coping, to decrease uncertainty, and to foster stronger, more effectively relationships with families. Areas of further study are identified and implications for nursing education are discussed. This research generates knowledge about mothers' perceptions of the demands of caring for children with very special needs at home and the impact of in-home professional services, and provides direction for improvement of care by nurses, other professionals, and policy makers.
# TABLE OF CONTENTS

Abstract ............................................................ ii

List of Tables and Figures ........................................ vi

Acknowledgments .................................................. vii

CHAPTER ONE: CONCEPTUALIZATION OF THE PROBLEM .......... 1
  Introduction ..................................................... 1
  Research Problem .............................................. 4
  British Columbia’s Nursing Respite Program .................. 5
  Hayes and McElheran’s (1993) Study .......................... 6
  Research Question .............................................. 8
  Methodological Perspective .................................... 8
  Assumptions .................................................... 9
  Summary ......................................................... 10

CHAPTER TWO: LITERATURE REVIEW ............................ 12
  Introduction ..................................................... 12
  Family Systems versus Individual Family Needs ............... 13
  Mothers as Caregivers ......................................... 14
  Stress and Coping ............................................... 18
    Stress .......................................................... 19
    Coping ........................................................ 21
    Personal Resources Enabling an Individual to Cope with Stress 22
  Chronic Illness and its Effect on Mothers ..................... 24
  Technology Dependent Children ................................ 27
    Home Care for Technology-Dependent Children ............... 27
    Nursing Respite for Technology Dependent Children ....... 30
    Other Respite Options for Medically Complex Children .... 33
    Key to Successful Home Care ................................ 36
  Factors Affecting the Parent-Professional Relationship ....... 37
  Families’ Views of Respite .................................... 41
  Summary ......................................................... 44

CHAPTER THREE: METHODOLOGY ............................... 47
  Introduction ..................................................... 47
  Research Design ................................................ 48
    Sample and Participant Recruitment ........................ 48
    Data Collection ............................................... 49
    Theoretical Sampling ........................................ 51
    Setting ....................................................... 53
    Procedures ................................................... 53
  Process of Data Analysis ...................................... 55
    Open Coding ................................................ 55
    Axial Coding ............................................... 58
    Selective Coding ............................................ 59
    Logistics of the Analytic Process ........................... 60
  Methodological Rigor .......................................... 61
  Summary ......................................................... 65
CHAPTER FOUR: FINDINGS AND INTERPRETATION

<table>
<thead>
<tr>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
</tr>
<tr>
<td>Description of Participating Families</td>
</tr>
<tr>
<td>Amount of Respite</td>
</tr>
<tr>
<td>Conversations with Mothers</td>
</tr>
<tr>
<td>Learning To Manage The System</td>
</tr>
<tr>
<td>Taking In</td>
</tr>
<tr>
<td>Learning the Skills Required for Care</td>
</tr>
<tr>
<td>Inflexible Respite Assessment Criteria</td>
</tr>
<tr>
<td>Assessment Criteria Do Not Tell the True Picture</td>
</tr>
<tr>
<td>Blindly Trusting</td>
</tr>
<tr>
<td>Losing Control</td>
</tr>
<tr>
<td>Transition from hospital to home care</td>
</tr>
<tr>
<td>Role of Uncertainty</td>
</tr>
<tr>
<td>System or Program Uncertainty</td>
</tr>
<tr>
<td>Professional Uncertainty</td>
</tr>
<tr>
<td>Illness Uncertainty</td>
</tr>
<tr>
<td>Living with Daily Uncertainty</td>
</tr>
<tr>
<td>Becoming Enlightened</td>
</tr>
<tr>
<td>Taking Charge</td>
</tr>
<tr>
<td>Learning the Rules of the Program</td>
</tr>
<tr>
<td>Taking It One Day at a Time</td>
</tr>
<tr>
<td>Taking Control</td>
</tr>
<tr>
<td>Keeping a Positive Outlook</td>
</tr>
<tr>
<td>Just Getting On with It</td>
</tr>
<tr>
<td>Seeking Social Support</td>
</tr>
<tr>
<td>Seeking Effective Collegial Relationships</td>
</tr>
<tr>
<td>Managing Effectively within the Constraints of</td>
</tr>
<tr>
<td>Inflexible Rules</td>
</tr>
<tr>
<td>Establishing Working Relationships</td>
</tr>
<tr>
<td>Mothers’ Recommendations for How to</td>
</tr>
<tr>
<td>Improve the Program</td>
</tr>
<tr>
<td>Summary</td>
</tr>
</tbody>
</table>

CHAPTER FIVE: SUMMARY, CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS FOR NURSING

<table>
<thead>
<tr>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary</td>
</tr>
<tr>
<td>Conclusions</td>
</tr>
<tr>
<td>Implications and Recommendations for Nursing</td>
</tr>
<tr>
<td>Nursing Practice</td>
</tr>
<tr>
<td>(a) Education</td>
</tr>
<tr>
<td>(b) Psychological Support</td>
</tr>
<tr>
<td>(c) Tangible Support for Caregiving</td>
</tr>
<tr>
<td>Nursing Education</td>
</tr>
<tr>
<td>Nursing Research</td>
</tr>
<tr>
<td>Mothers, Children with Medically Fragile or Complex Conditions and</td>
</tr>
<tr>
<td>In-Home Nursing Respite: Learning to Manage the System</td>
</tr>
</tbody>
</table>
LIST OF TABLES
Table 1: Number of Hours of Nursing Respite per Week .................. 69

LIST OF FIGURES
Figure 1: Mothers Learning to Manage the System ....................... 70
ACKNOWLEDGMENTS

First of all I would like to thank the families because without them this research study could not be possible. Their perceptions of caregiving demands and stresses and how they learned to adapt to the Nursing Respite Program provided me with rich data from which to develop my theory.

I would like to thank to Dr. Jinny Hayes who was a tremendous source of support throughout this research project. Your feedback has been invaluable in assisting me to learn the grounded theory method of qualitative inquiry. Your patience and expertise has made this thesis process a positive and enriching learning experience. I would like to thank Pam McElheran, the other principle investigator in this research project and Elsie Tan one of the Research Assistants, for facilitating my analysis. Thank you Jinny, Pam and Elsie for your input at the group analysis meetings which assisted me in deciding on a research question.

I would also like to extend a warm thanks to the other two members of my thesis committee. First, Judy Lynam. your knowledge and expertise in the area of Pediatrics and Family Nursing has significantly contributed to my understanding of these subject areas. Secondly, I want to express my appreciation to Connie Canam who has also shared her knowledge of Pediatric Nursing and Chronic Illness enriching my theory and thesis process.

I would like to thank my husband Hans for his ongoing support and encouragement. I would like to thank my children for their patience and understanding when I needed periods of time to myself and without interruption.
CHAPTER ONE
CONCEPTUALIZATION OF THE PROBLEM

This report details a qualitative investigation of mothers’ responses to respite assisted home care of their children with medically fragile conditions. It is well documented in the nursing and social science literature that caring for a child with a chronic illness at home significantly affects the physical, emotional and psychological health of other family members (Fleming et al., 1994; Florian & Krulik, 1991; Petr, Murdock & Chapin, 1995; Ray & Ritchie, 1993; Wegener & Aday, 1989). The primary caregiver, in most cases the mother, is the focus of the majority of research today, as there is an increasing body of knowledge suggesting that this is the family member most severely affected by the demands of child care. Mothers report many stress factors in their lives which often compound the demands associated with their ability to care for their children. Some of the stress factors include: a lack of time away from the constant demands, uncertainty related to their child’s future, chronic fatigue and social isolation, a lack of time for other responsibilities, and financial pressures (Fleming et al., 1994; Geary, 1989; Phillips, 1991; Ray & Ritchie, 1993).

Psychologists and sociologists have tended to be the leaders in research into stress and its relationship to coping (Lazarus & Folkman, 1984). Hill (1958) and Patterson and McCubbin (1983) are well known for knowledge development in the area of families coping with stress. The literature supports that an individual’s resources are one of the major personal strengths assisting to maximize his/her ability to cope with stressful events (Lazarus & Folkman; Ray & Ritchie, 1993, Sterling, 1990). Respite care is documented in the current literature to be one of the most important resources available to families with chronically ill children (Joyce, Singer & Isralowitz, 1983; Warren & Cohen, 1985), because it can provide the children with a properly trained individual to care for them, and allow the primary caregivers to have a temporary break away from child care responsibilities (Folden & Coffman, 1993; Warren & Cohen). In the last decade, there has been a gradual increase in the availability of respite relief for families caring for chronically ill children at home (Folden & Coffman). Literature, primarily from the United States and Great Britain dating
from the early 1980’s, describes respite programs for families caring for a child with mental retardation or severe behavioural disorders (Folden & Coffman; Joyce et al.; Warren & Cohen).

Benefits of these respite programs are well documented in these early studies. These include improved family functioning, improved relationships within the family unit, and improved mental health of the primary caregiver (Folden & Coffman, 1993; Joyce et al., 1985; Warren & Cohen, 1985). Another positive outcome of respite care includes an increased ability to cope with the disabled care member at home (Cohen, 1982; Warren & Cohen). In these early studies, parents identified several areas where the current programs could be improved in order to better service their needs. The majority of parents remarked that the number of respite hours allotted to their families was insufficient (Cohen, 1982; Joyce et al., 1983). Parents also perceived that there needed to be improvement in the quality and skill level of the trained respite care providers (Cohen, 1982).

In Canada, according to Statistics Canada’s Health and Activity Limitation Survey (1991), an estimated seven percent of all children in Canada are living with some form of disability (as cited in Canadian Association of Community Care, 1996). British Columbia ranks fourth highest of the provinces as approximately eight percent of the children are reported to be suffering from some form of disability. Findings from this recent survey identify that 11% of these children’s disabilities are described as moderate, and an additional four percent of these children’s disabilities are considered to be severe; however I was unable to locate any figures concerning the percentage of these children who are specifically technology-dependent or medically fragile. In the United States, it is estimated that ten percent of all chronically ill children are medically-fragile or technology-dependent (Hochstadt & Yost, 1991).

Technology-dependent children or medically fragile children are relatively new classifications of chronically ill children appearing in the more recent literature. Medically fragile or technology-dependent children fall under the classification of chronically ill children, although their needs are generally greater and more demanding, increasing the likelihood that the family and primary caregiver experience high levels of stress and burnout (Fleming et al., 1994). The
American Office of Technology Assessment (1987) provides a two-part definition which encompasses both of these terms. Technology-dependent children and/or medically fragile children: a) are technology-dependent in terms of needing a medical device to compensate for the loss of a vital function and substantial nursing care to avert death or further disability, or b) are not needing technology equipment but require skilled nursing care (Office of Technology Assessment, 1987). Some examples of the technologies needed by technology-dependent children include the following: gastrostomy, jejunostomy or nasogastric tube feeding; tracheostomies, oxygen therapy, apnea monitoring, ventilators, and parenteral nutrition or intravenous therapy.

Since the late 1980’s, there has been an increasing trend toward having technology-dependent children cared for at home once their conditions are considered to be stable. Lynch (1990) defines medically stable as “free from medical complications for at least two weeks, and is not expected to be in need of medical intervention for at least one month after discharge” (p. 170). There are a number of reasons why there has been a growing trend toward home care for this population of children. First, advanced technology has led to an improved survival rate of children with life-threatening pediatric diseases (Teague et al., 1993). Second, there has been a marked increase in the cost of in-patient medical care (Patterson, Jernall, Leonard, & Titus, 1994; Teague et al.). Third, governments have drastically cut their funding to tertiary care centres (Patterson et al.). Finally, there is growing concern regarding the potentially adverse developmental consequences for children who have spent prolonged periods of time in institutional care (Patterson et al.; Teague et al.).

The literature reviewed for this study suggests that while attempts have been made to put the proper services in place for these families to safely care for their children at home, there are some definite oversights and service gaps which significantly contribute to the family members’ stress and abilities to cope with their children’s day to day care demands. The first respite programs for families with technology-dependent children appear to have been implemented at the same time these children were being sent home from hospital (Patterson et al., 1994; Scharer & Dixon, 1989; Teague et al., 1993; Wegener & Aday, 1989).
Recently, the Canadian Association of Community Care formed an Advisory Committee to lead a national inquiry into the respite needs of families caring for this population of children. In consultation with parents and care providers, this Committee defined respite care as "a service whose main function is to relieve the parent/family/primary caregiver for a specific period of time while facilitating a positive and rewarding experience for the child with a chronic illness" (Canadian Association of Community Care, 1996).

Respite care providers can possess a wide variety of training and educational qualifications. If the child's condition is stable, a trained volunteer can be taught the skills necessary to safely care for the child. Examples of volunteer workers could include the child's grandmother or a neighbour. If the level of care is more advanced, the child may require the knowledge and skills of a registered nurse or possibly a licensed practical nurse. There is increasing evidence to support the view that registered nurses are required to care for the technology-dependent child because of the specialized knowledge needed to safely manage the child's complex equipment (Hurt, Brodsky, Gealt, & Hopper, 1988; Sherman, 1995).

Research Problem

To date, there has been minimal research which has specifically evaluated the merits of nursing respite programs as a resource for the primary caregiver of technology-dependent children. Research has documented that the majority of primary caregivers suffer from mental and physical exhaustion and do not feel comfortable leaving their children with friends or relatives due to the complexity of their care needs (Scharer & Dixon, 1989; Stevens, 1994). While a number of benefits to respite programs have been documented, the current evaluative research suggests that in many instances nursing respite is viewed as a mixed blessing (Patterson et al., 1994; Ray & Ritchie, 1993).

It is important that more evaluative research be conducted to assess whether nursing respite does in fact reduce the primary caregivers' burden and stress and increase their abilities to cope. What do these mothers view as needed in the way of nursing respite hours? What do these mothers believe are important attributes for the nurses to have in order to provide safe care to their children
and fit into the families lifestyle? As more and more governments make the move to shift care to community settings, there will be an increased demand for outcome research to document how well the present programs are meeting the needs of technology-dependent children and their families. Nurses caring for these children, both from administrative and direct care perspectives, need to know parents' perceptions of both what they think is good about the services and care being provided, and how their needs can be better met.

**British Columbia's Nursing Respite Program**

The Nursing Respite Program was established by the BC Ministry of Health in 1989. Its main objective is to support families caring at home for children with medically fragile conditions by offering them a temporary break, in the form of nursing respite, from their primary responsibilities of 24-hour per day caring (Hayes & McElheran, 1993a). My literature review was not able to specifically identify the percentage of children who are living with a serious illness, and who could be classified as “medically complex”; however, based on national figures and provincial percentiles, it is estimated that there are approximately 1,775 children in British Columbia (BC) who are living with severe disabilities. Families are usually referred to the Nursing Respite Program by a health professional such as a nurse who has been caring for the child in hospital.

There are seven Nursing Consultants hired by the Program who are responsible for assessing each child's eligibility. Following assessment, the Nurse Consultant's report is reviewed by a Screening Committee that determines if the child meets all the criteria for acceptance. Eligibility criteria are that the child must be under the age of 19, and have either a medically complex condition or be technology-dependent (Phipps & McNeil, 1995). Furthermore, the child must require the professional services (clinical judgment, technological skills) of either a Registered Nurse or licensed practical nurse. The child is then classified into one of five categories depending on the level of nursing care required (see Appendix A). Finally, the family is offered between four and 100 hours of nursing respite per week, with the number of hours based not only on the child's needs but also on the respite needs of the parents. Several of the factors considered when assessing the respite needs of the family include whether the family can carry on a typical
family routine and whether the parents are at a risk for exhaustion over time because of the child's care demands.

The nurse providing respite care is hired by the Nursing Consultant from a private nursing agency. An attempt is made to match the nurse's skills, and interests with the child's and family's needs in order to provide a safe and supportive working relationship. Once the Consultants have chosen a number of potentially suitable nurses for a family, the parents do interview the nurses thereby increasing the likelihood that the nurses will be suitable for the family and best meet their needs. One of the seven regional nurse consultants visits the family on a regular basis to offer support and to re-evaluate the child's and family's changing needs. The Consultants are further responsible for the ongoing supervision of the nurses' competency and skill level once they are working in the family's home. In 1994, a total of 70 children and their families were involved in the Nursing Respite Program, with approximately 30 families receiving services at any given time.

Hayes and McElheran's (1993b) Study

The purpose of these researchers' project was to evaluate the British Columbia Ministry of Health's Nursing Respite Program for families of children with medically fragile or complex health conditions. Appendix B outlines the complete list of the goals of Hayes and McElheran's (1993b) study. The study included both quantitative and qualitative components. They chose to use a combination of methods in order to provide both an empirical understanding of the outcome variables in relation to the independent variable (the delivery of nursing respite care to families), as well as provide a vivid picture (grounded theory) of parents' perceptions of how respite services affected their lives. The quantitative analyses examined outcome measures related to a total of nine variables that are believed to be influenced by nursing respite. The family members completed self-report instruments directed at the following variables: (a) overall annual costs of the child's care; (b) nature of direct nursing care; (c) changes in the ill children's activities of daily living; (d) changes in caregiving demands for parents and; (e) family system responses. For each of the variables, changes in caregiving demands, and family systems responses, three instruments were used to measure outcomes. (Further description of these three instruments are available from the
principal investigators.) In total, it took the family members approximately two hours to complete all of these instruments.

The variables of changes in caregiving demands and family system responses were also addressed through qualitative data gathering and analysis in Hayes and McElheran’s (1993b) study. The purpose of the qualitative component of the evaluation study was to generate theory about the experience of commencing and continuing with respite services. In this study, candidates were not selected and theoretically sampled according to the techniques of grounded theory because data were collected at three set interval times (Strauss & Corbin, 1990). Qualitative data were gathered using unstructured interviews which lasted approximately one and one half hours. The interviews were conducted by trained research assistants hired by the principal investigators. The interviews aimed to explore both parents’ perceptions of the process of using and adapting to pediatric respite care at home. Questions were intended to understand the perspective of the primary caregiver as well as all other family members. In Hayes and McElheran’s sample of 27 families all of the mothers participated in all three of the interviews. The research assistants encouraged the children’s fathers and other family members to share their perceptions of what home life was like with a medically complex family member, and how the services of the Nursing Respite Program was affecting their lives; however, the number of fathers and other family members who participated varied with each visit.

This study’s research question is a subsidiary of Hayes and McElheran’s (1993b) project. In this thesis, a decision to focus on only the primary caregivers’ views was based on a preliminary literature review which supports that in most families, the mother is the primary caregiver (Sterling, 1990; Teague et al., 1993). I will explore mothers’ views of how nursing respite affects their abilities to cope with their children’s care demands. Evaluative studies are important to the development of knowledge in this area in order that providers of care are informed about how well the current services are meeting the needs of this unique population of children and their families. The theoretical insight gained from this study may assist not only professionals directly involved in providing nursing respite, but also government officials and other health
ministry officers across the country. It is anticipated that our findings will provide evidence of how to improve this province’s Nursing Respite Program, as well as assist other provinces’ government health ministers to design similar nursing respite programs. The research question being asked in this study arose out of an identified need to know more about how well mothers (the primary benefactors) of nursing respite view British Columbia’s Program.

Research Question

The research question that was explored for this thesis research was: How do mothers who are primary caregivers of their technology-dependent children view the role of nursing respite in managing their stress and increasing their coping?

Methodological Perspective

The research question used a qualitative method of inquiry to explore mothers’ vision of nursing respite. Qualitative research aims to capture the complexity of real life context (Sandelowski, Davis & Harris, 1989; Strauss & Corbin, 1990). Grounded theory, one method within the interpretive paradigm, is the method of inquiry most appropriate to study this phenomenon. Since my study explored one question within of Hayes and McElheran’s (1993b) research project, the design was affected by the major research study.

Hayes and McElheran’s multivariate, one group, pre-post exploratory descriptive design incorporated both qualitative and quantitative methodologies. The qualitative component implemented a grounded theory approach to explore the parents’ adaptations before and after the introduction of nursing respite. The rich qualitative data collected during this two and a half year study included not only information about parents’ perceptions about nursing respite, but also their perspectives of the stresses involved in caring for these children 24 hours a day. Grounded theory methodology guided the way this research question was asked.

Grounded theory seeks to discover the reality of the situations through the identification of social processes present in human interaction (Strauss & Corbin, 1990). Leading scholars in the field of qualitative work argue the method is most appropriately used when little is known about a phenomenon, and when the researcher believes that the participants under study are the only ones
who can accurately describe the true complexity of their situation (Bailey, 1997). A preliminary review of the literature revealed that the experience of caring for a technology-dependent child at home is a complex subjective phenomenon that is deeply interwoven in physical, emotional, and social interactive processes, and these processes markedly influence how the primary caregiver perceives reality (Patterson et al., 1994; Ray & Ritchie, 1993; Scharer & Dixon, 1989; Wegener & Aday, 1989). The goal of nursing respite is to relieve primary caregivers from the burden of care, and increase their health and ability to cope. To date, very little is known about how well nursing respite is meeting its goal for the technology-dependent child and his/her family.

Assumptions

Benoliel (1996) criticizes the founders of grounded theory for not making the assumptions underlying this methodology explicit in their early writings. She notes that the method was built on implicit assumptions and fundamental provisions of symbolic interactionism and theories based in the social sciences. As a theory based on understanding basic social processes, grounded theory is based on the assumption that knowledge is not static; individuals are in a constant state of change, and their relationships with others influence the attainment of their goals. The focus of analysis is behaviour, and it is interpreted through concepts and social interactions (Wilson & Hutchinson, 1991).

As with other qualitative methodologies, grounded theory research is based on the assumption that in order to fully comprehend human behaviour, individuals must be studied in their natural context in order to fully capture the true story of their situation. The aim is to discover dominant processes in a social setting (Clarke, 1995). This requires the researcher to utilize multiple sources of data to validate that the theory is grounded in the data, and not a result of the researcher’s own interpretation or bias (Benoliel, 1996; Clarke).

Finally, a third assumption of grounded theory is that a core variable or central category will emerge from the constant comparative process of data collection and analysis which will explain most of the variation in the data (Benoliel, 1996; Donovan, 1995; Keddy, Sims, & Stern, 1996; Strauss & Corbin, 1990). The Keddy team criticizes Strauss and Corbin’s (1990) book
which was written to help clarify the underlying steps of simultaneous data collection and analysis. The main criticism reported in their 1996 article is that students learning the process are guided toward a linear thought process and therefore a rigid structure to the analysis, something the originators never intended. These critics strongly believe that the “constant comparative” analysis, which is not a linear thought process, is at the heart of grounded theory research. Several critics of recent developments in the methodology urge students who are learning the process to be in contact with a mentor who can assist them to capture the true story line in the data (Benoliel, 1996; Keddy et al., 1996). To assist their students to discover the core category, Keddy and her colleagues advise students to ask a very basic question of the data: “What do the participants anguish over the most?” (p. 451). Following Strauss and Corbin’s (1990) guidelines along with other more recent writings, I used constant comparative analysis using both inductive and deductive reasoning. I share the view of Kools, McCarthy, Durham and Robrecht (1996) that the human mind often reasons in linear and circular thought processes simultaneously. During the analysis phase of the project I used a variety of sources of data to assist me to identify emerging concepts, categories and theoretical constructs. During this process the core variable emerged from the data.

Summary

Grounded theory is an appropriate methodology to guide a research question when very little is known about the central phenomena. The proposed research question was concerned with mothers’ views of the role of nursing respite in managing their stress and increasing their coping. One of the goals of British Columbia’s Nursing Respite Program is to provide family members with a temporary break from their caregiving responsibilities. In most studies to date that focus on the stresses involved in caring for technology-dependent children at home, the mothers are cited most often as the primary caregiver (Fleming et al., 1994; Gravelle, 1997; Ray & Ritchie, 1993; Teague et al., 1993). Presumably mothers and their technology-dependent children would be the family members most likely to benefit from the support of nursing respite. Since 1989, this program has been available to families caring for their technology-dependent children at home, and
to date Hayes and McElheran's (1993a) project is the first research to evaluate how well the Nursing Respite Program is meeting its goal.

As more and more provinces in Canada shift health care responsibilities away from tertiary care facilitates to the community, the burden of care falls on family members to care for their loved ones. Health professionals on the front lines of the health care services need to hear how well the Nursing Respite Program is meeting the needs of families in this province. Further, the results can assist provincial health care professionals and government personnel to improve the quality of service this program provides to technology-dependent children and their families.
CHAPTER TWO
LITERATURE REVIEW

In addressing concerns related to primary caregivers' abilities to care for their technology-dependent children at home, a number of topic areas need to be explored in order to grasp the true complexity of the issue. Technology-dependent children fall under the classification of children living with chronic illness; although due to the nature of the care required for this population of children, their needs, and their families' needs will have unique characteristics. In order to understand how primary caregivers view the role of nursing respite in managing their stress and increasing their abilities to cope, a number of relevant topic areas need to be explored, including the following: mothers as caregivers; stress, coping and personal resources enabling an individual to cope with stress; chronic illness and its effect on mothers; technology-dependent children; home care for technology-dependent children; nursing respite for technology-dependent children; other respite options for medically complex children; the key to successful home care; factors affecting parents' relationships with health care professionals; and families' views of respite. The following discussion addresses the main issues related to each of these topic areas in order to gain an in-depth understanding of mothers' perceptions of how their lives are affected when they are faced with caring for their technology-dependent children at home.

In an attempt to enhance the abilities of families with technology-dependent children to cope, health care systems in Canada and the United States are beginning to develop and implement nursing respite programs designed to provide parents with a temporary break from their 24 hour responsibilities. To date, there is very little evidence documenting whether these programs are perceived by the primary caregivers to be a beneficial source of support. This review of the literature concludes with a discussion of what is presently known about how well nursing respite programs are meeting the individual needs of family members who are caring for technology-dependent children in their homes.
Family Systems Versus Individual Family Members

Recently, researchers in the behavioural sciences have begun to explore knowledge in the area of family systems and functioning, though this theory development is in its infancy (Hayes, McElheran, & Tan, 1997). While it makes sense that the quality of care children would receive at home would be closely related to the families' overall abilities to function, this assumption needs to be validated in order to use it as an index for assessing the effectiveness of interventions by health care professionals to enhance families' abilities to cope with stressful situations. Research has demonstrated that certain structural features of the family such as size of the family, the geographic area, can affect a family's ability to cope (Bradley, Parette, & Van Biervliet, 1995). While this study is specifically looking only at mothers' abilities to cope, it is important not to forget that mothers are members of a family unit and therefore their abilities to deal with their technology-dependent children will be influenced by how well the other members of the family are coping.

Research looking specifically at parental coping has supported that certain characteristics such as mental state, attitudes toward child rearing, attitudes toward disability, and the ability to attach to others, can influence the quality of care children receive (Bradley et al, 1995). Anderson and Elfert's (1989) study suggested that if parents have gained the necessary knowledge and skill to safely care for their children, their abilities to cope with care demands are also more effective. Socio-economic status and marital status have also been shown to affect parents' abilities to care for their children (Dunst, Trivett & Deal, 1987). Hayes et al. (1997) interpreting data from Hayes and McElheran's (1993b) study support that the demands on parents who are caring for technology-dependent children can range from minor to extreme, but for the majority of families these demands fall at the higher end of the spectrum, even when nursing respite is available. Examples of the kinds of demands, reported by the families in this study are, the persistent responsibility of caring for their children, the lack of control over certain aspects of their daily lives, the constant and extreme exhaustion, and the lack of time for themselves. Hayes and colleague's article concludes that the services provided by the Nursing Respite Program does assist
families to deal with these demands but presently this support is inadequate and the rigid and inflexible assessment criteria does not consider the individual needs of families and family members. These results suggest that the nature of support needed is not solely technical support—but technical support offered in a way that fits into other family commitments and responsibilities.

Family systems theory is important to understanding individual family members' behaviour, although realistically it is not possible to separate any family member from the family system. For the purpose of this research the primary caregiver's ability to cope and care for her technological dependent child will be the focus of much of the research reviewed.

Mothers as Caregivers

The research reviewed for this study suggests that in most families caring for chronically ill children it is the mother who assumes the primary parenting responsibilities, due to an increase in the flexibility of parental roles in our society, it is becoming more common for fathers to assume the role of primary caregiver. This increasing trend toward caring for loved ones at home comes at a time in our economic evolution when women are returning to work in order to ensure the family's financial survival (Bridges & Lynam, 1993).

Based on extensive review of the literature on caregiving encompassing the topic areas of caregivers' identity, the nature of caring responsibilities, the costs involved in caring, and the evaluation of state-provided services, Bridges and Lynam (1993) conclude that in Western society (referring mainly to Great Britain, United States and Canada) politicians have generally assumed that families will be available to provide any caregiving that government chooses to download to them. These authors point out that because of societal and economic values, it is assumed that women will be the primary care provider. When making public expenditure savings, such as shifting the responsibility of care for chronically ill family members to families, elected governments fail to recognize other competing demands many of these women face. Bridges and Lynam argue that changes need to be made to the current political and economic structure in order to ensure the caring role is taken on as a result of choice, and not out of obligation, and a lack of alternative placement for their loved ones. Governments and state personnel need to plan ahead and
allocate resources so alternative arrangements can be made to support families in assuming the caregiving role.

Bridges and Lynam's (1993) paper highlights the considerable personal sacrifices that family members assume in the role of primary caregiver. Often they are forced to give up their careers and suffer both personal and financial losses as a result of these decisions. The responsibility of care often leaves these women facing social isolation, and in many instances their own needs are put on hold in order to care for their loved ones. As Bridges and Lynam point out, the added strain on the caregiver could potentially lead to caregiver burnout. Respite care can offer the caregiver relief from this 24 hour responsibility, and rejuvenate personal resources ensuring his/her ability to provide ongoing care to the family member. This study provides one perspective of how a nursing respite program assists a group of caregivers to manage the ongoing stress of caring for technology-dependent children at home.

Anderson and Elfert (1989) conducted an ethnographic study that examined how families caring for chronically ill children at home conceptualize their experiences of illness. The project involved two phases. During the first phase, participant observation was combined with an open ended interview approach to gain a contextual basis for understanding the illness experience over time. Although Anderson and Elfert explain that data were collected from Euro-Canadian and Chinese families, and that for the purpose of the 1989 analysis, only data from the Euro-Canadian families was used, they do not mention how many families were involved in the analysis. Similar to Bridges and Lynam (1993), these scholars allude to the fact that while research questions often specify the concept of family when discussing the issues, it is the women, and not the family, unit that assumes the caregiving role.

During the second phase of the Anderson and Elfert project, data were obtained using in-depth ethnographic interviews. Consistent with the methodology, preliminary analysis was carried out concurrently with data collection. Emerging themes were validated with each member of the research team, and then further confirmed by the study participants. The results of the analysis revealed that the mothers felt an overwhelming need to feel competent in providing their children's
care. Their strong desire to demonstrate competency was motivated by their guilt at having given birth to a less than perfect child. This overpowering guilt or “blaming of self” (p. 738) drove these women to be vigilant in their care of their ill children.

In Anderson and Elfert’s study, 46% of fathers participated in one or more of the interviews, although the researchers encouraged their participation at every opportunity. Mothers in this study often spoke in the singular when discussing the care of their children, and several of the women openly admitted they felt totally responsible for the care. The analysis revealed that some mothers felt their husbands were not competent to look after the child. The mothers’ sense of competency often stemmed from the fact that they were the ones who spent the most time with their children, and therefore were more skilled and knowledgeable at interpreting their children’s behavioural cues. Society’s expectations surfaced in the authors’ interpretation of why mothers assume the burden of caregiving. Anderson and Elfert explain that a woman’s identity is interwoven in her ability to nurture and “she will do almost anything to ‘fix things’ ” (p. 741).

These researchers’ analysis also revealed that these women were also afraid that if they were found to be or suspected of being incompetent, this could result in unpleasant consequences (removal of the children from their homes). Similar to Bridges and Lynam (1993), these authors conclude that the affects of the caregiving role on women is rarely if ever a consideration when decisions are being made by health care professionals and program developers. Anderson and Elfert’s study substantiates that the role of primary caregiver is indeed a stressful one, and can often strain women’s personal resources, increasing their stress and decreasing their abilities to cope. Both Bridges and Lynam (1993) and Anderson and Elfert (1989) speak to the importance of some form of respite in order for these primary caregivers to successfully perform their caregiving responsibilities. May’s (1997) study further supports Anderson and Elfert’s findings that the caregiving role is demanding and can significantly interfere with mothers’ abilities to cope. Similar to the mothers in these two studies, mothers of premature babies have also been found to need additional support in order to manage their day-to-day care demands effectively.
The purpose of May's (1997) grounded theory study was to examine the process mothers use to seek help as they care for their low birth weight infants at home. Low birth weight in this study included infants who weighed between 1500 grams and 2500 grams. May’s sample included 14 women enrolled in a follow up clinic for high risk infants. This researcher reported clearly the steps she followed to ensure the credibility of her study. The core variable, “searching for normalcy” (p.18) emerged from the simultaneous data collection and analysis process. The process of caregiving was the central strategy these mothers used to deal with issues associated with their infants’ fragile health status. Caregiving directed the mothers’ search for normalcy and consisted of five processes. These processes were: learning caregiving, maintaining vigilance, normalizing, going alone with caregiver burden, and help seeking.

In May’s study, “learning caregiving” commenced as mothers began the process of bringing their infants home, and then living with their infants’ fragile conditions. Mothers reported caregiver burden included associated feelings such as guilt, disappointment, and inadequacy. The responsibilities involved in their children’s care caused time restraints, and mothers complained of physical and emotional strain, and dramatic changes in their lifestyle. The next process, “maintaining vigilance”, occurred anywhere from two weeks to three months after the infant was discharged from hospital. Mothers during this phase were searching for signs that their infant was making progress. The process of normalizing developed as mothers looked for evidence that the child was catching up on his/her development. During this phase, mothers compared their infants to other normal birth weight infants and felt reassured when the infant’s condition was improving. May’s article does not mention how mothers coped when their infant’s condition deteriorated.

The third process of “going alone” with caregiver burden” was only experienced by certain mothers. These mothers chose to work independently instead of seeking help from health care professionals. The exact reason for doing this is not clearly explained in May’s article, however she does mention that it was because of mothers own feelings, their perceptions of health care professionals, and/or perceived barriers in their eligibility for services. “Help seeking”, the final process involved in these women’s caregiving, occurred when these mothers recognized that they
needed assistance. Assistance could mean seeking information, seeking assessment and/or treatment, and seeking needed respite care and/or support.

May’s study suggests that often mothers had unrealistic expectations about their abilities to care for their children without any additional support. This notion may have stemmed from the fact, that they were so happy to finally be taking their infant home. However, after a number of months of caring for their infants on a 24 hour basis, the majority of the mothers were experiencing burnout, and came to the realization that they needed additional support and respite in order to cope effectively with the added responsibility of caring for their infants. These findings are relevant to my study because it supports one of the underlying assumptions that mothers who are caring for medically fragile children are in need of some kind of additional support similar to the services being offered by the Nursing Respite Program. The high care demands of this population of children put the mothers’ health at risk. The mothers in May’s study were better able to cope when they believed they had more resources. The two resources mentioned by the mothers included: having the necessary knowledge and skills to care for their children; and having access to a professional they trusted in times when they were experiencing a crisis or in need of someone to validate their concerns.

Stress and Coping

There is a vast amount of research explaining the relationship between stress and coping (Hill, 1958; Monet & Lazarus, 1977; Patterson & McCubbin, 1983; Crnic, Freidrich & Greenberg, 1983). The above mentioned authors’ work has focused primarily on family systems, though their research usually provides information about individuals within the family and how each member handles a stressful situation. Lazarus and Folkman’s (1984) work will be highlighted for the purpose of this research due to the fact their work has focused on individuals and how they cope with stressful situations.
Stress

Monet and Lazarus (1977) distinguish among three types of stress, namely physiological, psychological, and social. According to these theorists, all three types of stress are related, but empirical evidence is needed to clarify the exact relationship between them. Due to the nature of the research question asked in this study, a decision was made to focus on how psychological stress was expressed, as well as its relationship to the primary caregivers’ health and their abilities to adapt to the stress of caring for their technology-dependent children. This is not to discount the importance of mothers’ social and physical health effects, but based on the literature reviewed, the impact of psychological stress was seen to be more prominent in these women.

According to Lazarus and Folkman (1984), psychological stress is defined as “a particular relationship between the person and the environment that is appraised by the individual as taxing or exceeding his or her resources and endangering his or her wellbeing” (p.19). According to Lazarus and Folkman’s research, cognitive appraisal is an important process which an individual uses to determine his or her own personal interpretation of the stressful event. Cognitive appraisal relates to how stressful the individual perceives the environment or situation to be. Lazarus and Folkman (1984) suggest that cognitive appraisal has two dimensions: primary and secondary. Primary appraisal refers to an individual’s assessment of what is at stake when confronted with a stressful event. During primary appraisal, an individual can evaluate the stressful event to be irrelevant, benign-positive or stressful. For the purposes of this discussion, only a stressful situation will be elaborated on. Stress appraisals involve the individual’s perception that a situation will result in harm or loss, or threatened harm or loss. In the first situation, some degree of damage has already been sustained by the individual, such as the loss of a loved one. Threat relates to a harm or loss that has not yet taken place but the likelihood of damage is anticipated. Finally, an individual can appraise a stress as posing a challenge. If the stress is perceived to be a challenge, the individual focuses on the potential for growth as a result of his/her ability to cope with the stressful event. In all three situations, harm/loss, threat and challenge, the individual mobilizes coping resources in an attempt to adapt to the stressor.
Secondary cognitive appraisal refers to the coping options the individual uses to adapt to the situation. During secondary appraisal, the individual evaluates what the coping options are, and the likelihood that these strategies will be effective in reducing the perceived stress. During this phase, a number of other complex evaluation processes are occurring simultaneously. For example, the individual is evaluating the other demands in his or her life which are occurring simultaneously. The concept of vulnerability is frequently used in discussions relating to psychological stress and adaptation. According to Lazarus and Folkman (1984) vulnerability refers to the adequacy of an individual’s resources. An individual is considered to be in a vulnerable state when the internal or external demands are appraised as exceeding his/her resources.

Lazarus and Folkman (1984) assert that two important personal factors influence an individual’s cognitive appraisal of a potentially stressful event. The first factor, is a commitment expression of what the individual deems to be important in his/her personal life. The stronger an individual’s sense of commitment, the greater the potential for threat and challenge. Commitment, however, can also serve to strengthen an individual’s determination and ability to cope with the stressful event and increase the individual’s sense of hope. An individual’s belief system is another important influencing factor. The most important personal belief influencing cognitive appraisal is personal control and relates to an individual’s desire to master the stressful situation successfully. Existential beliefs are important in helping to create meaning to the situation and maintain hope that something positive will come out of the stressful event (Lazarus & Folkman).

Lazarus and Folkman (1984) further explain that certain situational factors also influence an individual’s cognitive appraisal. For the purpose of this discussion, only factors considered important to the current research study will be discussed. Event uncertainty is one factor considered relevant to the current research question. Technology-dependent children face an uncertain future due to the vulnerability experienced by their medical condition. In Hayes and McElheran’s (1993b) study of 27 families, four of the families experienced the loss of their children during the course of the project. According to Lazarus and Folkman (1984), event uncertainty is an extremely stressful situational factor because it immobilizes anticipatory coping
processes. For example, the coping strategies needed to cope with an improvement in the child's medical condition would be incompatible with the coping strategies needed to prepare for the child's impending death. A second important situational factor refers to the event's imminence. The more immediately the event will be happening, the more intense the appraisal. For the purposes of this study, the majority of primary caregivers had a great deal of time to prepare for their children's discharge, because in the majority of cases the children spent at least three or four months in the intensive care unit before their medical condition was considered to be stable enough to be discharged to their mothers. Time would allow these mothers to anticipate how they would cope with their children upon discharge; however, time could also cause these primary caregivers to worry more about their abilities to cope. A third important factor worth mentioning is the duration or length of time during which an event is occurring. Lazarus and Folkman explain that prolonged exposure to a stressful event can result in exhaustion.

Coping

Lazarus and Folkman (1984) define coping as “constantly changing cognitive and behavioural efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 19). When considering coping strategies it is important to remember that coping is a process, and that at certain times an individual relies more heavily on one form of coping. Lazarus and Folkman distinguish between two different kinds of coping. Firstly coping can be directed at managing or changing the problem causing the distress. This form of coping has been called problem-focused coping and is generally used when an individual appraises the situation as changeable. An individual’s attempt to improve the situation could be seeking information, deciding not to make snap decisions, and/or confronting the person or persons causing the hardship. Secondly, coping can be directed toward regulating the emotional response to the problem. Generally this form of coping is implemented when an individual appraises that there is very little he/she can do to alter the threat. Called “emotion-focused coping”, this form of coping refers to those thoughts or actions aimed at reducing the physiological
symptoms of stress. Examples of these coping strategies are: avoiding the problem, denying the problem, or detaching oneself from the situation.

**Personal Resources Enabling an Individual to Cope with Stress**

Lazarus and Folkman (1984) mention a number of personal resources which individuals draw on in order to cope with the demands of daily living. Health and energy is described as one of the most important resources an individual has. These researchers elaborate physical wellbeing is especially important when an individual is dealing with situations perceived to be particularly stressful and enduring. An individual who views his/her situation positively also is better able to cope with a stressful event, according to Lazarus and Folkman. Finally, problem solving skills, social skills and social support are also mentioned in these researchers’ work as an important personal resource.

The concepts of stress and coping were explored in some depth in this review of the literature because they are central phenomena to this research question. In order to define these concepts, it was necessary to review other scholars who have examined these concepts and their interrelationships. The theoretical perspective presented here is only one interpretation of these phenomena, however they provide the reader with a basic understanding of how stressful events can interfere with an individual’s ability to cope, and the relationship that an individual’s personal resources play in trying to maintain or regain a sense of balance and equilibrium.

The research of Crnic and his colleagues (1983) research is based on families caring for mentally retarded children, and highlights many of the same themes reported in Lazarus and Folkman’s (1984) work about stress and coping. Crnic et al.’s research conceptualized coping resources in five categories: (a) energy and morale, (b) problem solving skills, (c) social networks, (d) utilitarian resources (such as income), and (e) general and specific beliefs (including such personality traits as an individual’s feelings of worth, locus of control, and a belief in a higher purpose).

The majority of research concerned with chronic illness and its effect on stress identifies social support as one of the most important resources for increasing individual family members’
abilities to cope (Dunst et al., 1987; Ray & Ritchie, 1993; Scharer & Dixon, 1989; Stevens, 1994; Sterling, 1990). Social support can be accessed from a variety of individuals including family, friends, and spouses. In several studies, support from significant family and friends has been identified as more valued by primary caregivers, than support from health care professionals. In several studies, spouses were cited to be the most important source of support (Florian & Krulik, 1991; Geary, 1990; Stevens, 1990).

In a number of studies, knowledge about the child’s condition and treatment was mentioned as an important personal resource (Sterling, 1990; Stevens, 1990). Family members reported that they were better able to cope when they had acquired the knowledge and skills to safely care for their dependent child out of the medical context. In all of the above mentioned studies, mothers reported that even when several members of the family had acquired the necessary knowledge and skills, it was still be very difficult for them to care for their children at home without some form of outside assistance (Dunst et al., 1987; Ray & Ritchie, 1993; Scharer & Dixon, 1989; Stevens, 1994; Sterling, 1990).

Respite care is documented in the literature as an important situational resource which increases primary caregivers’ abilities to cope with the stressors incurred when caring for their chronically ill children. Within the last decade, there has been a gradual increase in the provision of some form of respite relief for those families caring for a chronically ill child at home (Folden & Coffman, 1993). Literature from the early 1980’s, primarily in the United States and Great Britain, describes respite programs for families caring for a child with mental retardation or severe behavioural disorders (Folden & Coffman 1993; Joyce et a., 1983; Warren & Cohen, 1985). About this time, articles began to appear in the literature indicating that parents were beginning to care for ventilator-dependent children at home. Research was providing evidence that families found their caregiving responsibilities to be stressful; however, the literature reviewed suggests that it was not until the early 1990’s that formal respite was available to the technology-dependent child and his/her family (Patterson et al., 1994; Scharer & Dixon, 1989; Teague et al., 1993; Wegener & Aday, 1989).
Technology-dependent or medically fragile children represent one type of chronically ill children. This population presents a unique set of problems for both the primary caregivers who are caring for these children at home, and the respite programs that are trying to offer their families a form of support and temporarily relief from their responsibilities. In the medically fragile population of children, the research to date strongly indicates that maternal and paternal grandparents are usually not used as a source of support because they were uncomfortable in taking care of their grandchildren (Folden & Coffman, 1993; Stevens, 1994). Technology-dependent children seem to require the expertise of a trained professional to safely meet their daily physical and psychological needs. The research to date documents why the families of medically fragile children are often in need of professionally trained nurses (Stevens, 1990; Stevens 1994; Sherman, 1995). Evidence suggests that these families require the unique skills and knowledge provided by a registered nurse in order to feel comfortable leaving their children in the care of a respite worker (Aday & Wegener, 1988; Hochstadt & Yost, 1991; Lynch, 1990). Respite caregivers need to be able to assess and respond to changing needs of medically-fragile children and be competent in the use of such technologies as tracheostomies, respirators, and suction equipment.

In the next section, the concept of chronic illness and its effect on mothers’ abilities to cope is explored.

Chronic Illness and its Effect on Mothers

Many researchers have investigated how caring for a chronically ill or medically fragile child at home impacts on other family members’ quality of life (Gravelle, 1997; Ray & Ritchie, 1993; Sterling, 1990). Twenty-nine parents participated in Ray and Ritchie’s study designed to examine parental coping relative to the degree of caregiver burden, and to describe factors that influence parents’ experiences with home caregiving. The degree of coping, caregiver burden, and level of stress were measured using three well established instruments, and results indicated that as the burden of care increased so did the caregivers’ levels of stress, and their abilities to cope effectively declined.
Three primary sources of stress were reported by parents in Ray and Ritchie's (1993) study. The majority of parents felt that the continual adherence to the children's care regime was the most stressful aspect of caring for them at home. The other two sources of stress reported most often by these parents included the struggle to balance family and care demands, and exacerbations in the child's illness. In all but one family, the primary caregiver was the mother. Coping strategies identified as most helpful were: (a) maintaining family strength, (b) maintaining a hopeful and optimistic outlook, and (c) getting the illness tasks accomplished. Having a supportive and helpful spouse was also mentioned by many of the mothers as a factor increasing their abilities to cope. In Ray and Ritchie's study there is no mention that respite relief was available to these families, though the parents did view the health care system as both a resource and a constraint. In additions many parents expressed the frustration they felt the health professionals did not acknowledge their expertise.

Gravelle (1997), using a phenomenological approach, interviewed eight families with children with complex conditions (eight mothers and three fathers). From the data analysis process a central theme of "facing adversity" emerged. Each new challenge in the child's illness can cause a new cycle of this central theme. According to this theory, each time the family is faced with a new crisis, the parents must redefine the adversity, and learn or adapt new strategies for managing the adversity. Parents in Gravelle's study experienced some form of loss as a result of each new challenge, such as a deterioration in the child's abilities. Generally each new loss resulted in increased care needs. Each loss also resulted in the parents feeling sorrow and grief, and time becoming a "precious commodity" (p. 242). Due to the extensive nature of the child's care needs, little time was left over for other essential responsibilities, and as a result, the mothers (who were the primary caregivers) experienced extreme fatigue.

While there is substantial evidence supporting that every member of the family is affected by the increased responsibility of caring for a chronically ill child at home, much of the research has specifically focused on the primary caregiver as there is increasing evidence that this member is more heavily burdened socially, emotionally, and physically (Florian, & Krulik, 1991; Phillips,
The majority of researchers identify the mother as being the primary caregiver (Fleming et al., 1994; Gravelle, 1997; Ray & Ritchie, 1993; Teague et al., 1993).

Florian and Krulik (1991) studied the relationship between loneliness and social support for mothers of chronically ill children. Two well established and reliable instruments were given to 90 mothers of chronically ill children and 92 mothers of healthy children. Similar to Ray and Ritchie’s (1993) findings, the majority of mothers identified that their husbands provided more support than family, friends, or health care professionals. Mothers of the sick children had significantly higher loneliness scores than mothers of healthy children, even though they reported to having a larger social network than mothers who were not caring for chronically ill children. Florian and Krulik’s findings suggest that even though mothers are receiving a certain kind of support, as in help with the physical care, they do not really get the amount or kind of emotional and social support that they need.

Phillips (1991) was interested in chronic sorrow in mothers of chronically ill children, and conducted a concept analysis using an established model designed for this purpose. Three mothers were interviewed in depth for a period of six weeks. Phillips’ findings supported a previous researcher’s work exploring the concept of chronic sorrow. This indepth concept analysis suggested that three important components of chronic sorrow include: hopelessness regarding progress, cure, and normalcy. Time is believed to be a crucial factor in the development of chronic sorrow. Chronic sorrow can cause feelings of apathy and depression which can interfere with the caregivers’ abilities to carry out responsibilities surrounding the child’s care (Phillips, 1991). Chronic sorrow was also an important concept in Gravelle’s (1991) study, and her results provide support for Phillips’s proposition that time and hopelessness are important components in this process.

As well as suffering from chronic sorrow, depression, loneliness, and a lack of support, mothers of chronically ill children often complain of chronic fatigue (Teague et al., 1993), guilt, anger, anxiety about the future (Murphy, 1991), social isolation (Murphy, 1991; Stevens, 1990), and a lack of time to engage in leisure activities (Geary, 1989). The findings from this group of
studies support that the primary caregivers of chronically ill children experience significant physical, emotional, and social strain as a result of their caregiving demands. In a number of these studies, there is no mention of whether mothers were able to have any respite from their burden of care (Florian & Krulik, 1991; Geary, 1989; Phillips, 1991; Ray & Ritchie, 1993).

In Murphy's, Gravelle's, and Teague et al.'s studies, mothers were receiving some form of nursing respite. Mothers in Murphy's study found the presence of the nurses a significant source of stress. The more hours of nursing respite they were receiving per week, the more problems they experienced with the nurses. In Gravelle's (1997) and Teague and her colleagues' (1993) studies mothers reported that the nurses were a valuable resource. A more indepth discussion of these three studies is provided in my section concerning home care for technology-dependent children. The studies mentioned in this section concentrated on some of the coping strategies used by parents when caring for their chronically ill children. In only these three of the studies was nursing respite mentioned by the parents as being an important resource. This finding suggests nursing respite plays an important role in the primary caregivers’ struggle to manage the day to day care demands, but at present this is a limited resource as not all parents reported having access to home nursing respite.

Technology-dependent Children

Home Care for Technology-dependent Children

According to Wegener and Aday (1989), ventilator assisted children were one of the first type of technology-dependent children to be cared for at home in the United States. The purpose of Wegener and Aday's study was to expand on an earlier project, and identify the factors which seem to contribute to family stress when caring for a ventilator assisted child at home. One hundred and twenty one families were interviewed using a semi-structured interview, and were given two standardized instruments to measure stress levels in the family and primary caregiver. The results suggested that the families most vulnerable to stress were dealing with stressors relating to family structure (such as single parents) and/or were facing financial difficulties. In addition, Wegener and Aday noted that families who had not been adequately assessed prior to their child's discharge
ranked higher on the instrument used to measure stress. Finally, families who were not under the care of a case manager (identified in this study as an important professional to co-ordinate the child’s services) were reported to experience increased stress.

Twenty-three couples participated in Steven’s (1990) study which looked at sources of stress for families caring for an infant on home cardio-respiratory monitoring. The instruments used were developed for this study, and the author did preliminary cross-validation to establish content validity. Results identified five main sources of stress including: persistent gravity of the situation (20 mothers and 16 fathers), fear of their own incompetency in assuming the medical/nursing care of the child (17 mothers and 10 fathers), inadequate respite care (17 mothers and 3 fathers) constant fatigue (12 mothers) and social isolation (12 mothers and 4 fathers).

A more recent study by Stevens (1994), found similar results about the factors that contribute to parents’ stress levels. Twenty couples were interviewed and given the same semistructured interview as in her first study. Eighty-five percent of the parents reported that the persistent gravity of the situation was the most stressful. This finding is consistent with Stevens’ earlier work. Secondly, 85% of these parents felt that it was equally stressful to think of their child being cared for by incompetent or non-nurturing nurses. In Stevens’ previous study, the parents had ranked this concern as third. The parents’ own feelings of inadequacy in caring for the medical aspects of their children’s care was recorded as the third most stressful event (reported second in the 1990 study). Finally, social isolation, constant fatigue, and financial concerns were reported to be a significant source of stress.

The purpose of Teague et al.’s (1993), study was to pilot test an instrument and the research method for a major study of caregivers of children who were technology-dependent. In Teague et al.’s study the two main sources of stress identified by 73 primary caregivers were financial concerns (in the American health care system) and the physical demands of providing care. Mothers who recorded higher scores on a instrument measuring depression were more likely to experience stress. Caregivers who had less financial concerns were more satisfied with their situation. The pilot was conducted using four agencies (in three metropolitan areas) that provide
home care. The nature of the children's dependency varied and included children who were ventilator dependent, dependent on intravenous therapy, and/or dependent on nutritional support equipment, monitoring devices or respiratory support. The majority of these children were being cared for by their mothers.

The purpose of Youngblut, Brennand, and Swegart's (1994) exploratory study was to provide a description of the typical decisions and problems families caring for medically fragile children face on a day-to-day basis. The study was also interested in exploring the coping strategies and resources used by these families. Youngblut et al. interviewed a convenience sample of ten families using a unstructured interview approach. Results supported the findings of Teague et al. (1993) identifying that continual adherence to the child's care regime was the most stressful aspect of caring for their technology-dependent child at home. Other sources of significant stress were the struggle to balance the family and care demands, and exacerbations in the child's illness.

All of the above mentioned studies support the notion that mothers experience high levels of stress when caring for their technology-dependent children at home. Sources of stress for these mothers included: (a) lack of spousal or partner support (Wegener & Aday, 1989), (b) added financial pressures from expenses not covered by their insurance (Stevens 1994; Teague et al., 1993; Wegener & Aday), (c) inadequate preparation prior to their children's discharge (Wegener & Aday), (d) the physical demands of providing continuous care (Teague et al.; Youngblut et al., 1994), (e) persistent gravity of their children's condition (Stevens, 1990; 1994; Youngblut et al.), (f) chronic fatigue (Stevens 1990; 1994), (g) lack of confidence in their abilities to care for their children (Stevens, 1990; 1994), (h) social isolation (Stevens 1990; 1994), (i) inadequate respite (Stevens, 1990, (j) incompetent nurses (Stevens, 1994), and (k) chronic fatigue (Stevens, 1990; 1994). The Teague team of researchers found that there was a correlation between the level of depression and level of stress in mothers.

The above mentioned studies provide substantial evidence that caring for technology-dependent children is a source of considerable stress. A number of studies allude to the fact that nursing respite was an important resource enabling primary caregivers to have a temporary break
from the ongoing responsibilities associated with their children’s high care demands. Mothers in Steven’s (1990) research projects indicated that they were not receiving adequate respite to sufficiently manage their stress levels. In Stevens’ (1994) more recent study, mothers reported that often the respite nurses significantly increased their levels of stress, because they were perceived by these primary caregivers as lacking the necessary knowledge and skills to safely care for their children. These results support the need for the current research study, as it would seem that there is a definite need for nursing respite in these mothers’ lives. The above mentioned studies do suggest that respite is an important form of support, however the majority of these mothers believed that currently this support was not adequate. Mothers were still experiencing significant levels of stress from their caregiving responsibilities. These studies do suggest that if nursing respite is to be perceived as a useful resource, the nurses must be able to respond to care demands and fit into family life.

The current study’s purpose is to explore mothers’ views of what is needed in order to allow these caregivers to manage their care demands when they are caring for technology-dependent children and who have qualified for nursing respite. Some of the questions which remain unanswered to date include: What mothers view as needed in the way of nursing respite hours; What do mothers feel are important qualities for the nurses to have? These are questions for which the proposed study may be able to offer some insight.

Nursing Respite for Technology-Dependent Children

Research suggests that nursing respite is a necessary resource for the family in order to ensure the members are able to cope with the increased burden of caring for their technology-dependent children at home (Murphy, 1991; Scharer & Dixon, 1989; Sherman, 1995; Stevens 1990; 1994). Many mothers report that while there are many benefits of nursing respite, often this resource is seen as a mixed blessing (Patterson et al., 1994; Ray & Ritchie, 1993).

Mothers who received home care in the Teague team’s (1993) research study nursing felt that the nurses were an important resource enabling them to have a temporary break. All of the mothers were pleased with the quality of care their children received when in the nurses’ care.
Respite nurses in Scharer and Dixon’s (1989) study were also seen to be resource persons, although all five mothers expressed several problems, including difficulty finding and keeping competent nurses. Coping with the frequent turnover of nurses was problematic, mainly because of the time involved to interview and train them. Other complaints included a lack of flexibility in nurses availability, and canceling scheduled shifts at the last minute (Sharer & Dixon). A lack of privacy was a problem for two of the families who were receiving nursing care 24 hours per day. Similar complaints were expressed by the primary caregivers in Stevens (1990; 1994) research, so this suggests that these problems may be common complaints amongst this population of caregivers.

The purpose of Murphy’s (1991) study was to explore the perceptions of family members caring for a medically complex child at home. Twenty-one families participated and a total of 28 parents offered their perceptions of their situations. Twenty-five parents indicated that the most difficult aspect of home care was dealing with home care nursing. At the time of the study, 19 families had nurses from five to seven days per week, and nine of these families were receiving nursing care 24 hours a day, seven days a week. All of the families experienced some problems with their nurses. While poorly trained nurses and/or poor nursing care was reported by six families this problem, these were not considered to be paramount by participating parents. Eighteen parents reported that the nurses were disrespectful of parental authority. Loss of privacy and personality differences with various family members was reported by 13 parents. Other complaints included inconsistency in staffing, a lazy attitude toward their responsibilities, and a small percentage of parents felt judged by the nurses.

Unlike the current study, the majority of families in Murphy’s study were receiving nursing respite round the clock for between five and seven days a week. This may have contributed to these mothers being more critical of the nurses because they were in such close contact with these professionals. According to the Nursing Respite Program’s criteria, families can not receive respite 24 hours a day, seven days a week. Families in British Columbia’s Program can receive a
maximum of 100 hours therefore it may be that some of the concerns expressed by the mothers in this study may be significantly different than for the families in Murphy’s study.

In a number of studies, mothers reported a lack of adequate nursing respite hours (Gravelle, 1997; Petr et al. 1995; Sherman, 1995; Stevens, 1990). One final common complaint mentioned in several studies was a need for nursing respite in an emergency situation (Sherman, 1995; O’Connor, Vanderplatts, & Betz, 1992). Even when nursing respite had been made available to these mothers, the studies reviewed suggest that having access to nursing respite does not necessarily ensure that the nurses are providing adequate support to decrease the mothers’ stress levels and improve their coping abilities. The lack of suitable respite was a recurring theme in Diehl, Moffitt and Wade’s (1991) study. Parents in Diehl et al.’s study also expressed concern about the quality of respite care. Parents were uncomfortable leaving their child with a relative or friend because of the high level of skill required to safely care for their child. Twenty-five percent of the families reported having no respite relief at all (Diehl et al.). The findings from the above mentioned studies suggest that more evaluative studies are needed to substantiate how these primary caregivers’ needs can best be served, so that their energy levels are maintained in order to continue to care for their medically fragile children.

The purpose of Sherman’s (1995) study was to evaluate whether the implementation of home-based pediatric respite care reduces stress and improves the quality of life for families caring for chronically ill children. Although the original sample (n=73) is quite large, high attrition rates resulted in only 26 families where there were complete data sets. Close to two thirds of the families were of Hispanic or African American descent, with only one third of the families being Caucasian. Further, over half of the families were headed by single mothers. Due to the fact that the sample in Sherman’s study is not comparable to the characteristics of Hayes and McElheran’s (1993b) sample, it is not possible to generalize Sherman’s findings to other families with medically complex children. Another consideration is the fact that Sherman’s study was based in the United States and there are significant differences in the medical insurance system between these two countries.
Sherman's pre-post evaluation design is similar to Hayes and McElheran's (1993b) study, because the families were interviewed at two intervals, six months apart. The first interview took place prior to receiving respite services, and then again after six months of participation in the program. Primary caregivers' stress was measured using two well established instruments. In all the families, nursing respite had a positive effect on the primary caregivers' and the children's wellbeing. Mothers reported a significant decrease in somatic complaints (such as feelings of anxiety and depression) after receiving nursing respite. Caregivers also remarked that they experienced less stress surrounding the day to day demands of caring for their children.

Other Respite Options for Medically Complex Children

Medically complex children or medically fragile children, as they are often referred to, pose a unique set of challenges to the health care delivery system. Presently, there are very few programs available to support families with such children outside the traditional medical care setting (Hochstadt & Yost, 1991). Literature originating in the United States suggests that because of a lack of available community resources, in some states, there is a slightly increasing number of technology-dependent children being cared for in acute care hospital settings (Hochstadt & Yost). The tertiary care setting is unable to meet the developmental and psychological needs of these children (Wong, 1991), and poses obstacles for parents who are trying to meet their children's needs, such as: disruption of normal family routines, time for traveling to and from the hospital, and a lack of time for other family members.

In an attempt to meet the needs of this unique population of children, one state piloted a project aimed at developing home care resources for their medically complex children (Hochstadt & Yost, 1991). The goal of Hochstadt and Yost's research program was to investigate if a pediatric hospital and a child welfare agency could work collaboratively to develop the appropriate community resources to successfully integrate medically complex children from the hospital into home care. The population of children targeted in their program were medically complex children who were presently living in hospital; and for whom a return to their biological parents was not
feasible. Hochstadt and Yost’s program involved two components, a theoretical review of what was needed in the way of services and then a pilot test of a federally funded foster parent program.

Their theoretical review revealed that in the United States several states have attempted to develop community-based family services for the increasing number of medically complex children. Community-based programs for this population require the collaboration of a multidisciplinary model of health care in order to adequately meet the demands these children place on their families. Several of the multidisciplinary services mentioned in Hochstadt and Yost’s article relate to health care, child welfare, and social services.

Based on their theoretical review of available services, Hochstadt and Yost’s (1991) were able to receive federally funding to pilot test a foster parent program for medically complex children. The Medical Foster Parent Program was designed to provide foster care to children requiring high levels of technology support and skilled nursing care. In the beginning phases, 11 children were referred to the program for transition to community care. At the time of the first preliminary evaluation, Hochstadt and Yost had been able to successfully transfer six of these children to community foster care. In three other situations, program personnel had been unable to find suitable foster homes. One other child was to be returned to his biological family and finally one child was being placed in a pediatric nursing home until a suitable foster family was found.

These authors cite that during the operational phase they were able to identify some of the barriers involved when placing children of this unique population into the community. Further, they believe that they were able to overcome some of these barriers in their own community. The primary challenges which occurred during the implementation phase related to problems with the different personnel involved in the process. The personnel mentioned in this project as facing challenges include the community based service providers, the health care providers, the families, and the children.

According to Hochstadt and Yost (1991), the community based service providers are challenged because they must learn new skills, unfamiliar medical terminology, work collaboratively in their respective roles, and develop cooperative relationships with
multidisciplinary team members. Presently, there are few guidelines for how to integrate these children into the regular school system. School teachers, parents, health care providers and community agencies must negotiate new rules and relationships if the medically complex child is to receive the same educational opportunities as that of normal children.

Potential conflict can occur between the health care personnel and the family members. Families can experience a loss of privacy, and the health care personnel must learn to adjust their roles and responsibilities to the family's structure. All participants must learn to work collaboratively and draw on each others' strengths and resources (Hochstadt & Yost, 1991). When medically fragile children are being discharged from hospital into a foster home setting, both sets of families, depending on their degree of involvement with their natural or foster children can experience profound feelings of loss and separation. These complex family situations can create challenges as the two families attempt to define their varied roles. Hochstadt and Yost cite the most difficult challenge for the medically complex children stems from the fact they have spent a prolonged period of time in the hospital which causes a delay in their normal growth and development. Hochstadt and Yost identify that in order for these children to be successfully transferred to foster care all of the agencies and personnel involved in the process must be committed, flexible, creative and persistent in seeking to reduce obstacles and reach suitable solutions to placement difficulties.

The literature reviewed in this section suggests there are numerous challenges for governments and program planners who are attempting to plan and successfully implement community respite and other support services for medically complex children. This population of children have complex needs and require the expertise of professionals who are knowledgeable in their particular care demands. Hochstadt and Yost (1991)'s pilot project supported that if these children are to be successfully integrated into the community there needs to be a multidisciplinary approach to care. Both the professionals in the acute care and community settings need to work collaboratively with the families who will be providing care in order to ensure the needs of the children and families are best served.
Key To Successful Home Care

Wong (1991) believes that successful home care is very often a “complex balancing act” (p. 4). I visualize this balancing act as similar to a child’s teeter-totter. On the one end are health professionals’ criteria for establishing the degree of caregiver burden. The Nursing Respite Program’s criteria are strictly based on the child’s need for some form of technological support (such as ventilator support, total parental nutrition (TPN), tracheostomy care, oxygen therapy, gastrostomy tube feedings and home dialysis). Other children who may qualify for the program include those who require complex neurological or metabolic treatments or children needing palliative care (British Columbia Ministry of Health, 1992). On the other end of the teeter-totter is the family’s resources and ability to cope. Wong identifies five important factors to assess: the family’s physical resources, emotional resources, educational resources, social supports, and their competing demands for time and energy. Wong believes it is essential to have a case manager assigned to each family, because of the number of health professionals involved, owing to complexity of the children’s and families’ needs. Having a case manager helps to co-ordinate services, avoid duplication and fragmentation of services. Further, a case manager can assist the various disciplines to work collaboratively, thereby ensuring the family members can reach an optimal level of functioning.

In her article, Wong (1991) also stresses the importance of a thorough and well thought out discharge plan. She mentions five important components which need to be included: (a) assessment of the child and family for home care, (b) assessment of the community for those services the family requires, (c) development of a comprehensive care plan, (d) education and training of the family and other caregivers, and (e) evaluation of the ongoing plan. Finally, Wong points out that there needs to be at least two family members trained in the child’s care in order to prevent excessive strain on one family member. Many of Wong’s ideas have been expressed by other researchers and theorists. Petr et al. (1995) support Wong’s sentiments that families needs should be assessed on an ongoing basis by a case manager in order to optimize communication.
between the health professionals and ensure co-ordination of services, not only during the discharge planning phase but also when the child is at home.

Gravelle (1997) stresses the importance of respite services being implemented while the family is still able to cope effectively with their child's care demands. A crisis situation is not a suitable time to initiate respite as the family is already experiencing exhaustion and burnout. Mausner (1995) criticizes the current agencies for viewing respite as a luxury, rather than a necessity, as frequently it has only been arranged after the family exhibits significant stress.

Wheeler and Lewis (1993) raise an interesting dilemma involving the medically fragile child who is not technology-dependent. These researchers believe there is a gap in services for these children and their families, in that these children's care needs are still extensive, but they often do not qualify for nursing respite programs. Parents are often faced with co-ordination of all of their child's care services. Wheeler and Lewis further argue that in some cases while the home environment is the best place for the technology-dependent child, it is essential that the family want the child at home, or else the home environment is not conducive to the child's development. These authors believe that there is a shortage of placement options for these children. While foster homes can be a suitable alternative, there is presently a shortage of these homes.

Factors Affecting the Parent-Professional Relationship

In several of the studies reviewed, parents mentioned that one of the reasons nursing respite was a source of stress was because there was a strain in their relationship with the nurses providing care to their children (Murphy, 1991; Stevens, 1994). This is a recurring theme in the chronic illness literature: often families have difficulty establishing and maintaining a therapeutic relationship with service care providers, both in and outside their home.

Recently, researchers in various health care disciplines have begun to analyze why there is such a high level of dissatisfaction with health care professionals. There is evidence that dissatisfaction can stem from the effects of technological advancement which requires closer relationships between the recipient of health care and the professional (Thorne & Robinson, 1988). Thorne and Robinson explain that as the technological needs increase the health professional's
energy and time is channeled away from the whole individual, and the psychological needs are not the priority. These researchers argue that while there is a substantial amount of literature discussing what is theoretically missing from the client-professional relationship, there is minimal interpretative research addressing family members’ perceptions regarding the difficulties in their relationships with health care professionals. Due to the nature of the research question being asked in this study, it is probable that these results will offer some insights into what these mothers’ believe are necessary components of a therapeutic working relationship with the Nursing Respite personnel and the nurses providing care to their technology-dependent children.

Thorne and Robinson (1988) conducted a secondary analysis using data from two separate research projects which had been conducted earlier by these two principal investigators. Both of the original studies used subjects who in some way were involved with a family member who was living with a chronic illness. The total sample for the secondary analysis was 26 members of 14 families. Using a phenomenological approach, theoretical sampling was used to identify target groups who were considered by the researchers to have expertise concerning the phenomena of interest. Thorne and Robinson’s analysis revealed that the family-professional relationship is an evolving process made up of three phases: naive trust, disenchantment, and guarded alliance.

At the outset of the family members’ experiences with chronic illness, the members assume that their perspective is shared by the health professionals involved in the ill member’s care. Based on this assumption, family members anticipate that their expectations and goals for the ill family member are understood and shared by the professional. This naive trust leads the family members to believe that as the primary health care providers, decisions concerning the ill member would be collaboratively and mutually decided between the two parties.

Eventually, family members realized that their views of what was best for the ill member was not the same as the health professional, and they became disenchanted with the relationship. Thorne and Robinson’s (1988) research illustrated that the phase of disenchantment was characterized by dissatisfaction with care and feelings of frustration, anger, and fear. During this
phase, the relationship with the health care personnel deteriorated, and family members often became assertive and/or aggressive in their encounters with professionals.

The last phase of the relationship has been given the label of guarded alliance by Thorne and Robinson (1988). Guarded alliance was accomplished when the family was able to reestablish a trusting relationship with the professionals. The relationship naturally progressed to this stage, because of the ongoing nature of the chronic illness, and the fact that the members did need the health professionals to ensure their loved ones were adequately cared for. During this stage, both parties learn to work collaboratively and express their own perspective and arrive at a decision which is mutually acceptable. Due to the longitudinal design of Hayes and McElheran’s (1993b) study, the process of analysis may reveal that these families also progress through similar phases in their relationships with health care professionals. At the time of the third interview, if the same health care professionals (nurses providing respite and agency personnel, are involved in the child’s care), it may be that these primary caregivers have reached the third phase of the relationship, and be in a guarded alliance with the their health care personnel.

Similar to Thorne and Robinson (1988), Knafl, Breitmayer, Gallo and Zoeller (1992) performed qualitative theory analysis using data from a previous research project. Interview data were taken from 102 parents (51 families) of children with chronic illness. The original study’s purpose was to conceptualize how families define and manage a child’s chronic illness using an open ended interview style. The Knafl team’s project was designed to explore behaviours that parents believed promoted and sustained a positive working relationship. Thirty percent of mothers and 43% of fathers emphasized the importance of receiving accurate and complete information about their children’s illness and its management. Mothers more than fathers (M=51%; F=36%) felt the most important aspect of the relationship with the professional was the interactional style. Both parents preferred a style that communicated a sense of empathy and genuine concern for the family’s situation. Both parents also believed that it was important for the health care professional to establish a relationship with the child, however again a greater percentage of mothers valued this aspect in the relationship.
The purpose of Patterson et al.'s (1994) study was to assess the parent professional relationship with parents who were receiving nursing home care for their medically fragile children. Forty-eight families were surveyed using five standardized self-report instruments and open-ended interview questions. Data were collected at two different interval times in order to obtain follow-up information concerning the long-term impact (two and a half years later) on their families. Arising from their analysis, the Patterson team reported two main themes relating to the positive and negative aspects of the parent-professional relationship. The first theme related to behavioural competence and skill, and was concerned with how well the home care staff was trained to look after the child. The second theme portrayed the attitudes of the professionals in the home toward the child, parents and other family members. Aspects of parental concern supporting this theme included whether nurses were supportive and caring. Additional concerns related to family boundaries, privacy, and the professionals' ability to work collaboratively with the family. Patterson et al.'s (1994) qualitative analysis revealed an equal number of positive and negative aspects of the professionals' behaviour in the relationship. The aspects seen as important by both parents were: (a) being supportive to parents and other family members, (b) genuine caring for the child, (c) competency and skill level of staff, and (d) being respectful and collaborative with the family. Parents viewed the invasion to their privacy as the most significant negative aspect of the relationship. Other behaviours which were unacceptable included: unprofessional and untrained staff; lack of respect for the family; and unreliable and undependable nurses; and frequent staff turnover.

The Patterson team also used a number of quantitative instruments to measure family functioning resources, family coping, marital satisfaction, and social support. The quantitative analysis revealed that a number of resources were associated with less perceived strain in the parent-professional relationship for mothers (Patterson et al., 1994). Mothers who perceived themselves to have social support from their community reported less dissatisfaction with the relationship. The higher the educational level of the mother, the less was the perceived strain from home care nursing. Finally, mothers who reported more satisfaction with their marital relationship
were less unhappy with the behaviours of the professionals. Mothers who received more hours of home care per week reported more dissatisfaction, presumably because there was more of a likelihood they would experience an invasion of their privacy.

The Patterson team’s (1994) study has relevance to the current study, because similar issues might be raised by the mothers in this study, concerning what characteristics are needed in the nurses providing respite care. It might be that the primary caregivers in this study who are able to have consistency in their nurses, may reach a state of guarded alliance sooner and express that nursing respite is effective at decreasing their stress and increasing their abilities to cope. Further, mothers who have a strong social support network from family and friends and who are in a stable relationship might be less reliant of the services of the nurses in this study.

Families’ Views of Respite

If a family’s needs are to be met, it is essential that health care professionals understand what it is that family members feel will best meet their needs. Many professionals believe that because they are the experts in the health care field, they know what is best for the family. Current research is demonstrating that professionals frequently assume incorrectly what the families needs are (Diehl, et al. 1991; Horner, Rawlins, & Giles, 1987; Walker, Epstein, Taylor, Crocker, and Tuttle, 1989).

Horner et al. (1987) were interested in identifying the program, socioeconomic and health care needs were of chronically ill children as perceived by their parents. Their article offers no details about the particular types of questions being asked in their survey. The survey was mailed to 493 families and 164 parents returned the mailed questionnaire. Eighty-seven percent of the participants were the children’s mothers and the majority of the women were married (76%). This ratio is comparable to the mothers participating in this study as 8 of the ten mothers were still married to their children’s fathers. The majority of parents in Horner et al.’s study felt that planning for their child’s future was their greatest need (55%). Three other significant needs reported were: identifying appropriate community resources, understanding how the illness affects their child’s future, and improving communication among the children’s health care providers.
Parents in Horner et al.’s (1987) American study had numerous concerns in trying to obtain health care for their children. Their biggest worry (66%) was the cost of care. Other significant concerns related to waiting too long for appointments, having questions in-between appointments, conflicts with their ill children’s appointments and other family commitments, and not receiving answers to their questions. A large number of parents expressed frustration with health care professionals who did not seem to listen to them or understand their problems.

The Walker team (1989) of researchers in the United States used a survey approach to gather information about parents of children with chronic health conditions and their use of health services, out of pocket expenses for health care and other related items. The study was also designed to obtain information parents feelings about health and support care services. Nine hundred and ten parents were included in the analysis (a response rate of 38%) The questionnaire was developed by the researchers who enlisted the help of parents from the various parent organizations. Further content and construct validity was reviewed by experts in questionnaire design, and the questionnaire was pilot tested prior to the major study.

In Walker et al.’s (1989) sample of children, some of the more common chronic health problems included children with mental retardation, seizure disorder, cerebral palsy, congenital heart disease, spina bifida, and Down’s Syndrome. Approximately one third of the parents responded to the question requesting information about aspects they liked about specialty services. Fifteen percent indicated they liked the friendly and understanding staff, who showed a genuine interest in their children. The second most positive aspect of special needs services was the dedication, professionalism, and skill of the staff.

A significant number of parents in Walker et al.’s study felt were experiencing considerable financial burden; as they had numerous out-of-pocket expenses which were not covered by their health insurance. Some of the expenses mentioned were travel expenses (65%), parking fees (52%), drugs and medications (50%), lost wages due to child’s hospitalization or medical visits (25%), specialty equipment (23%), and babysitters for other children (22%). Only 11% of the sample reported no out of pocket expenses. One of the implications of the fact that Walker’s study
is based in the United States is that all families do not have access to universal health care like they
do in Canada. The sample in Walker et al. ’s study only included families who had access to these
kind of respite programs and health insurance. The differences in these two countries health care
systems makes it difficult to compare families’ financial concerns in Walker et al.’s study and the
types of financial concerns which may be addressed by mothers in the current study.

Using a focus group approach, Diehl et al. (1991) also explored the needs of parents of
children with complex needs in the United States. The focus group interview is a qualitative
technique that has the advantage of offering an indepth approach to information gathering. A total
of 80 caregivers (71 females and 9 males) were included in the study. The nature of the children’s
health problems included debilitating diseases of one or more physiologic or organ systems that for
the most part made them dependent on 24 hour a day on some form of medical supervision.
Parents were interviewed in groups of six to ten for approximately two and a half hours (Diehl et
al., 1991) Each session was mediated by a trained moderator and one assistant. Questions used in
the interviews had preliminary reliability and validity, and were approved by an advisory
committee. Members of each group were first asked to write down their biggest perceived need.
These needs were then discussed as a group, and additional questions and techniques of probing
followed.

The most important concern for the parents in Diehl et al.’s (1991) study was the stress and
strain of the child’s condition on the family structure. The burden of care impacted all levels of
family dynamics and every family member. A major concern was the family’s inability to be
spontaneous as a family unit. Parents expressed that they rarely did things as a couple. Many
parents expressed that support groups and counseling were a helpful resource in assisting their
coping abilities.

Parents in Diehl et al.’s (1991) study were not very complimentary about health care
professionals. Parents often stated they needed to be assertive and informed when communicating
with any professional. They felt that the professionals who were doing a good job were the
exception, and the only professionals mentioned as being supportive and helpful were
physiotherapists, occupational therapists, social workers and teachers. Most of the parents felt that they were carrying the majority of the responsibility for the quality of their child’s care, and felt that they need a competent case manager to coordinate services. Other significant issues related to financial reimbursement. Similar to Walker’s (1989) study middle income families were frustrated because they did not qualify for any reimbursement, and yet they were facing massive medical expenses.

This group of studies provides more evidence that families caring for technology-dependent children at home are facing high levels of stress due to the nature of their daily responsibilities (Diehl et al., 1991; Horner et al., 1987; Walker et al., 1989; The studies reviewed in this section suggest that even middle income families in the United States who have adequate health insurance face tremendous financial strain in trying to provide the necessary health care for their children. In Canada, families in all income brackets have access to identical health coverage. The implication of universal coverage is that the lower income families in Canada will likely be experience more financial hardship by the out-of-pocket expenses than the families mentioned in Diehl et al.’s, Horner et al.’s and Walker et al.’s studies.

In Horner et al.’s (1987) and Diehl et al.’s (1991) study parents expressed frustration with the health care professionals who they felt were insensitive to their needs and often did not take the time to listen to the issues which were at the forefront of their minds. Do the primary caregivers in the current study also face significant additional expenditures when caring for their technological dependent children at home? Are these mothers frustrated with the Nursing Respite Consultants and the other health care professionals providing services and support? Is there any evidence that the health care system contributes to these mothers’ stress levels, rather than increasing their abilities to cope?

Summary

Trends in health care indicate that there is an increasing likelihood that technology-dependent children will be cared for outside the traditional health care system in the future. Escalating costs of institutionalized care and a concern for the children’s development are two of
the main reasons for this change in health care practice. While the home environment may be the ideal setting both for the children and their families, to date there are many barriers preventing this situation from being an ideal and positive experience for the family.

The 24 hour burden of care affects the primary caregiver the most severely. The studies examined for this literature review revealed that in the majority of studies the caregiver was the mother. Mothers report feelings of extreme exhaustion, loneliness, and depression. The uncertainty relating to many aspects of the child’s care increased the likelihood that caregivers would experience anxiety, anger and frustration stemming from the stress associated with their daily responsibilities. Further, mothers felt pressured to become aggressive in fighting for needed respite and equipment to ensure the health and well-being of their children and the other family members. The majority of caregivers believed that they would not be able to care for their children at home without receiving some form of respite care. Parents of technology-dependent children are not comfortable with leaving their children with friends and relatives due to the complexity of care and the specialized training needed to manage the medical equipment. Nursing respite has been recognized as a needed form of support for these families, however research is indicating that parents perceive the presence of a nurse in their home as a mixed blessing.

This review of the literature identified a significant gap in the knowledge development of how well the current nursing respite programs are meeting the needs of mothers of technology-dependent children. Program evaluation research is important to enable policy makers and service providers aware of how best to meet the needs of its targeted population. This review suggests that policy makers have not thought through the full impact on families of caring for their medically fragile children at home. While this shift in health care delivery may be saving governments and funding agencies a significant amount of money, it appears to be at a significant cost to the primary caregiver and the family unit. Even when families have access to health insurance the studies reviewed suggested that financial concerns are a substantial source of stress for families living in the United States. The current study based on the Canadian health care system is likely to provide
some information about whether families in British Columbia share similar financial hardships from these hidden expenses.

The purpose of the present study is to explore how the primary caregivers of technology-dependent children in British Columbia view the role of nursing respite in managing their stress and improving their abilities to cope. The Nursing Respite Program was developed to give relief to the primary unpaid caregiver as well as provide the medically complex child with a competent and nurturing substitute caregiver (Phipps & McNeil, 1995). Presently, it is not known how well this provincial program is achieving its goal. In the provincial government's attempt to decrease global health care costs, and shift more and more of the responsibility of care to the family unit, it is important not to jeopardize the health of the caregivers. These very important care providers need to maintain their health and wellbeing in order to be able to continue to care for their children. Further, parents need to be assured that the nurses providing care have the necessary knowledge and skills to safely care for their children. If the technology-dependent children are to receive optimal care ensuring their physical, emotional, and social development, it is essential that the children's primary caregivers' health and wellbeing also be maximized by the support of adequate and safe nursing respite care.

The research question being explored in this study will provide more information about what these mothers need from a nursing respite program in order to maximize their own coping and ensure they are able to continue to care for these very demanding children without jeopardizing their own wellbeing. Grounded theory is an appropriate method to explore this question, because presently there is minimal information available concerning these phenomena and their interrelationships.
CHAPTER THREE
METHODOLOGY

The goal of research conducted within the interpretative paradigm is to provide methods for “understanding the complex world of lived experience from the point of view of those who live it” (Schwandt, 1994, p.118). Qualitative researchers study humans in their natural surroundings with the intent of understanding or interpreting phenomena in terms of the meaning people bring to them (Clarke, 1995). One assumption within the qualitative paradigm is that there are many different but equal realities (Benoliel, 1996; Clarke). Unlike quantitative methods of inquiry which attempt to find the “truth”, qualitative methodology aims to understand meaning people ascribe to their experiences (Clarke). This study used a qualitative method known as grounded theory. As a method of inquiry, grounded theory is focused on discovery or the generation of theory (Benoliel, 1996). Researchers employing this method are asking researchable questions dealing with social concerns to which individuals must adapt (Benoliel). According to Strauss and Corbin (1990), grounded theory is used by researchers in the social and behavioural sciences who are interested in understanding human behaviour and relationships. In recent years, nursing scholars have recognized that if they are going to be successful in helping to improve their clients’ health care habits, they need to understand the context of their environment and their social relationships, both of which are believed to strongly influence their health related behaviour. Such questions are amenable to examine through qualitative inquiry.

An important belief underlying qualitative methodology is that behaviour can only be understood in the context within which it occurs (Clarke, 1995). In grounded theory, the researcher starts with data about the lived experience of the participants, and attempts to reconstruct their reality. Each participant’s lived experience shapes how the researcher collects and analyzes data (Charmaz, 1990). Through the process of simultaneous data collection and analysis, the developing theory becomes substantiated through the process of constant affirmation, examination and refinement of the developing themes (Charmaz). In grounded theory research, the emerging theoretical categories shape future data collection as well as organizing the analytic phases of
coding, condensing codes into categories, memo writing, and synthesizing the developing theory (Charmaz).

Grounded theory was an appropriate method of inquiry to explore the question of how mothers' view the role of nursing respite in managing their stress and increasing their abilities to cope with the care demands of their technology-dependent children. The unstructured interview format encouraged the participants to share whatever was significant for them. By allowing the primary caregivers to express their impressions and feelings in a non directive and candid manner, the data are more likely to reflect a true picture of parents' reality. As a method of inquiry, grounded theory is guided toward discovery or the development of theory (Benoliel, 1996).

According to Strauss and Corbin (1990), a grounded theory question is most suitable to exploring areas where little is known about a phenomenon. Since the British Columbia Nursing Respite Program was fairly new when Hayes and McElheran (1993b) embarked on their evaluation study, evaluations of nursing respite programs had rarely been reported in the literature, and the impact of respite programs on children, caregivers, and families poorly understood, grounded theory was a suitable method to use to explore primary caregivers' views of the role of the Program in relieving their stress. The outcome of this grounded theory study will provide more valuable knowledge about the role of nursing respite in increasing mothers' abilities to cope with their technology-dependent children at home, a trend which is increasing in today's society due to the escalating costs of health care. There is increasing evidence that the physical, mental and emotional health of these caregivers is markedly affected by their increased responsibility, and to date very little is known about how to ensure these mothers' wellbeing. Evidence suggests that nursing respite can be a valuable resource for enhancing the wellbeing of these primary caregivers' health, although recent studies have provided conflicting results.

Research Design

Sample/ Participant Recruitment

Hayes and McElheran's (1993b) potential sample for the main research project included all the families newly admitted to the British Columbia's Nursing Respite Program for a period of
fifteen months commencing in April 1994. The sample fell short of the projected numbers, as Hayes and McElheran had estimated that between 40 and 45 families would be admitted during that time, and in the end only a total of 27 families participated in the study. For various reasons there is incomplete data on 9 families, leaving only 17 families where there is a complete set of three transcribed interviews. In two cases, the families voluntarily withdrew from the study, in four families the children died, and in three situations the families were discharged from the program prior to the scheduled third interview.

Other than being admitted to the Nursing Respite Program, the families had to meet several other criteria for inclusion in the evaluation study. These criteria included: (a) all the family members must consent to participate; and (b) family members must be able to speak and read English well enough to participate in interview, and complete the pen and paper instruments that were a requirement of the quantitative research questions.

Data Collection

When I joined the project in May 1996, the data collection phase of Hayes and McElheran’s (1993b) project was nearly complete. Consistent with grounded theory philosophy, the qualitative component of Hayes and McElheran's study implemented an unstructured interview format and participant observation to collect data. In the qualitative component of the major study, Hayes and McElheran were interested in exploring parental caregiver burden and family system responses to the program, and how it enabled families to care for medically fragile children in the home context. True to grounded theory and qualitative inquiry, the interviewer was careful not to direct the flow of the conversation except to clarify or validate what the participants were sharing. When there were any lapses in the conversation, open ended questions, or focusing or reflective statements were used to stimulate the discussion again. Although during the two and a half years that data were collected there were four research assistants (including myself), a turnover that partially jeopardized interview consistency and rapport, Hayes and McElheran were careful that prior to visiting the families’ homes, the interviewer had read the previous transcripts, and was clear on what were the main issues and concerns for the family. By being knowledgeable of the primary
issues for the families, the research assistant was able to check out and build the key codes or concepts. In other words, with each subsequent interview, the research assistant could enhance the analytic process by providing more evidence of the variation within the developing categories.

My research question evolved from initially becoming familiar with the grounded theory evolving in the major study. Over several months, I read a number of the families’ transcribed interviews and conducting a very general analysis of what I interpreted were the main themes present in the data. In order to gain a more global picture of the project’s findings, I attended several of the group analysis meetings where the principal investigators and one of the research assistants were participating in a discussion of the common themes which were recurring in the data. I prepared for these analytic sessions by reading and coding the same transcripts as the other team members. During these meetings I was able to share my perceptions of the families’ experiences with the Nursing Respite Program. Over the course of these few months, I sought Dr. Hayes’ support and expertise to assist with formulation of a suitable research question. Once the question to be asked was established, time was spent in several of the group analysis meetings analyzing the data in relation to my specific question, and in conjunction with the other elements of the umbrella context, “trying to have a life”.

I volunteered to assist with any of the final interviews, in order to have some first hand exposure with several families’ experiences with the Nursing Respite Program. Further, by conducting interviews myself, it enabled me to explore more information about my particular piece of the overall project. I also believed it was important to see the context of the families’ environments and be able to witness how the parents interacted as a couple and with their children, and the different roles they took on in relation to caring for their sick children. In order to prepare for the planned third interviews, I read both the previous transcripts, and made some notes about the issues I wanted to follow up on. One final step in my preparation involved a conversation with Dr. Hayes to ensure I was not missing any important information about the family. The first family lived near my urban area, so I was able to carry out the interview in the family’s home. Unfortunately, the only other family I was able to converse with lived out of town, and travel
budget restrictions made it necessary to conduct this interview over the phone. In both these visits, both parents participated in the conversation, and shared their perspectives of how the Nursing Respite Program was affecting their lives. Consistent with the way data were collected in the study, both conversations were audio-taped and I also recorded field notes at the beginning and end of each interview. These were later professionally transcribed.

Due to the fact that Hayes and McElheran's (1993b) study employed a quantitative component, and the interviews were conducted at 3 set interval times (prior to commencing respite services, and six and 12 months after the initiation of the program), there is a violation of true theoretical sampling, because there is a lack of flexibility in the time and ways data were collected. According to Strauss and Corbin (1990), rigidity of interview structure hinders theory development. Charmaz (1990) explains that in grounded theory research, researchers follow cues, hunches, or any interests they find or recognize in the data. Analysis begins with the first collection of data and as themes or codes are discovered, the researcher in subsequent interviews asks questions and explores these codes further in order to substantiate their presence in the data. Optimal theoretical sampling is not possible because data were collected on a predetermined schedule. However, because in grounded theory data bits and not people are sampled, it is possible to conduct grounded theory research with pre-existing data (Strauss & Corbin).

**Theoretical Sampling**

In grounded theory, sampling proceeds on the basis of concepts that have proven to have relevance to the evolving theory (Strauss & Corbin, 1990). In other words, sampling proceeds on the basis of incidents, not individuals (Strauss & Corbin). Using theoretical sampling, the data from the families' interviews were analyzed looking for incidents which were repeated. For example, one of the first concepts which repeated itself in the data was the inflexibility in the Nursing Respite Program's assessment criteria.

Proceeding with concurrent data collection and analysis with each new set of data, I was looking for verification that the emerging concepts or categories identified in previous data were present in each subsequent piece of data. Using the example of inflexible Nursing Respite
assessment criteria, I continued to analyze across families’ transcripts, I was not only looking for more incidents of whether this was an issue for all of the caregivers, but I was also interested in learning more about each parents’ views of what “inflexible” meant to their situation. If the developing category has relevance to the theory, the process of theoretical sampling will result in each category having the necessary variation and depth to ensure that it has earned its place in the evolving theory (Strauss & Corbin, 1990). In other words, the researcher collects new data to “fill out” (Charmaz, 1990, p. 1163) and elaborate theoretical categories.

Building on the example of inflexibility of assessment criteria, each caregiver interpreted this idea in a slightly different light. For example, for one mother, inflexibility meant that the technical equipment did not “represent” the “true story” of what was involved in her son’s care. Yes, he needed oxygen in order to stay alive, but what about the fact that he could have as many as 50 seizures a day, and that with any one seizure he could stop breathing? The oxygen did not prevent her son from seizuring and therefore even with this life support, there was still the possibility he could die from a lack of oxygen. For another mother, inflexibility meant that the assessment criteria should consider the caregiver’s and family’s needs, not just the child’s physical care. This mother was caring for premature twins, and only one of them qualified for respite, even though both twins had medical problems and required close supervision. Having respite for one child did not offer any relief for this mother, because she was still left to care for her other child.

For both these mothers the concept had similarities, adding density to the category; but also each reported interpretation varied also, because to each of these mothers inflexibility meant something slightly different. If inflexibility in assessment criteria is a valid concept in the theory, the data bits will reveal more and more evidence of its existence. Each new datum will add dimension and begin to explain the properties of the category, and this process aids the researcher to conceptually understand the relationship between the various categories. Theoretical sampling proceeded similarly with each new category. If a category does not develop significant density and variation during the process of theoretical sampling, then the category is discarded from the theory (Strauss & Corbin).
Setting

Most of the interviews were conducted in the families’ homes. Hayes and McElheran believed that this would be the most comfortable and safe environment for the families to share their experiences. Another valid reason for using their homes relates to the fact, that these families are too busy to come to another location, to say nothing of the fact that they would be unable to leave their children. When the research assistant phoned to schedule the interview, the entire family was encouraged to participate in the research visit. In the beginning phases of data collection, the research assistants traveled throughout the province to visit all families; however, due to funding difficulties, some of the second and many final interviews were conducted over the telephone for out of town families. When the visits were in the families’ homes, the data collection process was enriched due to the fact that the researcher was able make use of her observation skills. When interviewing face to face, one is able to make note of the non-verbal cues and gestures, as well as observe the physical appearance of the family members. By having access to the home environment, the researcher can also make note of the artifacts of daily family living. Further, the researcher is able to gain some insight into the family’s interaction patterns, and how individual family members cope with the daily routines of caring for the medically complex children. One final consideration concerns the value of seeing the family within the context of its community, which further enlightens the researcher about the family’s reality. Grounded theory aims to reconstruct the participants’ realities, and without the added visual picture of the caregivers’ real world, it is difficult if not impossible for the researcher to recreate the true meaning of Nursing Respite Program within families, and how it impacts the lives of the primary caregivers.

Procedures

Ethics approval was received from the review committee at the University of British Columbia. Prior to commencing Hayes and McElheran’s (1993a) project, the appropriate agency personnel were informed of the study’s purpose. Personnel notified included nursing consultants, agency contacts, and Ministry of Health personnel. When a family’s eligibility for the Nursing Respite Program had been established, and program personnel had informed the research assistant,
a letter was sent to the family explaining the evaluation project’s intent, and requesting the family’s participation. The initial written contact was followed up by a telephone call, where one of the research assistants answered any of the family’s questions, and provided additional information. Parents’ verbal consent to participate was confirmed with a written consent during the initial visit, and the process was assumed to be as “informed” as possible. The consent form had a place for the parents to give permission for the children’s participation in the study, when this was developmentally appropriate (see Appendix C). There was also a place for the child’s signature to assent to his or her participation in the study. Demographic information was obtained during this initial visit, and the instruments designed to collect quantitative data usually were administered. Each visit lasted between two and a half and four hours. The format of the visit involved a brief introduction which was followed by an hour to an hour and half unstructured conversation about family life with the child’s condition and its management, and the role respite might play in this family situation. Usually the quantitative instruments were completed at the end of the visit. During the visits, the research assistant encouraged every available family member to participate in the conversations. Follow-up phone calls were made when necessary to obtain any missing quantitative or qualitative data.

The second (six months after starting respite) and third (12 months after receiving respite) visits, and data collection procedures proceeded in a similar fashion, with the additional exploration of the “impact of respite services and the nature of nursing care. The qualitative interview component generally lasted between one and a half to two hours. Following each of the three data collection periods, the family received an additional four hours of nursing respite as a stipend for their participation, through arrangements made by the research assistant and the Nursing Program’s nurse Consultant. A total of 27 consenting families met the eligibility criteria, and commenced nursing respite care during the project’s projected intake period of 15 months. The entire data collection phase lasted 27 months, due to the time frame needed to conduct the second and third sequential interviews.
Prior to each scheduled interview, consent was obtained to ensure the family was still comfortable with the procedures and data collection techniques (Appendix C). Further, the family members were informed that they could refuse to answer any question at any time without jeopardizing the child's care. The interviews were carefully labeled as to family number, interview number, number of tapes used, and date of the interview. To ensure confidentiality, the interviews were transcribed verbatim using only number codes. Finally both the original tapes and a written copy of the transcribed interviews were locked in a secure place at the university where only the research team members could access them.

Process of Data Analysis

Data analysis proceeded following the techniques outlined by Strauss and Corbin (1990). The constant comparative method of data collection and analysis was conducted on a subset of Hayes and McElheran's (1993b) entire data set. Out of the complete set of 27 families interviewed, ten were selected for the purposes of this study. The criteria used for selection of this subset of data were: that the family needed to have participated in all three data collection periods; and that the parents and observations spoke to the issues of respite and parental stress and coping. In order to ensure adequate variation in the data, I felt it was important to analyze the parental role over the entire course of 18 months that the family was involved in Hayes and McElheran’s study. In two of the ten families selected for this study nursing respite was discontinued prior to the completion of the data collection period. In these two situations, the mothers still offered input into how the respite program had assisted them to cope with their children during the initial transition to home care. These mothers experiences with their children once respite services had been discontinued also provided variation to the categories relating to how families learn to cope with the day-to-day care demands of these children.

Open Coding

True to grounded theory methodology, initial coding involved a line by line analysis with the first few transcripts. In my case, for the previously collected data, a family’s complete set of interviews was coded prior to proceeding to the next family’s. For the two families for whom I
personally collected the data, the first two sets had been open coded by the research team both prior to and after my joining. Selective coding of these (and other) families' data progressed while I was a team member, and in addition, I reread and recoded data from the first two visits before I conducted the families' final contribution to the study's data. During open coding, the first step of data analysis, two procedures were followed to ensure the process of constant comparison. The first step, as outlined by Strauss and Corbin (1990), is to make constant comparisons of the data-bits. The second step involves asking questions of the data.

In this analysis, incidents relevant to the research question were identified and then compared to other incidents which arose out of the analytic process. Once incidents were noted to be recurring frequently in the data they were given a preliminary label. For example, three of the initial concepts which emerged from this analysis were: lack of flexibility, rigid assessment criteria, and inadequate respite. As initial codes were identified, I kept a list close by and referred to these code words with each subsequent family's transcripts. Consistent with the process of grounded theory, these initial concepts recurred frequently in the data. This initial stage of coding is called the identification or naming phase of grounded theory coding (Strauss & Corbin, 1990).

In the beginning, as recommended by Strauss and Corbin (1990), no attempt was made to group the ideas or phenomena together. Analysis naturally progressed to the next step which involved re-examining the initial codes for their similarities and then collapsing these initial codes into substantive codes and grouping them into categories (Strauss & Corbin). Similar to the process of open coding, each category was given a preliminary label. For example, the initial codes of lack of flexibility, rigid assessment criteria, and inadequate respite were grouped together, and given the label of "inflexible nursing respite assessment criteria". The process of concurrent data collection and analysis naturally progressed to the next step of discovering in the data the properties and dimensions.

As mentioned earlier, asking questions of the data is one of the most effective ways of progressing with grounded theory analysis. Examples of some of the questions I asked of the data were: (1) Under what conditions do the mothers feel they are coping effectively and have control
over their situation? 2) What consequences emerge from their reality of being in control? 3) What factors contribute to some mothers feeling the need to fight for more respite hours? By asking questions I was able to open up my thinking about the phenomena being studied. The process of questioning, according to Strauss and Corbin (1990) enhances theoretical sensitivity. Strategies which increase theoretical sensitivity stimulate the inductive reasoning process, and help the researcher to stay in tune with the meaning in the subjects’ experiences with the phenomena.

During this analysis, other strategies used to increase theoretical sensitivity included: the flip-flop technique and systematic comparison of two or more phenomena (Strauss & Corbin, 1990). For example, using the flip flop technique, I asked myself: “Why do some mothers seem content with the number of respite hours they have qualified for, while others feel the need to advocate for their children and their situation? Is there a relationship between the number of hours the families received, and the mothers’ feelings of contentment? Is there a relationship between the degree of social support the mothers report having, and their level of contentment with the number of respite hours they qualify for? Or does there seem to be a relationship between the child’s medical condition (level of stability), and the mothers’ perceived contentment with the number of nursing respite hours they qualify for?”

The systematic comparison method was also an effective strategy for increasing my theoretical sensitivity. For example, I considered the category of “flexibility of nursing respite hours”. What did the word “flexible” mean to these primary caregivers? What were the mothers’ expectations with regards to how they wanted to spend their respite hours (i.e., work, chores, social outings or just a mental break)? Did a mother’s expectations differ from the reality of how she was able to use her respite hours, and how did this affect her perception of flexibility? Did a mother who used her hours for work have a different perception of how flexible the hours were, than a stay-at-home mother? Were the mothers’ expectations of the Nursing Respite Program realistic given the situation and the number of hours they qualified for? These above mentioned techniques aided in identifying properties and dimensions of the emerging categories, and were
validated by examples in the data. Once categories and dimensions were validated for each
category, I moved on to the next step of grounded theory analysis.

**Axial Coding**

The goal of the process of axial coding is to develop conceptual density to the theory, that
also has enough specificity and variation to be able to apply the theory to many different situations
where the phenomenon is present. At the axial level of coding, the links between the important
categories are beginning to surface as patterns appear in the data. In other words, the researcher,
according to Strauss and Corbin (1990), should notice how clusters of properties, conditions,
strategies and outcomes relevant to the phenomenon interact with each other to bring about more
variation.

During the process of open coding, the data were taken apart in order to understand the
various dimensions and properties of relevant concepts found during the simultaneous process of
data collection and analysis. Axial coding served to put the various pieces of data back together in
order to understand “the story” of the participants. From a theory development perspective, axial
coding explained the relationships between the identified categories and their properties and
dimensions. The process of axial coding assisted me to explain the context in which the
phenomenon was present, and offered insight as to conditions which increase or decrease the
phenomenon’s significance. In other words, for the purposes of this research question, I was able:
(a) to identify in what contexts nursing respite was viewed by the mothers as adding more stress to
their daily lives and; (b) to identify in what contexts nursing respite decreased mothers’ stress and
increased their abilities to continue to care for their themselves, their medical fragile children and
the other family members. Further, this step of analysis assisted in adding variation and a greater
depth of understanding of the important concepts emerging from the analysis process (i.e.,
flexibility of nursing respite, skill levels of the nurses, security of respite hours) (Strauss &
Corbin, 1990).

During the entire analysis process, I was moving between inductive and deductive
reasoning, consistent with this method of theory development. For example, using deductive
reasoning, I hypothesized that mothers who perceive respite as a gift and use a positive outlook on their situation may be more likely to not fight the system for more hours and/or are probably generally more satisfied with the Program and the nursing care. Using inductive reasoning, I returned to the data to validate and find evidence for whether or not the data supports this deduction. According to Strauss and Corbin (1990) this back and forth movement is what makes the theory grounded. The data must support the hypothesized relationship over and over again. Once I reached saturation of all the major categories, I moved on to the last step in the analysis process.

Selective Coding

The process of selective coding involved identifying all the categories around a core variable (Corbin & Strauss, 1990). The core category explains the central phenomena of the study. According to grounded theory methodology, the other categories are related or linked to the core variable in terms of either a condition, an actional or interactional strategy, or a consequence. Selective coding also involves both deductive and inductive reasoning, and applies all of the same processes described in the other two steps of coding. The aim of selective coding is to relate all the major categories identified during axial coding to the core variable. As Strauss and Corbin recommend, I began this process by writing a few sentences or mini story line about what I believed is the main problem facing the mothers who are receiving nursing respite. Once this description was on paper, I returned to the data, and began to conceptualize the story by linking the concepts identified earlier to the story line. Similar to the other processes of coding, I moved back and forth, looking for the conditions, strategies and consequences which ground all the categories and their relationship to the main story line.

I was able to arrange the main categories into a paradigm, making sure that they fit the main story, and provided an analytic interpretation of this story (Strauss & Corbin, 1990). As this process of selective coding progressed, I was able to recognize patterns in the relationships between the properties and the dimensions of the categories (Strauss & Corbin). For example, it became apparent that the mothers were progressing through a process of learning about the
Nursing Respite Program and as they gained experience and knowledge about the program, its personnel and how it operates, they were beginning to realize what they needed out of the Program in order to have this service best meet their individual needs.

The outcome of the process of selective coding involves the selecting of a core category (Strauss & Corbin, 1990). The core category must relate to the other categories, and needs to explain most of the variation in the data (Strauss & Corbin). Finally, the core variable validates the relationship between the other categories. From the process of selective coding, I was able to conceptualize a theoretical framework or “map” which would assist my writing of these mothers’ stories into a logical and systematic story.

**Logistics of the Analytic Process**

There were two main sites where the analytic process took place: at home in my computer room and in the graduate students’ computer lab located at the university. At both locations, I was able to spread my computerized code notes, field notes, and memos out on a large table. I kept my notes sorted into piles according to themes. While working on the computer, I would frequently refer to these notes, flipping back and forth as I moved through the various techniques of open, axial, and selective coding. On several occasions it was necessary to return to the original transcripts in order to search for more evidence of the recurring codes, categories (their dimensions and properties) and their interrelationships. When this review was done, more notes were made and added to the appropriate stage of the analytic process. The main story line was conceptualized using a diagram, in order to have a clearer and more complete picture of the categories, core variable and their relationships.

Strauss and Corbin (1990) stress the importance of keeping memos as a part of the analytic process. A memo is a written record of our abstract thinking about the data (Strauss and Corbin). During the entire research process code, I kept written code notes on the computer describing the emerging categories and themes. With each subsequent transcript, I would frequently refer back to these code notes to substantiate that these themes were recurring frequently in the data. As I progressed to a higher level of conceptualization with these categories, and their properties and
dimensions were being identified, I drew a conceptual diagram of the relationships which were developing between the various key concepts. I found the process of memo writing to be invaluable especially during the final stages of theory development. My written memos assisted me to identify the “holes in my thinking” (Strauss & Corbin, p. 200), and also were beneficial in writing the main story line when I was attempting to tie in all the loose threads in the data. The next section will explain how the various techniques and procedures used during the analysis process assisted in ensuring the scientific credibility of this research study.

Methodological Rigor

The issue of achieving reliability and validity in qualitative research has been the focus of much discussion and controversy in the last decade (Benoliel, 1996; Clarke, 1995; Sandelowski, 1986; 1993; Strauss & Corbin, 1990). In the nursing literature, Sandelowski (1986) was one of the first scholars to address how to ensure the scientific merit of research within the interpretative paradigm. Initially, many critics of qualitative inquiry judged the scientific merit of this work with the same criteria used to evaluate quantitative research, a practice which does not do justice to qualitative methods (Corbin & Strauss, 1990).

Clarke (1995) explains that the basic assumptions and values underlying grounded theory violate the positivist notion of internal and external validity, thus making these concerns invalid to apply to this method. The researcher’s subjectivity inherent in the qualitative process interferes with internal validity (Clarke). According to Clarke, several factors enhance the validity of the method, including: the constant comparative method of data collection and analysis, the typically lengthy periods of data collection, and the fact that usually more than one method of data collection is used, for example, interviews and observations.

Grounded theory was first described by Glaser and Strauss (1967) and in the last 25 years the basic structure of this method has not changed; however, the procedures used have evolved and been elaborated on as scholars in the social and behavioural sciences have used the method (Corbin & Strauss, 1990). A basic assumption underlying this method of theory development is that phenomena are not static, but are continually evolving and changing with the passage of time.
Therefore, it is important that the grounded theorist incorporate change into the process of theory development (Strauss & Corbin, 1990). Sandelowski (1993) also alludes to the importance of the change process in grounded theory, and the fact that quantitative criteria for evaluating the rigor of a study are not appropriate to use when judging the scientific credibility of qualitative work. Sandelowski explains that validating information in a previous transcript can be problematic, because the nature of being human often makes us change our stories from one telling to another, as new experiences or events happen in our lives. Therefore, she believes that the practice of validating information at a later date is an invalid and inaccurate means of assessing the reliability of the theory. For the purposes of this study, I found these mothers' conversations clearly articulate their stories, and I did not find I needed clarification on any of the issues they were experiencing with the Nursing Respite Program.

A second important underlying principle of grounded theory, according to Corbin and Strauss (1990), is that human beings are seen to have the ability to control their destinies by their responses to situations. This second principle is important for the grounded theory researcher to consider during data collection and analysis, because if the theory is to be truly representative of the social processes surrounding the phenomenon, the researcher must be able to capture not only the relevant conditions of why nursing respite is perceived to be necessary, but also how the primary caregivers respond to environmental or situational changes surrounding the issue of respite, and further how they respond to the consequences of their behaviour. For example, is it beneficial (or a hindrance) for the primary caregiver to act as an advocate for her child when the issue of number of respite hours allocated by the Nursing Respite Program is perceived by her to be inadequate? In order for the theory to be precise, accurate, and valid, it must capture the true complexity of the social processes which determine behaviour (Benoliel, 1996).

In an article published by Corbin and Strauss (1990), they remark that qualitative methods can be systematically evaluated only if their canons and procedures are made clear. Corbin and Strauss explain that it is impossible to maintain rigor in a grounded theory study if the recommended procedures for data collection and analysis are not followed. In their discussion,
these researchers identify 11 main steps which must be adhered to in order to ensure that the theory is valid. In this study, careful attention was placed on each of these steps. First, according to Corbin and Strauss, data collection and analysis are interrelated processes. In this study, analysis commenced with the initial reading of the first transcript, and this same format was followed throughout all thirty transcripts reviewed. Second, Corbin and Strauss outline that in grounded theory concepts are the basic units of analysis. During the process of open coding, I identified code words (or concepts) which I felt best explained the event being discussed by the mothers. Concepts which recurred frequently were maintained as data collection and analysis progressed. Adhering to the third step, code words with similar meaning were grouped into categories and their relationship to the other categories was determined.

The fourth step according to Corbin and Strauss (1990), is that sampling must proceed on theoretical grounds. In other words, I sampled the data on the basis of concepts which proved to have theoretical relevance to the evolving theory (flexibility of nursing respite hours, skill level and competence of nurses, mothers’ view of the adequacy of the number of nursing respite hours they were receiving). Corbin and Strauss identify that in the fifth step, sampling techniques must make use of constant comparisons. For the purposes of this study, I would look for incidents to substantiate or disprove that mothers who had consistency in their nurses viewed nursing respite as a source of support. Did caregivers who had a frequent turnover of nurses view nursing respite as a source of stress?

The sixth step for ensuring rigor states that patterns and variations in the data must be accounted for. In my study, one example of a pattern is that both the mothers whose children’s primary medical diagnosis was seizure disorder felt they were not adequately assessed for nursing respite and that the assessment criteria needed to look at the whole child, not just the equipment the child was dependent upon. An example of variation in the data relates the fact that the degree of uncertainty associated with their children’s illness affected whether these mothers viewed nursing respite as a source of support or stress. For instance, one mother whose son was suffering from an unpredictable seizure disorder was very unsatisfied with the Nursing Respite Program and felt she
had been inadequately assessed. Another mother whose daughter’s illness was presently in a stable state in its trajectory had a very positive experience with the Program and its professionals. In the next chapter, this concept of illness uncertainly is fully described, accommodating the full breadth of its variation.

The seventh step of ensuring rigor according to Corbin and Strauss (1990) is that process must be built into the theory. This step implies that the human experience with the phenomenon is not static, and will vary over time and different events. In this study, the mothers’ perceptions of how well the Nursing Respite Program was meeting their children’s and their own needs varied on a number of factors including: whether nursing respite commenced as soon as their children were discharged; the amount of uncertainty in their children’s illness trajectory; and how well the skill level of the nurses matched the children’s individual care demands. Eighth, memos are an integral part of the analytic process and should begin with the first coding sessions (Strauss & Corbin, 1990). Adhering to the eighth step, I wrote memos about my developing perceptions, ideas, questions as I progressed through the various stages of data collection and analysis. Following the ninth step, I developed hypotheses about possible relationships among categories and verified these relationships throughout the research process. For example, I hypothesized that mothers who believed respite was “a right” would view the role of nursing respite differently from the mothers who believed nursing respite was a gift. Generally, the two mothers who felt nursing respite was a right were less satisfied with the Program, as they discussed more problems with the program through all three of the interviews.

The tenth step states that the grounded theorist researcher need not work alone, and for the purposes of my study, I frequently sought validation for my developing theory with the research team and on several occasions I met with the Dr. Hayes when I felt that I was not progressing in my analysis. My contribution to the discussion, was also helpful to the other committee members, as my perspective offered another interpretation of the meaning in the data. I found input from the research team to be very helpful as their ideas challenged my thinking, helped to stimulate new ideas, and forced me to question my assumptions and beliefs. The final step explains that it is
important to analyze the broader structural conditions. In this study, an attempt was made to analyze the Nursing Respite Program's role in the province's health care system. In the concluding remarks, suggestions and implications were offered concerning how the results of this study could assist funding agencies plan and successfully implement nursing respite programs in the future.

Sandelowski (1993) cautions qualitative researchers to not become too rigid and inflexible in their attempts to maintain rigor, because in the process you can destroy creativity and sensitivity, important components of the beauty and art of this method of theory development. In this sequel to her original article on rigor, Sandelowski criticizes qualitative researchers for being too defensive and sensitive about the issue of ensuring rigor. In the process, scholars have forgotten that the whole purpose of this field of inquiry is to create true to life stories and meaningful conceptual pictures of the human experience.

Summary

Grounded theory is an appropriate method of inquiry to use when little is known about the phenomenon of interest. The current study is using a subset of data from a larger research project, the purpose of which was to evaluate how well British Columbia's Nursing Respite Program is meeting the needs of families receiving its services. Hayes and McElheran's (1993b) study included both qualitative and quantitative research components. In the qualitative component the major study used grounded theory to generate theory about the experience of commencing and continuing with nursing respite services. This study's research question is a subsidiary of the larger research project, and therefore it was necessary to design a research question using the same qualitative approach to inquiry.

Following the steps outlined by Strauss and Corbin (1990), the constant comparative method of collecting and analyzing data were carried out when interpreting the meaning in a subset of the data. Hayes and McElheran (1993b) used a unstructured interview format when talking with families; therefore participants were encouraged to share whatever was significant to them concerning the phenomenon of interest. Open coding began simultaneously with the reading of the first transcribed interview and naturally progressed through the other analytic phases of axial and
selective coding. In the process, relevant concepts emerged which were later condensed into categories and their properties and dimensions. Finally, the relationships between the relevant categories were determined, and the constant comparative method of data collection and analysis continued until there was saturation of all the relevant categories. During the analytic process, a core variable was conceptualized which encompassed all that has been explained in the mothers’ stories about the role of nursing respite in decreasing their stress and increasing their abilities to cope. This picture of maternal stress and coping in the presence of their children’s demanding conditions and in home nursing respite services is developed in the next chapter.
CHAPTER FOUR
FINDINGS AND INTERPRETATION:
MOTHERS LEARNING TO MANAGE THE SYSTEM

In this component of our study about families, nursing respite care, and their children’s medically fragile condition, data collection and analysis continued until there was saturation of all the major categories related to mothers’ views of the role this care had in helping them manage their stress. The core concept or process in my component of the analysis has been named Learning to Manage the System. In turn, this core concept is seen to have four phases: Taking In; Losing Control; Taking Charge; and Managing Effectively within the Constraints of System Inflexibility. Mothers initially expected much from the Nursing Respite Program, and most anticipated their children’s arrival home positively. However, as hospital discharge approached, they became aware that rules and relationships within “the system” disturbed their pre-conceived notions of what home care and family life would be like (Hayes & McElheran, 1995). In describing how they learned to manage the system, they simultaneously illustrated their process of changing relationships with health care professionals in control of their children’s care; these I have named Blindly Trusting; Becoming Enlightened; Seeking Effective Collegial Relationships; and Establishing Working Relationships. In this chapter, I will describe pertinent concepts articulated by mothers about these stressful aspects of their experiences and offer some interpretation of these findings, using other authors’ theories throughout.

Description of Participating Families

To achieve this, a sub-set of 10 families who were caring for technology-dependent children at home were selected from the overall sample of 27 families. In all 10, the mothers were the primary caregivers. Seven of these were in relationships with the children’s fathers. One mother had never been married to the child’s father, and in another situation the mother had separated from the child’s father subsequent to being geographically separated from him for the six months the child was hospitalized in this large urban city. One couple was an Associate Family who had been caring for the child for the past eight years. (The Associate Family program in British Columbia reimburses the family to care for the child in their home, similar to a foster
family. In this association, the biological parent[s] remains involved with the child). However in this situation, the biological mother was minimally involved, dropping in on the Associate Family occasionally and helping with some decisions concerning her daughter’s care. Three of the families included in this analysis lived in Vancouver, and the remaining families lived in remote rural communities.

The technology-dependent children’s ages ranged from five months to 16 years. Seven children were under one year of age, and two other children were in the toddler stage of development (one being 2 years of age, and the other being 21 months). One was an adolescent living with an Associate Family. In total, there were five boys and five girls in this group of children with chronic conditions. The children’s diagnoses varied considerably, and include such health problems as seizures (n=1), meconium aspiration resulting in cerebral palsy and seizures (n=1), Nager Syndrome (n=1), chronic renal failure (n=1), bronchopulmonary dysplagia (n=3), tracheal malasia (n=1), and short gut syndrome (n=2). The primary reasons that the children qualified for nursing respite were for tracheostomy (n=2), gastrostomy tube feedings (n=7), home oxygen (n=6), jejunostomy tube feedings (n=1), and (TPN) (n=2). Eight of the children were dependent on more than one of these life saving measures.

In a total of seven families, the technology-dependent child was the parents’ first child. One infant was a twin, and although his sibling also had complications, he did not qualify for the Program. One child had an older sibling, and in the Associate Family the child had a 22 year old foster brother who was developmentally delayed. The Associate Mother’s biological children no longer lived at home.

**Amount of Respite.** There was a wide range in the number of nursing respite hours the families were receiving at the time of the study (see Table 1). The number of hours the family had been allocated at the time of the initial interview ranged from four to 48. In the majority of instances the hours allocated per week were not flexible, meaning that unused hours from one week could not be saved and utilized at a later date. Only one family had been assigned “flex” hours, which means the caregiver could accumulate unused time in order to have a larger block of
nursing respite hours away from her caregiving responsibilities. At the time of the third interview, two families had been discharged from the Nursing Respite Program, and one additional family was due to have services discontinued in the near future.

**TABLE 1: Number of Hours of Respite per Week**

<table>
<thead>
<tr>
<th>Family #</th>
<th>Initial assessment of hours</th>
<th>At second visit</th>
<th>At third visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family 1</td>
<td>16 hours of flex time*</td>
<td>24 hours of flex time</td>
<td>16 hours of flex time</td>
</tr>
<tr>
<td>Family 2</td>
<td>8 hours</td>
<td>24 hours</td>
<td>24 hours (request for increase refused)</td>
</tr>
<tr>
<td>Family 3</td>
<td>48 hours (requested additional 7 hours)</td>
<td>48 hours</td>
<td>48 hours</td>
</tr>
<tr>
<td>Family 4</td>
<td>24 hours</td>
<td>24 hours</td>
<td>24 hours</td>
</tr>
<tr>
<td>Family 5</td>
<td>8-12 hours</td>
<td>Discharged</td>
<td>Discharged</td>
</tr>
<tr>
<td>Family 6</td>
<td>4 hours</td>
<td>16 hours</td>
<td>16 hours (to be cut next month and then discontinued)</td>
</tr>
<tr>
<td>Family 7</td>
<td>8 hours</td>
<td>8 hours</td>
<td>8 hours</td>
</tr>
<tr>
<td>Family 8</td>
<td>16 hours</td>
<td>16 hours</td>
<td>16 hours</td>
</tr>
<tr>
<td>Family 9</td>
<td>24 hours</td>
<td>24 hours</td>
<td>24 hours</td>
</tr>
<tr>
<td>Family 10</td>
<td>40 hours</td>
<td>70 hours</td>
<td>70 hours</td>
</tr>
</tbody>
</table>

* Flex hours may be used by the family at members’ discretion.

**Conversations with Mothers.** As mentioned in the previous chapter, the initial intent of Hayes and McElheran’s (1993b) study was to conduct all interviews in the families’ homes. However, in the latter months of the project it became necessary to interview families over the phone due to projected cost overruns. In this sample of 10 families, a total of 18 interviews were carried out in person by one of three research assistants (myself included). That is, at Time 1, there were nine home visits and one telephone interview, at Time 2, five home visits and five telephone
interviews, and at Time 3, four home visits and six telephone interviews, for a total of 18 in-
person conversations and 12 telephone interviews. Only one participant family had all three of the
families’ interviews conducted over the phone.

Learning to Manage the System

The mothers in this grounded theory analysis each told a similar story of *Learning to Manage the System* in order to maximize the benefits of nursing respite, specifically to decrease their own stress and increase their abilities to cope. The requirement to “learn the system” started immediately for a mother when it became apparent that her child’s (baby’s) condition was serious and needed tertiary-level medical intervention in order to sustain his or her life. Refer to Figure: 1 for a conceptual diagram of the various phases of *Learning to Manage the System*.

<table>
<thead>
<tr>
<th>Taking In</th>
<th>Losing Control</th>
<th>Taking Charge</th>
<th>Managing Effectively within the Constraints of Inflexible Rules</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learning the Skills Required for Care</td>
<td>• Transition from Hospital to Home Care</td>
<td>• Learning the Rules of the Program</td>
<td>• Mothers’ Recommendations for How to Improve the Program</td>
</tr>
<tr>
<td>• Inflexible Respite Assessment Criteria</td>
<td>• Role of uncertainty</td>
<td>• Taking one Day at a Time</td>
<td></td>
</tr>
<tr>
<td>• Assessment Criteria Do not tell the true picture</td>
<td>• System or Program Uncertainty</td>
<td>• Taking Control</td>
<td></td>
</tr>
<tr>
<td>• Blindingly Trusting</td>
<td>• Professional Uncertainty</td>
<td>• Keeping a Positive outlook</td>
<td></td>
</tr>
<tr>
<td>• Becoming Enlightened</td>
<td>• Illness Uncertainty</td>
<td>• Just Getting On with It</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Living with Uncertainty</td>
<td>• Seeking Social Support</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Establishing Working Effective Collegial Relationships</td>
<td></td>
</tr>
</tbody>
</table>

*Figure: 1: Mothers’ Learning to Manage the System*  Mothers’ experiences of caring for their special children and adjusting to respite were conceptualized as evolving through a four stage process: *Learning to Manage the System: Taking In, Losing Control, Taking Charge, Managing Effectively within the constraints of inflexibility*. Mothers simultaneously moved through four phases in their relationships with the health care professionals: *Blindingly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships* and *Establishing Working Relationships.*
The length of stay in an acute care facility at the time of diagnosis varied from four months to 20 months. During the time the child was in hospital, the mother learned a great deal about her child’s illness: how to deal with setbacks and disappointments in her child’s illness trajectory, and to live with uncertainty. The chronic illness literature clearly documents that mothers find the uncertainty associated with their children’s illness very stressful and generally survive by taking one day at a time (Cohen, 1993; MacDonald, 1996).

The period prior to the initiation of respite, including initial contact with the health care personnel in the Nursing Respite Program, has been conceptualized as the *Taking In* phase. During this phase, mothers seemed to be taking in the knowledge and skills needed to care for their children and were becoming aware of the enormous responsibility of living with their special offspring.

*Taking In*

During the *Taking In* phase of *Learning to Manage the System*, mothers spent a great deal of time and energy responding to situations which arose concerning their children’s care. As previously mentioned, this phase involved gathering the necessary information to prepare them for taking over the responsibilities of caregiving. Mothers’ experiences with hospitalization were generally very positive during this phase and their stories reflect a trusting relationship with the doctors and nurses involved in their children’s care. For example, two of the participants lived in cities close to the Alberta border; consequently during their pregnancy they were being monitored by obstetricians in that province. Both of these mothers’ children had been born in the same Alberta hospital and spent the first few months in its Special Care Nursery. In both cases, these children’s care was transferred to physicians at British Columbia’s Children’s Hospital once their conditions stabilized for transfer. The mothers had become so close to the health care professionals who had initially saved their children’s lives that they continued to travel out of this province at their own expense for follow-up assessment and treatment.

*Learning the Skills Required for Care.* Generally, mothers used the time that their children were hospitalized to become familiar with treatment and management schedules, and the majority
of the mothers anticipated their children’s discharges with extreme optimism and excitement. These 10 mothers had spent a great deal of time with their children during their hospitalizations. Hence, during the first interviews, all the mothers stated that they felt confident in their ability to manage their child’s care at home by the time of discharge. This indicates that their time with their children in hospital was seen as having been spent productively. There were two mothers who did not discuss their experiences of hospitalization. In the first, the Associate Mother had not known the child and family at the time of the diagnostic hospitalization, although she had been caring for the 16 year old for the past eight years. In the second instance, the mother’s initial experience with her son’s illness had simply not come up at the time of the first interview. For the other eight mothers, this initial period of their children’s life was reported to be extremely valuable because it allowed them to gain the knowledge and skills to prepare them for their responsibilities once their children were discharged from hospital.

Inflexible Respite Assessment Criteria. One variable which significantly affected mothers’ abilities to initially Take In details about “the system” was the rigid assessment criteria used to establish and maintain their children’s eligibility for the Program. Mothers described their difficulties with these criteria by focusing on a number of different issues, including that rules were too rigid, had the wrong focus, and did not consider the family’s “true situation.” Further, the majority of mothers in this sub-set felt that the number of hours of respite they had been allocated per week was inadequate. The main target of their complaints was the Nursing Consultant because she represented the agency (the Nursing Respite Program) and its rules. In describing her experience with the assessment phase, one mother described her feelings as follows:

A nurse should go into the home for a week and assess the child and the whole thing, and get to see what the parent looks like every day, the main caregiver and stuff, and the nurse go in and give a report because when you just come in for a 45 minute visit or an hour and a half you may see nothing. When they first came, he slept through the whole visit so they thought he was okay, meanwhile they really didn’t realize how bad it was.
This mother's son had a severe seizure disorder and he regularly experienced eight seizures in a twenty-four hour period. The mother described her son's seizures as life threatening because he would stop breathing and turn blue. During her first interview, she described the Nursing Consultant's initial assessment and was critical of the oversimplification of her son's care because the Program's criteria considered only his G-tube when assessing his respite needs.

Mothers often expressed concerns about their lack of a trusting relationship with the Nursing Respite Consultant. During the same interview, this mother stated: "If the first one [Nursing Consultant] would have taken the time of day to ask me to sit and talk and hear the whole story like the second one did, they would have seen the whole picture of [son]." This mother felt the first consultant took bits and pieces of information; therefore, her advice to the Consultants was to "listen first and then ask questions." At one point in the first interview she had this to say about her situation:

So that's where the threat lies with him, not in the fact he has seizures, but it's the fact that when he comes out of them he's not breathing. And I know the nurses mark it down as cyanotic but that means diddly-squat to me.... I call it "death blue" because that's how blue he is.... And for them to turn around and tell me I should train a non-nursing person to come in and care for him, they've got to be nuts.

The implication is that the Consultant was not competent; consequently the mother lost trust in the Consultant and the system she represented. This same primary caregiver also said she believed that the assessment criteria had the wrong focus. In her opinion the criteria should consider the mothers' needs as well as the needs of their children. In her words: "So we're looking at getting more hours and [the Consultant] based it on the fact, well— [Son's] increased seizure activity, and not the fact that mum is just totally worn out and can't do much more."

One mother vented her frustration with the assessment criteria this way:

I think the assessment certainly [laughter], in my opinion anyways—...It]was totally inadequate in that, you know, we went from 24 [hours] care [in the hospital] at five thousand dollars a day, and then one thousand dollars a day, to zero. Then
we were given 8 hours a week of nursing respite which I just about laughed at when I heard because—I was not looking for the sky for sure.... I was happy to get the 8 hours, but I thought eight hours, well maybe I can go to the bank twice.

This is an example of a mother venting her feelings because her expectations of respite care failed to be met by the actual care delivered. Receiving minimal respite for these mothers was almost worse than receiving none. Earlier, this same mother expressed her frustration in this way: I thought, how am I going to use that eight hours? I'm not going to use it for one night because that will just make the next two or three nights seem so much more difficult.... You have to get into a routine if your body is more accustomed to this many hours [so you can] sleep consistently.... So hopefully your body will adjust.

Due to the inflexible respite rules, families are generally not allowed to accumulate unused respite for future use. Many mothers commented that, when their children became ill, they usually were in need of more respite because of the increased care demands. One mother reported that she felt chronically tired and, when her daughter became sick, her exhaustion became unbearable. Her daughter's fragile medical condition required the use of a respirator at night to help her breathe, thereby qualifying the family for 70 hours of respite per week. The young mother ran a motel with her husband during the day and therefore, felt it was most important to have the nurses provide respite at night. The majority of this family's respite hours were used from 11pm to 7am (8 hours X 7 days = 56 per week) and then the additional two hours was used during each day of the week (2 hours X 7 days = 14 hours per week). Even though this family was receiving more respite hours than any other family involved in this study, both parents were suffering from exhaustion. In her second interview this mother commented “We’re tired” several times, and the father echoed his wife's sentiments by the confirming statement “We’re tired people.” This young family was able to get an additional four hours of respite a week, and used the time from 7pm to 11pm to catch up on their sleep.

There were a total of seven nurses involved in meeting this family's respite needs. Even though the nurses cared for their daughter at night, the respirator was so noisy that the child's
father slept in an empty room in the motel. This mother admitted that so far they have not had any problems with the nurses cancelling their shifts, but this possibility scared her. Because their daughter frequently needs to be suctioned while on the machine, her mother was afraid that because of her chronic fatigue she would fall into a deep sleep and would not hear her daughter’s breathing problems. In her own words: “Sometimes it’s really hard ....But the night one [respite nurse] is the most important one .... Because I’m so scared of falling asleep when she’s on the machine .... Because you can’t hear if she needs suctioning.”

**Assessment Criteria Do Not Tell the True Picture.** As well as the Nursing Respite Program having inflexible assessment criteria and not providing enough respite to cope adequately with their caregiving responsibilities, mothers complained that the assessment criteria either did not consider the whole family’s situation, or did not tell the “true picture” of what providing care to their technology-dependent child was really like. The mother of twins had this comment about the assessment criteria’s focus:

They should look at us as a family and not just separate [members], you know.  
Because he’s [twin not receiving respite] only got one kidney that works.... So we’ve got one sicker child and one semi-sick child so it’s not just taking care of one child. Plus they’re twins [implying at least double the work involved in care]....  
They should have looked at us more as a family, than as an individual [just the twin receiving respite].

One single mother, who had originally been turned down for respite, could not believe that her son’s condition **had to deteriorate** before she was able to qualify for the program. When she finally did qualify, her son needed the life support of three machines (oxygen, suction, and a monitor to measure his blood oxygen). Further, this mother required an inter-room sound monitor because of his fragile medical state. Initially, this mother had only qualified for eight hours of respite per week, although, by the time of the third interview, this had been increased to 24 hours per week. When she lived in Alberta, she was eligible for 26 hours and, at that time, her son was not dependent on any auxiliary equipment. This situation illustrates how the rules can vary from
province to province and how previous knowledge of another program markedly influenced this mother’s perception of what this province’s Nursing Respite Program should provide.

Three mothers had more than one child to care for and they all complained that respite was only there for their children who were technology-dependent. When the respite nurse was in the home, the families had to find someone else to look after the other children. The Associate Mother, who had previous experience with another (non nursing) respite program when her daughter was not as acutely ill, told this story: “Before we had someone who could stay with both children, but now, under this Program, we can’t have that.” As was mentioned in the above paragraph, the mother of twins also expressed frustration that the respite was only there for one twin and, therefore, she chose to use her respite at night in order to obtain a break from both children. Out of the ten mothers involved in this analysis, four mothers used their respite hours mainly at night.

Six mothers mentioned that the technical equipment used to assess the child (for example tracheostomy, feeding tubes and oxygen) did not represent a true picture of the child’s situation. Several mothers felt seizure management should be included in the criteria and another mother mentioned that her son was deaf and needed concentrated time blocks in order to teach him sign language. Several mothers commented that they felt their children “fell between the cracks.” One mother was especially articulate in her story:

It is so much work and I feel frustrated because you’re already dealing with and coping with disabilities, things [her son] will have to deal with.... It’s been a roller coaster ride for us.... And I’m just exhausted...trying to get some more hours, trying to get some more help and it seems that everywhere we turn there’s no answers. Nobody can seem to give us help, we don’t qualify for the respite program for the mentally handicapped because [our son] is not really mentally handicapped.... We don’t qualify for daycare because he is a trach child, so [our son] is a child that really falls between the cracks.
This young working mother had spent many hours crying because she did not feel she was receiving enough respite. In her own words: “I’m always juggling to fight the system to get more hours.” At a later interview, the research assistant asked the mother why she had not been able to get any more respite and the mother’s response was “They won’t give me anymore.” Another mother reinforced the same theme:

There’s a lot [of children] that are in this grey area, probably more than are actually considered for nursing respite—.... Kids that aren’t getting anything and I know how hard it was for me to function for that four or five months with nothing.... I really think that everybody [“The system”] should be able to cover up those grey areas—...make sure these kids are taken care of because if they are not taken care of, the parents are not taken care of, and you’re going to end up with a whole bunch of these little kids somewhere on your [“system’s”] doorstep.

In both these scenarios it is implied that there is a gap in services for the caregivers of chronically ill children. Although the Nursing Respite Program appears to be able to service the needs of that special classification of chronically ill who are technology-dependent, these mothers believe that there are not enough other forms of respite support available for these children once they are no longer dependent on technology for survival. The lack of alternate respite options that is illustrated in our study was also a concern in Wheeler and Lewis’s (1993) research. Further, a survey conducted by O’Connor et al. (1992) supported the premise that in California there is a lack of respite options for caretakers of chronically ill children.

For some families a Catch 22 situation arose, because for at least two of the mothers, the assessment criteria placed them in a dilemma. They were reluctant to have their children’s condition improve to the point that they were no longer dependent on the technology because they would then no longer be eligible for nursing respite. In the words of one mother: “When [he] goes off antibiotics for over a month...then it [respite hours] will be cut back to thirty two hours and if he goes off TPN and antibiotics we won’t have any [respite].” For another family whose technology-dependent child was also in need of TPN, their dilemma was also related to their daughter’s health.
This mother expressed her frustration at the fact that physicians were going to cut her daughter’s TPN down to eight hours a day, with the consequence her nursing respite would also be cut back to eight hours. In this mother’s words:

Starting now, start cutting her back.... Get her down to eight hours.... That’s my other question—...her demands don’t change, just her times change.... So then they [Nursing Respite Consultants] say once her TPN starts getting cut back, the hours of nursing [also get cut back].... So that’s another question.... You still need to hook up and lock off...there’s still the [same] responsibilities, it’s just a bigger block of time in between...so that’s my question.

This mother’s primary concern was that she felt the most time-consuming aspect of her daughter’s care involved the sterile procedure needed to access her central line to receive the TPN. Due to her child’s developmental phase (toddler), two people were needed to perform this function. According to her logic, the time involved to access and disconnect the central line was the same no matter how many hours the TPN was infusing, therefore, it did not make sense to cut the nursing respite hours just because the total number of TPN hours was being cut back. This mother does not believe her hours should be cut back, just because the total volume of fluid being infused is decreased. In her view the real work involved with the TPN infusion relates to the times when her daughter’s central line is accessed and disconnected.

Prior to their initial contact with the Nursing Respite Consultants, mothers were very trusting of the system and assumed that their children’s transition from hospital to home would progress smoothly. Mothers assumed that the Nursing Respite Consultants would be trustworthy and had a vested interest in ensuring that families would receive sufficient nursing respite to allow them to function. As the two above examples illustrate, as the time grew closer for the nursing respite to begin, mothers became disillusioned with the Program because most believed that the Program failed to live up to their expectations. Families where respite commenced at the time of discharge (or close to the time of discharge) experienced less disenchantment with the professionals than those who were left with their children’s total care responsibilities for any length
of time. In eight families in our study, nursing respite was scheduled to start soon after the child was discharged from hospital. This first phase of mothers’ evolving relationships with the system’s health care personnel has been conceptualized as the Blindly Trusting phase of the relationship.

Blindly Trusting. A central element of learning to manage a child’s medically fragile condition at home is the development of relationships between the parent and health care providers. The present analysis provides evidence of the development of this process in four stages, parallel to the four stages of Learning to Manage the System:: Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships, and Establishing Working Relationships. Initially mothers innocently trusted that the Nursing Respite Program would be the answer to all their concerns and would allow them to care for their children safely while still “Having a Life” outside of their caregiving responsibilities (Hayes et al., 1997). Mothers in this grounded theory analysis assumed that they would not only qualify for the Nursing Respite Program, but that they would be able to receive enough hours to ensure their children’s and their own physical, mental and social wellbeing.

Nine mothers had developed good therapeutic relationships with the doctors and nurses providing care during their children’s initial hospitalizations and had begun to trust and depend on the health care professionals who had supported them and had provided information for them during this period. Many of the mothers roomed in with their children for their entire hospitalizations, which contributed to their feeling safe and secure because of the competency and skill levels of hospital professionals. Although the majority of hospitals do not offer a formal teaching program for caregivers, most of these of mothers reported feeling skilled, knowledgeable, and competent with their children’s care by the time of discharge. They trusted that future relationships with community-based providers would be the same.

This initial phase is similar to the naive trust phase of Thorne and Robinson’s (1988) theory, that describes family members’ assumptions that their goals and objectives for ill family members’ health are congruent with those of the health care professionals. In Thorne and
Robinson's theory, similar to our evolving theory, the families were also caring for a member with a chronic illness. Family members in Thorne and Robinson's work believed that decisions concerning their loved one's care would be collaboratively decided and mutually negotiated. Thorne and Robinson's conceptualization of families' evolving health care relationships support a three phase process: naive trust; disenchantment; and guarded alliance, in comparison to the four phases suggested in our data.

In another study, Wuest and Stern (1990), using the grounded theory method of inquiry, investigated the experience of parents with persistent middle ear problems. Wuest and Stern's study postulates that families progress through a social process of "learning to manage" family life successfully (p. 556). Similar to our theoretical perspective on health care relationships, Wuest and Stern trace, four phases in families' relationships with physicians when they are caring for a child with otitis media. They further suggest that the four phases of this relationship are entrusting, becoming disillusioned, learning the rules, and negotiating. During the entrusting phase most families believed that their physicians could cure the illness and therefore entrusted their ill children to the system. A parallel analysis can be drawn in our study: The mothers trusted that the Nursing Respite Program and other community resources and supports would be sufficient to allow them to carry on a fairly normal family life. As described by these caregivers, normal life meant having the time to do their chores (both inside and outside the home), and time for themselves (e.g.: attending an aerobic class, going for a walk, or going to a movie with a friend). Several other mothers yearned to be able to return to work, because this would improve their sense of self-worth, as well as providing them with a break. All of the mothers included in our grounded theory study stated that life would be normal if they could get their regular night's sleep (Hayes et al., 1997).

Mothers often assessed the adequacy of the number of respite hours by whether they were able to get enough sleep. Mothers who were able to get sufficient sleep generally viewed the Nursing Respite Program and the number of hours they were receiving much more positively. Similarly, all 10 of the mothers in our study reported feeling less stressed and better able to cope when they managed to get enough sleep. For example, the mother in the next scenario,
described her overwhelming exhaustion and blamed the system for not providing enough respite hours. In her words:

Like, I’ve gotten to the point where everyday I’m always crying now.... I’m always tired. My respite is Mondays, Tuesdays, Thursdays, and Fridays and if I don’t sleep for a full four hours on Tuesday, I find that Wednesdays I’m so wrecked. You know, I’m sitting in a chair and I’m falling asleep.... I need more hours.... Like, I don’t eat properly anymore, I don’t sleep properly; I can’t say I’m losing weight because I don’t do enough to lose weight. But, yeah, I find that I’m catching everything that’s going around.

The literature reviewed prior to the commencement of this research study supported that mothers caring for chronically ill children frequently complain of suffering from exhaustion (Stevens, 1990; 1994; Teague et al. 1993). For a period of four months this mother had been receiving an extra eight hours: “Oh, it was great. I felt relaxed and calm and able to cope with everything, cope very easily. Whereas now, like I said, I’m ready to pounce on anybody”. Another mother expressed how important sleep was to her ability to cope:

Like if you can sleep all night, then you can handle the day. But it’s when...you only get two hours of sleep in between each time.... So when you’re up that much at night you can’t function as well.

The next phase of Learning to Manage the System in our study has been called Losing Control. Mothers experienced a loss of control when care demands were excessive and they found themselves in a situation where they were not coping effectively.

Losing Control

The majority of mothers, at some point during the initial months of caring for their children experienced a sense of Losing Control. Mothers described this sense of Losing Control as living with disorganization and precarious degrees of uncertainty. These two factors caused their lives to be unpredictable and left them feeling unable to plan ahead and/or gain a sense of control over their children’s and their own daily care and management routines.
**Transition from Hospital to Home Care.** Having their children home for any length of time, without some form of support or the necessary equipment, significantly contributed to some mothers’ experience of *Losing Control*. Having a delay in the commencement of respite services also significantly biased their views about the Nursing Respite Program, and the professionals associated with it. When mothers were left alone with the total responsibility of their children’s needs at home, they experienced increased stress, exhaustion and feelings of “losing their minds”. Of the ten mothers involved in this analysis, four had been caring for their children for a period of several months without any nursing respite. In another three families, their children’s discharge was delayed because the At Home Program had not supplied them with needed equipment and supplies. (The At Home Program began in 1989. The Program provides funding to families for both medical and respite benefits. A family’s eligibility is based on an assessment of the child’s dependency in four areas of daily living: eating, washing, dressing, and toileting. Families who qualify for the services of the Nursing Respite Program automatically are eligible for the services of the At Home Program). This increased stress caused these caregivers to criticize the program substantially more than families whose transition from hospital to home had proceeded uneventfully. In one family, the mother’s work load was significantly affected because of a delay in receiving her supplies. In her own words:

> I said “No I didn’t get my supplies” and what I did was— I went out and bought it. You can’t find that many in [her home town], I found some [supplies] here and I found some in [a town one hour’s drive away] and I was washing things, like I only had so many syringes, and I had to wash them twice a day.... I didn’t know whether I would get reimbursed for it— and I can’t afford them.

One mother was extremely frustrated by the setbacks in her daughter’s condition which delayed her projected initial discharge date by eight months. At the time of the first interview her child was due to be discharged any day. This next scenario clearly tells this mother’s story of how a rocky transition from hospital impacted her ability to cope. As she explains:
They were going to send her home in May. Then they discovered that her breathing wasn’t very good—...it set her back...and then—...her feeding as well. They [physicians] kind of jumped the gun I think....They were preparing us for discharge and they hadn’t sorted her feeding out...and then it seems like—...that was May right—...end of May.... And it’s been like June, July, August, September...thinking she’s coming home and then one thing after another. And it’s like 67 different doctors [with each new problem a new specialty service became involved in their daughter’s care]...so it’s frustrating.

At the time of this conversation (before respite began), the mother was predicting that her daughter might be discharged about a month later. The research assistant scheduled the next 6 month interview, but at this time the daughter had only been home for three weeks. Even after an eight month delay in their daughter’s homecoming, the necessary supplies were not available until a few days after her arrival. As this mother explains, “Our supplies weren’t at home, that was all kind of delayed.... So we never got our supplies, she came home on Saturday and we never got our supplies until that Wednesday.” Once their daughter was finally home, things improved for this mother. She had no difficulty with scheduling nurses and she felt comfortable with their level of competency. At the time of the third interview, this mother still had only positive things to report about the Nursing Respite Program and the nurses involved in her daughter’s care. In her words: “We’re lucky, we’ve got lots of support...with the nurses and that.... She’s got lots of mums...everything works out excellent...no problems at all”.

**Role of Uncertainty.** Uncertainty is not a new concept in the chronic illness literature (Cohen, 1993; 1995; MacDonald, 1996; Mishel, Padilla, Grant & Sorenson., 1991a; Mishel & Sorenson, 1991b; Sharkey, 1995). Mishel (1993) defines uncertainty as “the inability to determine meaning of illness-related events” (p.47). According to her, uncertainty is a cognitive state produced when an individual is unable to make sense of a situation because of a lack of cues (Mishel, 1993). With uncertainty, one is incapable of predicting the outcome of a situation (Mishel, 1988). Mishel (1993) further describes the stressful characteristics of uncertainty as “not knowing
when tragedy, difficulty, untoward events or whatever else will occur; not knowing what form it will take; not knowing what to do about it; and not knowing how to manage or survive it” (p.47). Uncertainty has been shown in numerous studies to be a prominent psychological stressor not only for the patients living with chronic illness, but also their family members (Cohen, 1993; MacDonald, 1996; Mishel, 1988; Sharkey, 1995).

Comparable to other scholars’ works exploring the effects of chronic illness on family life, our study identified uncertainty as a significant source of stress for mothers (Cohen, 1993; Mishel, 1988; Mishel & Sorenson, 1991; Sharkey, 1995). High degrees of uncertainty significantly influenced their perceptions of how well the Nursing Respite Program was helping to decrease their stress and enhance their abilities to care for their children. Uncertainty affected many aspects of these mothers daily lives including: uncertainty relating to the ongoing assessment of their eligibility for nursing respite; uncertainty concerning the Consultants inability to find suitable nurses to cover specific scheduling requests; uncertainty surrounding the lack of dependability and/or competency of the nurses providing respite care; and uncertainty pertaining to the unpredictable nature of their children’s illness trajectory. Uncertainty relating to the Program or more generally the Health Care System has been called System or Program Uncertainty.

System or Program Uncertainty. Mothers in our study specifically experienced uncertainty related to the unpredictability of their pre-existing assigned nursing respite hours. This dimension of Program Uncertainty arose because a family’s eligibility for the Nursing Respite Program is reviewed at regular intervals, and at any time services can be cut or discontinued. Many of the mothers expressed fear in relation to this Program Uncertainty because they were afraid not only for themselves but also for their children’s wellbeing. One young working mother had this story to tell about her feelings of uncertainty:

You don’t know what up the road brings, so I don’t know what’s going to happen. Now everything is set up and it’s kind of perfect. Eventually his [her husband’s] insurance money will run out too. Like we’re only allowed so many nursing hours...in a life time...in a lump sum...so once that runs out then we don’t know.
We don’t know if that will run out before [our son] has surgery, or if it runs out after—we don’t know. So there’s fear up the road—then what do we do?

Another single mother who had received the benefits from a similar program in Alberta could not help but compare this province’s Program to what she had experienced with the former nursing respite program. In her words:

To get this program, it’s wonderful. But it can be taken away from you as fast as you got it—In Alberta, I have no idea, [whether services would be cut or discontinued] but it was never said to me that we’re going to cut your hours or in a month or two...we’re going to review it [her eligibility], and you may not get it.... Don’t plan too much in your life because it could end.

In this last comment she is warning other parents not to count on the Nursing Respite Services. At a later interview, the researcher asked this mother “Any idea of things that would bother you?” This mother’s response:

Bother me? Getting cut off! For sure, big time!... Like, I’ve been talking to people about it.... Like here in BC I find...unless you are at you’re wit’s end...they [Nursing Respite Consultants] can’t help you.... If I lose Nursing Respite because [her son] has done so well...because he’s in a clean environment [meaning in his home].

This mother goes on to explain that the only other respite option is a community-based centre: “I can handle that, but can he handle it?... I don’t know, and that’s something that really scares me.” This mother was afraid of the respiratory infections her son was prone to everytime he was exposed to other children in this facility.

Although the rules for receiving Nursing Respite require that the primary caregiver cannot be employed outside the home, in three families the mothers chose to ignore this requirement and returned to their previous jobs. For two of these mothers, scheduling their respite hours around their work schedules was a source of Program Uncertainty because the mothers found the nurses and/or the Consultants to be unreliable and undependable, resulting in a lack of trust in these
professionals. For example, one young working single mother experienced *Program Uncertainty* due to the agency’s Nursing Consultant’s inability to find nurses to fill her specific respite requests. As this young caregiver explains:

> I’ve had a few problems here and there with scheduling on Tuesdays and I needed another nurse hired because...the couple of nurses that they [the Consultants] had hired could not make it on any of the Tuesdays.... They hired another nurse to do Tuesdays, and then another nurse that was hired could only do Mondays...so then they ended up hiring another one again [for the other day she was at work].

This child’s father cared for their daughter on the days she was not receiving nursing respite (Wednesday, Thursdays, and Fridays) and she therefore needed the nurses to work on the days she mentions in the above quotation.

Another single mother indicated that the uncertainty associated with the Program and the continuation of respite hours was a factor in her decision not to return to work:

> I’m just scared of what I will do in the event that things get cut or I end up losing the Program.... But unfortunately, like, I can’t go to work because it’s [the Program] not something that’s consistent in the sense that it’s normally only good for four to six months and then you get reviewed.

This young parent felt there was too much uncertainty in the allocation of respite services, and, therefore, she would be unable to depend on the nurses to care for her son when she was at work.

*Professional Uncertainty*. In our study, *Professional Uncertainty* was a major source of concern for the majority of mothers. *Professional Uncertainty* has been conceptualized as any professional’s lack of accountability and responsibility in fulfilling his/her professional obligations to the family. A total of four mothers complained to some degree about the uncertainty associated with the nurses providing care to their children, but for two of these mothers their complaints were described as isolated incidences and not a major source of stress. Only two mothers reported experiencing substantial difficulties in their relationships with the nurses. One mother expressed her frustration about the nurses’ lack of compassion and inability to understand her perspective:
You know some of those nurses...the younger ones especially...thinking...."Well, I'll just call in sick".... They don't realize the ramifications of them calling in sick. You have a family depending on their service for that particular day or night.... That was a biggee [source of stress/uncertainty] for a long, long time.... We...were ready to pull out our hair.

This mother was frustrated because nurses were regularly canceling their shifts at the last minute, leaving her feeling very vulnerable. There were several occasion when she was unable to go into work because nurses had let her down on their commitments. There were also a number of occasions when she was forced to stay home from work because she felt she could not trust the nurses to safely care for her son's tracheostomy. As she explains, “I remember just fearing for my life and I had to call up and cancel shifts because they [the Consultants] had a nurse coming on days who wasn’t even orientated with our son yet.”

In another conversation, she mentioned that the Nursing Respite Program did very little to ensure that the nurses were sufficiently competent to be left alone in her home. This next scenario is an example of Program and Professional Uncertainty. As she explains:

They would never leave a nurse alone...in hospital.... There’s not a lot of difference between how they [technology-dependent children] were in hospital and how they were at home. I mean, there’s a lot of kids living at home on respirators.... The parents are having to fire the nurses, or get into conflict with them because they don’t feel confident with their nurses.... Which is not always the nurse’s problem, because there’s no feedback...there’s no supervisor to go back to, so it’s the parent’s responsibility [to supervise the nurses].

This mother was the only one to address the issue that nurses were not adequately supervised in the home. She felt that there needed to be some guidelines in place to ensure that the nurses were competent to care for the children. At another time during this interview, she raised the following: If a problem arose in the middle of the night and the nurse needed to validate the best course of action, this mother believed the nurse would be reluctant to wake a family member, especially if
the nurse was aware the family’s main reason for using respite at night was to catch up on their sleep. The mother’s fears were well founded and based not only on her own experiences but also the experiences of other families receiving Nursing Respite whom she had come to know in the months her son spent in the hospital’s Special Care Nursery.

**Illness Uncertainty.** In our study, high levels of *Illness Uncertainty* were experienced by four mothers. Of these, two of the children’s primary diagnoses were a severe seizure disorder, one son suffered from the unpredictable symptoms of Nager’s syndrome, and the Associate Mother’s daughter was dying from chronic renal failure. One mother expressed her feelings like this:

In the back of your mind everytime he gets sick: “Is he going to make it through this?” And if you just fretted about it all the time, you’d drive yourself crazy. And the reality is, he may not make it through it and that doesn’t mean we love him any less...but its painful, painful.

One of the mothers, whose young toddler suffered from an uncontrollable seizure disorder, described her son’s symptom’s as follows: “I’m not asking for a cure, but I would love for his seizures to be fully controlled to where I wouldn’t have to be on edge and sleep with one eye open all night.” At the time of the second interview her son’s seizures had increased from 49 to 80 per month. His seizure pattern remained unpredictable at the time of the third interview. During this final conversation, his mother explained the *Illness Uncertainty* like this: “He may only have a seizure once a month for the next six months or none for the next six months, but it doesn’t mean in the seventh month that he’s not going to have a whole bunch.” The initial literature, reviewed at the proposal stage of this research study, supported that illness or symptom uncertainty is a significant source of stress for family members caring for chronically ill children and technology-dependent children (Gravelle, 1997; Ray & Ritchie, 1993; Stevens, 1990; 1994; Teague et al., 1993; Youngblut et al., 1994).

**Living with Daily Uncertainty.** In our grounded theory study, *Living with Daily Uncertainty* was shown to interfere with these mothers’ abilities to cope effectively. Several of the
mothers said that they experienced a decrease in their sense of self because of the restrictions placed on their own lives. In these examples they are discussing self interest activities that they enjoyed before they brought their children home. All of these caregivers expressed varying feelings of loneliness and/or social isolation because of the restrictions placed on their time by the 24 hour care demands of their technology-dependent children. Mothers who were not working outside the home seemed to be the most severely affected by these feelings of isolation.

As well as the care demands, mothers also complained about a lack of other suitable respite options for their children, which affected their ability to have a break and maintain a life outside the home. Mothers expressed frustration because they no longer saw friends, and/or family. Many of the mothers were frustrated because they were not able to spend time with their spouses and other children. One mother described *Living with Daily Uncertainty* as follows:

> Yeah, you don’t have a chance to figure out next week. We don’t plan for anything, like planning [their older child’s] birthday was just so overwhelming.... And you know if [the technology-dependent child] gets sick, and it’s always what if he gets sick and you can’t see beyond a week, we don’t see beyond a day.

Charmaz (1983) explores the concept of uncertainty and has suggested that, in certain instances when individuals are living with sustained uncertainty, a coping strategy sometimes used by them is to restrict their lives voluntarily in order to minimize the effects of unpredictability. Examples of how individuals might restrict their lives include quitting work, limiting social engagements, and avoiding other social activities (Mishel, 1993). While only three of the mothers in our study had returned to their previous paid jobs outside the home, two other mothers stated that though they would have liked the option of returning to work for their own mental wellbeing they did work only at home to help stay in control. For one mother, the *Illness Uncertainty* associated with her son’s seizure disorder was one of the primary reasons she felt unable to look for a job. In her own words: “His condition is just so up in the air that I don’t feel...I don’t know how consistent I would be able to work if [he] is so sick...he’s really unpredictable, really unpredictable.” According to this mother’s story, she has had to resuscitate
her son three times since he was born 18 months ago. This young single mother had recently moved to British Columbia from Alberta where she had been able to hold down a part time job. This mother explained that when she was able to get away from the situation at home it was "really good therapy" for her.

Seven out of the eight mothers who were still in relationships with their children's fathers mentioned that there was no time in their lives to be together as a couple. In the eighth family, although a lack of couple time was not specifically mentioned, the mother mentioned that her husband would often babysit on the weekend so that she could have a break. Several of these mothers used a number of catch phrases to emphasize their lack of a satisfying relationship with their husbands. One mother stated for instance "We have to make an appointment to talk." Another mother stated that "we lead separate lives." In the next sentence she elaborated on this comment by saying that the only time they have to talk is when they are driving their daughter to one of her scheduled check-ups. Still another mother remarked: "We sort of wonder when we will have time for ourselves...so that our marriage can grow and continue to grow and not fall apart because we don't have any time for ourselves at all".

While Charmaz (1983) discusses the fact that individuals suffering from chronic illness will voluntarily restrict their lives, for the mothers in our study, the opposite was often true. Due to a lack of suitable alternative child care options, these women were unable to participate in activities they used to enjoy. Although literature reviewed in preparation for this study suggested that families with technology-dependent children do not leave their children in the care of families and friends, because they lack the confidence and comfort to do so, three mothers in our study cite a different reason for failing to lean on families for respite relief: geographical distance. Only one mother occasionally left her child in the care of family members. In addition, three mothers stated that their children had had various bad experiences when they had left them in local community respite facilities.

The two single mothers said they felt socially isolated, and one of these mentioned that, because she used her respite hours for paid work outside the home, she needed some time for
leisure activities. One single mother and two of the married mothers mentioned that they had no one they could talk to about their situation. Several mothers stated that they would not have time to attend a support group even if there was one available. The Associate Mother mentioned that she had no spontaneity in her life. For instance, sometimes she had a particularly bad week and just wanted to be able to take off with her husband for the weekend, but she was unable to do so because she had to schedule the nurses weeks in advance. Two mothers mentioned that they are unable to take holidays.

*Living with Daily Uncertainty* and high levels of *Program* or *Professional Uncertainty*, markedly affected these primary caregivers’ physical and emotional well-being. For example, one mother explained the toll that uncertainty played on her emotional health:

The time isn’t there [there is no time to take care of anyone or anything else]....
You’re too tired.... Your brain is just in a frazzle and your nerves are jumping....You get to the point where you start snapping at one another and it’s not because you want to.... It’s just like boom, you explode, and then five minutes [later] you’re sitting there and you’re feeling sorry because you knew that it never should have happened. So then you apologize...I’ve broken down so many times from it, you know from being tired.

This young mother was expressing a lack of control over her emotions and her actions caused by exhaustion. The above quotation illustrates how *Losing Control* is stressful and has interfered with this mother’s ability to react and/or cope effectively. Mishel notes that high levels of uncertainty can immobilize an individual’s ability to cope. In two studies conducted by her and colleagues in the early 1990’s, uncertainty was shown to weaken an individual’s abilities to master a situation (Mishel et al., 1991a; Mishel & Sorenson, 1991b). Mastery has been described as “the ability to behave in a way that can mitigate the aversiveness of an event” (Pearlin & Shooler, 1978). While in both Charmaz’s (1983) and Mishel’s work it is implied that the individual taking these precautions is the one who has the chronic illness, in our analysis it was the primary caregivers of technology-dependent children who experienced *Living with Daily Uncertainty*. 
Although all of the ten mothers involved in this study experienced a loss of control, for seven of them this phase was a relatively short one in their process of *Learning to Manage the System*. There were a number of factors which influenced the degree to which these mothers experienced the phenomenon. The two most important factors were the transition to home and the degree of uncertainty; both of which have been discussed in detail earlier in this chapter. Mothers experienced an extreme sense of *Losing Control* when they felt they had been unfairly assessed in the initial assessment for their eligibility to the program. Four mothers fought the system to try to obtain more respite hours because they felt they had been unfairly assessed. All but one of these mothers was unsuccessful in their pleas to increase their respite. All four discussed at length the added stress this experience caused them. Further, they all stated they did not have the time or energy to pursue this fight, but felt it was essential for their own sanity and their children’s wellbeing.

During the *Losing Control* phase of *Learning to Manage the System*, mothers were also entering the second phase in their relationship with the professionals involved in the Nursing Respite Program. The second phase of these mothers’ relationships with the health care professionals has been termed *Becoming Enlightened*.

*Becoming Enlightened* for these mothers meant they were coming to the realization that the health care personnel involved in the Nursing Respite Program and the At Home Program were not able to truly understand or empathize with their care responsibilities. The mothers in this study frequently referred to their problems encountered with health care professionals, in particular the Nursing Respite Consultants. Several mothers also described difficulties in their relationships with the nurses providing respite care to their technology-dependent children. Early on in their relationships with the Nursing Respite Consultants, mothers were becoming aware of the fact that the Nursing Respite Program was not living up to their expectations. Many mothers had anticipated that they would be able to have Nursing Respite on demand, and that it would enable them to have a normal life. Further, these mothers had assumed that they would be able to have more choice in
how and when they used their nursing respite hours. Because the Consultant was the primary professional coordinating the services, the majority of mothers targeted their anger and mistrust at this particular individual. A number of other mothers talked in more general terms, not directly targeting their complaints about the Program at the Consultants and/or the nurses. When no particular individual (or group of individuals) was the focus of the mothers’ concerns, they tended to blame “the system”.

In both Thorne and Robinson’s (1988) and Wuest and Stern’s (1990) grounded theory studies, family members also developed problems in their relationships with the health care professionals involved in their or their children’s care. Similar to our study, some families in Thorne and Robinson’s study were caring for chronically ill children at home. In Wuest and Stern’s study, the families were learning to manage caring for their children who were suffering from chronic otitis media. Parallels can be drawn between both these studies and ours interpretation of the evolving relationship families go through in their struggle to achieve a therapeutic relationship with the health care professionals involved in their children’s care.

_Becoming Enlightened_ has similar characteristics to the “disenchantment phase” described by Thorne and Robinson’s (1988) theory. In their study, disenchantment was the result of families feeling they could no longer trust the health care professionals because they realized their views about what was best for the ill family member were significantly different from those of the professionals. This phase of the relationship was characterized by discontentment with care, consequently families vented their frustration by becoming angry. Similar to our studies findings, when mothers felt a loss of control over their loved one’s care, they would often attempt to regain control by advocating for their ill family member. In Wuest and Stern’s (1990) research, the second phase of the families relationship with their physician, was called “becoming disillusioned”. They found that, families became disillusioned with the physicians when they realized that there were marked differences in the way their children’s health care needs were perceived by these professionals. For example, families perceived a crisis situation when their child experienced an acute ear infection, and this situation was described as “only an ear infection”
by the physician (Wuest & Stern, 1990, p. 559). These results are not unlike our research, which found the mothers also expressed that the Nursing Respite Consultants were unsympathetic, or did not really understand the true experience of caring for their medically-fragile children on a full time basis.

Only one mother in our study questioned the competence of the Nursing Respite Consultants. For her, this concern arose because she felt the Consultant did not really understand her son’s fragile medical state. During the first two interviews, she mentioned several times that she was afraid for her son’s safety because the Consultant had underestimated the skill level needed by the respite nurses to safely care for him. Three mothers experienced difficulties with their nurses’ skills not matching the care demands of their children. These mothers described how this affected their ability to trust “the system”, the nurses, and the Consultants responsible for placing the nurses in their homes. Questioning the professional’s competency was shown to be an important dimension of becoming disillusioned in Wuest and Stern’s (1990) theory of the evolution of health care relationships in chronic illness. In Thorne and Robinson’s (1988) theory family members often responded to this incompetence on the part of the health care professionals by becoming aggressive, or assertive, in their dealings with these individuals. Similarly as described in the next phase of Learning to Manage the System, about half of the mothers in our study became advocates for their children and themselves when they believed the Nursing Respite Program had unfairly assessed their needs.

Mothers in our study did not remain in this second phase of Learning to Manage the System for very long, because feelings of Losing Control were uncomfortable. As these mothers fought to gain a sense of control, they were naturally progressing to the next phase of Learning to Manage the System, which, in our study has been called Taking Charge. In order to gain some control over their situations these mothers used a number of coping strategies which enabled them to regain a sense of power over their lives. Taking more control over their situations enabled these mothers to focus on the positive aspects of their lives.
Taking Charge

Taking Charge enabled these mothers to feel more in control of their situations and the many aspects of their lives in which they were experiencing uncertainty. Examples of strategies used by the mothers in our study include: (a) Learning the Rules of the Program, (b) Taking It One Day at a Time, (c) Taking Control, (d) Keeping a Positive Outlook, (e) Just Getting On with It, and (f) Seeking Social Support.

Learning the Rules of the Program. In their struggle to take charge, mothers used a coping strategy, Learning the Rules of the Program. In order to take more control over the inflexible respite rules, some mothers spent many hours becoming familiar with the rules, in order to advocate for their situation. Five out of ten mothers used this strategy to “fight the system” for more respite hours or, in two situations, to receive at least some nursing respite. “Learning the rules” was the only coping strategy mentioned in Wuest and Stern’s (1990) theory of how parents learn to manage the care involved in their children’s chronic otitis media. In both Thorne and Robinson’s (1988) and Wuest and Stern’s studies, certain family members became aggressive in their dealings with health care professionals when they felt their children’s needs were not being adequately served. Gathering information was another strategy which emerged from this analysis. Other researchers have reported similar findings (Cohen, 1993; Mishel, 1993; Mishel et al., 1991; MacDonald, 1996; Wuest & Stern, 1990).

Taking It One Day at a Time. Taking It One Day at a Time was a central theme running through many of these mothers’ stories. One mother explained that this was a coping strategy she learned from her initial months of living at the hospital. In her words: “One big thing that I learned in hospital was to take it day by day and for the most part we still do”. Another mother expressed similar feelings about how she was able to cope with the situation. She had received nursing respite for only six months between the first interview and second and, at the time that these comments were made, she was no longer receiving the benefits of the program. In her own words:

No one knows what it’s like until they experience it themselves and everybody has a different way of dealing with things. The only thing is...you just have to take it
one day at a time, and not get frustrated because sometimes it's very frustrating.
And you find yourself feeling very emotional about things, and you've just got to
deal with it.

One single mother who was forced to work full time in order to support her daughter also
used this strategy to deal with the day to day stresses of balancing work, leisure time and her
caregiving responsibilities. She explains: “Just don’t worry about it” and “go day by day” and
“take it as it comes”. This mother admits she is “bound and determined” to get what she feels she
needs in order to cope. By being bound and determined, this mother is illustrating another coping
strategy that she uses control over her own situation: not allowing the negative aspects of her life
take charge of her child’s and her own destiny. During the same interview she explains: “Go with
your instincts on how you feel about your child and if you really feel something, argue, and don’t
listen to what the doctors have to say: just take it day by day and see what happens.”

Taking Control. Taking Control for these mothers meant gaining charge of the aspects of
their lives that it was possible to control. In these caregivers’ day-to-day existence there were many
aspects of their lives that remained beyond their control. Many mothers expressed frustration and
anger about the number of respite hours they qualified for, their struggle to find competent and
caring nurses, and the lack of coordination among the various community services that were
supposed to assist them to care safely for their children at home. For example, one mother was
frustrated by the fact that her daughter’s discharge had been delayed several times because the
oxygen equipment she needed had not arrived at home. Still another mother was given no warning
that Nursing Respite Program services were about to be discontinued and, therefore, she had to
take control of what she needed in order to continue to cope effectively. When asked how she felt
when she first learned services were going to be cut she replied:

Well, I was kind of shocked because at first they [Nursing Respite Consultants],
like they told me the middle of August...They were going to cut me off in
September. I’m like, well, wait a minute, I need a little bit of notice so I can find
someone, I’m not just going to hire Joe Blow off the street. I want to be able to take
some references and find someone that I want to look after her...so they extended it for a month, half time.

Establishing a routine was another way many mothers would take control over their lives. Many caregivers planned set days for nursing respite, and explained that doing so helped to ensure that the preferred nurses were available for them. For some women, their routine was established out of necessity because they were utilizing their respite hours for work. Even mothers who used respite for a break found the Program worked better for them when they were able to establish a routine. One mother’s story about her need for consistency, familiarity and control is:

Yeah, that’s how I like it, I like to know.... Like, I phone the Nursing Respite Consultant and I said I’d really like to have J, this one particular nurse every Friday because that is the only shift she’s able to do.... Because she’s in school.... They’re [Nursing Respite Consultants] really good at accommodating me for that.

Finally, one mother’s efforts to take control involved ignoring the Nursing Respite Program rules for controlling the scheduling of the nurses. This Associate Mother took the situation into her own hands in order to meet her own respite needs. According to her, respite was her right, and she believed she should be able to have respite on demand. This mother believed that she should have her nurses’ phone numbers in order to have some control over when she used her respite hours. Further, she explained that sometimes the responsibilities involved in her daughter’s care were so overwhelming that she would like to have an entire weekend away, but because of the way the Nursing Respite Program was structured she was unable to do so. She was inconvenienced by the necessity of scheduling her nurses “weeks and weeks in advance”, and a Program rule states that the caregiver must be present during a shift change of nurses. The implications of this rule for this mother is that it is impossible to have 24 hours of respite in sequence. In her own words:

I like direct [meaning direct contact with the nurses].... I want to be able to pick up the phone and say to the girl “Can you come?”.... Okay I’ll phone Paramed and say “Hey such and such is willing to come for a few hours if—it’s okay with you
guys.” But they want it the other way around.... So I feel I should be the one who decides when, and what, and not someone in Victoria or in Nanaimo.... Respite is for my convenience.

Taking Control for certain mothers meant fighting with the health care personnel for what they felt they needed in order to cope. Five mothers used this strategy to assist their coping. Three mothers had to fight “the system” to even qualify for any hours and an additional two mothers chose to fight to receive more respite hours. For one mother, the decision to advocate for more hours stemmed partially from the fact her son was tracheostomy dependent, and she knew of other families whose children had a similar diagnosis who were receiving more hours than she had qualified for. She also believed that the system discriminated against middle class professional working mothers and that she was being unfairly treated by the system. Finally, her desire for more hours arose out of concern for adequate sleep and her overall health. Even though she qualified for 48 hours, she is only able to get a good night’s sleep four nights (4 nights X 7 hours = 28 hours), because she uses the other 20 hours for child care while she is at work. On the nights when she does not have night time respite she was only averaging four to five hours sleep.

Three mothers fought to qualify initially for the program. Two of their children had medically-fragile seizure disorders and both women were suffering from exhaustion and sense of Losing Control because of the nature of their children’s care demands. One of the mothers had to apply three times before she was finally accepted into the Program. The third family who initially had not qualified had twins. These children were born prematurely out of province, and the neighbouring hospital refused to discharge the one twin until he qualified for the Nursing Respite Program in B C. According to the mother, the head nurse of the Special Care Nursery in this Alberta Hospital even phoned the Program coordinators in an attempt to get this child on the Program. In the end, the family qualified for 16 hours. All of the mothers stressed the fact that they did not have the time or energy to pursue this fight, but felt it was essential in order to cope with the care demands involved with their children. Two of these children’s diagnoses included severe seizure disorders, and also the uncertainty associated with their children’s illnesses further
contributed to their stress and their need to gain control over other aspects of their lives. The mother who had to apply three times describes her response to being rejected for the program:

When [her son] was first assessed, he was denied and...I went through a long process of writing a letter myself and getting the doctors and nurses to write in, stating that [he] should be on the Program because of his medical condition. Well, I guess just from my letter alone...they [Consultants] came back and reassessed and he was accepted...I was ready to fight, oh I was ready to fight. And it was a big problem because the person who came and assessed him was saying that, well, there was nothing she could do.

Another mother, whose son had a seizure disorder, had this to say about the effect fighting had on her stress levels:

It's absolutely ridiculous, that I had to go to the lengths that I had to go to, to get on the Program. I have enough stress in my life caring for my son with all his appointments and everything to have to fight and fight and fight to get eight hours a week, finally. It's sickening and it's sad, it really is.

In the next sentence she says: “It’s been terrible. It’s just been a nightmare.”

Of the five mothers who chose to fight the system, only the one of the ones who sought more hours was unsuccessful. The family was originally assessed for only 12 hours, though this turned out to be a mistake and the consultant returned and informed parents that she had added up the hours incorrectly, and they were eligible for 48 hours per week. This mother still felt this was not enough, but was unsuccessful in her bid to get more. She described her fight as “a nerve racking experience” that left her exhausted. She went on to say: “I’m just so tired of the system and so tired of dealing with people and just always seeming to hit a brick wall constantly, and just getting the run around and we’re just sick of it.”

Keeping a Positive Outlook. Several mothers reported that trying to maintain a positive outlook helped them to cope. One mother mentioned that she often reminisced about how awful her pregnancy was, and how sick her little girl was when she was first born, thereby helping her to
manage the stress and pain associated with her situation. Later on, in the same interview, this mother used a variation of this strategy known as “compare their situation to someone else who was less fortunate” (Sharer & Dixon, 1989) when she recalled that she often thinks “Yeah I could be single; I could be a single mother.” One of the mothers, who is now separated from her daughter’s father, talked about the fact that the stress and strain associated with being forced to live separate from her partner near the tertiary referral centre during the initial six months contributed significantly to their relationship problems. Yet this mother also mentioned that maintaining a positive perspective was an important coping strategy. During the second interview she described herself like this: “I try not to let myself get down about it.” Later in the same conversation she stated:

If I’d find myself thinking about it, I’d just get upset. I mean, you really can’t do a lot when you’re upset about it, and it portrays through to the child that something is wrong, so just kind of shake it off and go on. Try to pick any positive thing out of the day that you can find and go with that, rather than dwelling on what’s wrong. Like even with her heart surgery...I didn’t really think it bothered me, but I guess I had just put it in the back of my mind and even the people around me said “wow, you are like white ...white as a ghost”.... I didn’t even realize I was doing that, but I guess that’s the way I dealt with it, just kind of put it back there.

Keeping a positive outlook is also mentioned as an effective coping strategy used by parents in Ray and Ritchie’s (1993) study. Using a well established instrument for measuring parental coping Ray and Ritchie’s analysis supported that the majority of parents used strategies designed to maintain a positive outlook on their situation. Parents in Ray and Ritchie’s study also mentioned that they survived by “living one day at a time”, an important coping strategy also mentioned earlier in this chapter.

Just Getting On with It. Another coping strategy used by mothers in this study could be described as similar to a fatalistic attitude, or resignation that “there is nothing one can do about the
situation, so it’s best just to make the best of it.” One mother, in particular, used this technique to help her cope with her situation. In her own words:

Sometimes it’s very frustrating and you find yourself feeling very emotional about things and you’ve just got to deal with it and you say to yourself. “There’s nothing I can do about it, it’s just got to be done and dealt with it”.... That’s kind of the way I think about things.

Another mother explained the phenomenon in these words:

You can’t live your life dwelling on one family member’s sickness and yes we focus on him and he probably gets more attention than anybody else does.... But for me, I have come to a time when I am away from him I try not to even think about him. That may sound heartless but otherwise you become permanently absorbed with it, and there has to be something else in your life or you wouldn’t survive emotionally.

Seeking Social Support. Our grounded theory supports that these caregivers prefer to find emotional, social, and respite support from their partners. Eight of this subset of mothers were currently still in relationships with the fathers of their children. In all but one family, the fathers were actively involved in helping with the caregiving responsibilities when they came home from work outside the home. In these seven families, the mothers all commented how important the support from their spouses was in enabling them to cope with their responsibilities. One mother had this to say about the support her husband offered: “We have an excellent partnership, but I can’t do it without my husband.” Still another mother had this comment about her spouse’s support: “It really doesn’t help to talk to other parents really, because we’re comfortable. Like we’ve dealt with this since day one. It’s difficult sometimes, but you know we’ve got each other and we deal with it.” The pediatric chronic illness literature states that mothers of children with special needs frequently seek support from spouses, family and friends as a way to increase their abilities to cope (Florian & Krulik, 1991; Geary, 1991; Ray & Ritchie, 1993; Sterling, 1990). In studies where seeking support is mentioned as a parental strategy, the majority of mothers report
that they prefer to seek support from their spouses, rather than from other family members and friends.

In only one of the two parent families was there any evidence that the father was only minimally involved in the day to day responsibilities of caring for their special needs child. In this family, the mother expressed feelings of exhaustion, and often felt she was “losing her mind”. This same mother was described by the research assistant as looking older than her age and very tired and worn down. Her situation was further complicated because she received minimal support from her family, further compounded by having no friends. At the time of the second and third interviews, the mother’s young niece had moved in with the family and was assisting with some of the caregiving responsibilities. However, the uncertainty associated with her son’s fragile condition, and the fear that respite would soon be discontinued, continued to cause this mother difficulty coping with her child’s care demands. At one point during the final interview, she stated that, even with respite she was too tired to go out. Further, she added that “I don’t go to any support groups because I really don’t have the time; I’m either too tired or I’ve got too much to do.”

In two families where the children’s fathers were not living in the home, mothers reported mixed involvement from their ex-husbands. In one family, the child’s father resided in another province and according to the child’s mother, was not involved in her son’s care. This young mother had moved to BC in order to live with her parents and receive some emotional support. The maternal grandmother did assist her daughter by helping with grocery shopping and laundry, but even with this familial support, the medically fragile child remained solely the biological mother’s responsibility. She was unable to have any respite during the night (an option she would have liked) because the family home was small, and privacy was an issue for her father. Thus this single mother was also restricted in when she could use her nursing respite hours because her father did not wish to be home when the nurses were present. She described herself as feeling chronically tired, worn out, cranky, and depressed. She described the last few months as “a nightmare.” She believes that the system penalizes the biological family, and that her son would be
better off if her parents were his foster parents and she remained the primary caregiver. She feels the 24 hours of nursing respite she is receiving per week are inadequate, but she has been unable to get any more. As for the other single parent, the child’s father was quite involved in the daily care responsibilities. He cared for his daughter three days a week while mother was holding down a full time job. In this situation, nurses from the Nursing Respite Program were caring for the child the other two days that her mother was at work outside the home.

During this phase of *Taking Charge*, mothers were also beginning to take control of the problems they were having with the health care professionals involved in the Nursing Respite Program. This next phase of the relationship has been called *Seeking Effective Collegial Relationships*. 

*Seeking Effective Collegial Relationships*. Despite the difficulties they were facing with various aspects of the Nursing Respite Program and the Consultants who were the primary gatekeepers to their accessing its services, mothers were starting to accept that they needed the support of these professionals in order to continue to receive the benefits of the Program. These primary caregivers were beginning to compromise their expectations in order to receive the maximum benefit from their nurses and the Program. Even the parents who complained the most initially about the problems with inflexible rules and insensitive Consultants, seemed to become relatively content with them. At the time of the third interview, one of the single mothers who had initially been refused access three times to services said this about the nurses involved in her son’s care:

They’re getting him into a ...jacket which is something he hasn’t been able to wear since October because of his chest problems and getting him sitting and stimulating him and playing with his toys and seeing how he reacts to them.... They also participate when his physiotherapist comes.... The one nurse actually had his physiotherapist to herself to make sure she [the nurse] was doing it properly.

Another mother who was initially denied services, and still at the time of the third interview felt she needed more hours, found positive things to comment on about the Program:
It’s a really good Program due to the fact it does help parents.... I really like the way they try to match the nurses to the medical needs of the child.... I’m sure lucky to have it because if I didn’t, I don’t know what I would do.

The mother whose son suffered from Nager’s syndrome and had a tracheostomy, and who was denied more than her initially assigned hours, said this at the time of the final interview:

Originally we had some problems... but the problems seem to have been weeded out.... We’re going through a really smooth period.... We’ve got good shift coverage; we’ve got nurses that really care about [our son].... Two of them are very committed to working with our son, they’re both fluent signers...and that’s really difficult to find.

Finally, the mother who had stated at the time of the first interview “How am I going to use that eight hours.... Well maybe I can go to the bank twice” had this to say during the third interview:

Once it got going, it was fabulous and it certainly was heaven sent, I’ll tell you.... It gave us a chance to do something other than care for [our son] who was so sick in those days.... It gives the family the energy to keep up with the kind of care that’s required.

As can be implied from all four of these examples, when the Program was running smoothly, and the families had minimal difficulties with incompetent or unreliable nurses, the mothers generally forgot about their initial difficulties. Having reliable, caring nurses enabled the families to cope with the Program’s shortcomings.

When these mothers were able to take control of their lives and were satisfied that their children were well taken care of by the nurses, they were progressing into the fourth and final phase of *Learning to Manage the System*. In our grounded theory, this final stage has been called *Managing Effectively within the Constraints of Inflexible Rules*. 
Managing Effectively within the Constraints of Inflexible Rules

Managing effectively means that mothers are able to have control over their lives. Having control enabled these mothers to feel content with their situation because they were able to predict certain outcomes in their own and their children's lives. This control over their lives was mainly achieved by using the coping strategies described in the Taking Charge phase of Learning to Manage the System. For example, mothers who focused on the positive were able to mobilize more coping strategies for dealing with their situation. One mother who used this strategy started to organize other forms of child care when she knew that respite services were going to be cut. Unlike many of the mothers in our study, this mother felt comfortable having family members care for her daughter. In the weeks prior to respite services being cut, this young working single mother spent time training her sister and her daughter's maternal grandmother to take over child care responsibilities.

Another family found great support and strength from attending an international conference on their child's rare condition. On their way to the conference they were able to stop over in Ontario and spent a few days visiting family and friends. To accomplish this vacation, they organized nursing respite for their son so they could spend this time as a couple visiting their family and friends. This was a very important trip for them because their son was scheduled to have jaw surgery in a few months and this mother was very concerned about how the surgery would affect both his and her own lives. During the third interview, she often remarked that at present life was fairly predictable and she felt quite comfortable with the routine that had been established (balancing work outside the home and their child's care schedule). She also remarked that they had good, reliable, and caring nurses and that their son's condition was relatively stable. This mother was very worried that the upcoming surgery because this would disrupt their routine, and more important by the possibility of anaesthesia-induced respiratory problems and decreased mobility. She further explained they have to be careful when to schedule his surgeries because of the increased risk of respiratory infections in the winter months. However, she remarked that
seeing other children who have already successfully undergone this operation did help to reassure them that there would probably be a positive outcome.

Only one of the ten mothers involved in this analysis had possibly not reached this fourth stage of *Learning to Manage the System*. This mother, at the time of the third interview was still extremely tired. Her nursing respite hours had been cut back from 24 hours to 16 hours per week and she is complaining she is worn out and run down. This mother blames her inability to cope on the fact she needs the additional 8 hours which she had been receiving for a few months previously. As she explains:

They granted me an extra 24 hours for the [3] months and that was it. Meanwhile, there was 69 somewhat hours I had not used and I could not use them, so it really upset me because what they don’t understand is I’m back to my 16 hours per week.... And it’s because [my son] is okay, well [my son] might be okay health wise, but his sleeping pattern is no good, so mum is starting to get sick and totally run down, they don’t think of that, it’s not him [referring to her son] that’s handling the respite, it’s me.

This mother goes on to elaborate on her situation and the difficulties she is having since her hours were cut back:

It made a difference for my physically, emotionally, and mentally because it got to the point where in the mornings if he’d get up in at a quarter to three in the morning I’d lay there in bed holding him crying because I didn’t want to get up and wake anybody else up, and when I had those 24 hours it wasn’t a problem.

**Establishing Working Relationships.** *Establishing Working Relationships* meant that mothers were able to reconstruct a trusting relationship with health care professionals. This trust was based on mothers accepting both the professionals strengths as well as their limitations. All of the ten mothers involved in this component of our study told stories of the many positive aspects of the Nursing Respite Program and described establishing trusting therapeutic relationships with the Consultants and the nurses providing care.
Thorne and Robinson (1988) called the final phase of families’ relationship with health care professionals “guarded alliance”. According to their theory, this phase occurred when families are able to establish trust based on information rather than naive assumptions. Similar to the our study’s findings, families in Thorne and Robinson’s study entered into this phase with reservation, due to the fact they were unable to trust professionals unconditionally. Also comparing our findings to Thorne and Robinson’s, mothers in our study still experienced frustration with the system, and feared the unknown, even when they had established working relationships with the Nursing Respite Consultants and respite nurses.

In our study, the transition to this next phase of their relationship with health care professionals, however, could be described as a bit of a roller coaster ride, in that at any given time the relationship could regress. Situations which could cause a regression in their relationships involved some form of change which upset the stability of their daily lives. Some of the events which could trigger the relationship to undergo a setback included; a frequent turnover of nurses, respite hours being cut or discontinued, or a deterioration in the child’s illness.

They spoke of not wanting to “upset the apple cart” because it would throw off their delicate balancing act. For example, one mother whose child would need jaw surgery in the near future had very mixed feelings about the outcome of this potentially positive surgery. Surgery for this mother would significantly upset her routine, and the many aspects of her life she was generally able to control. Many mothers stated that having their children in hospital was not a break for them, because they were often faced with the uncertainty associated with the regression in their children’s illness trajectory. If their children were hospitalized for any length of time they also risked losing their home care nurses or respite, who would be forced to look for additional work. Hospitalization also meant there was a possibility that care demands would increase, which might necessitate a need to fight for additional respite hours.

Wuest and Stern (1990) conceptualize this phase as “negotiating”. According to their theory, during this period, families are attempting to regain control over their relationship with their physicians and the health care system. In our study mothers rarely mentioned their relationship
with physicians, but talked at length about their relationship with the Nursing Consultants, as their primary health care professionals. But all the mothers naturally progressed to the next phase of their relationships with health care personnel, conceptualized in this analysis to be the Establishing Working Relationships.

Mother’s Recommendations for How to Improve the Program. A number of the mothers expressed concern that the Nursing Respite Program was not well coordinated. These caregivers grew tired of having to “tell their story” to so many different personnel. One mother stated that during the assessment phase of the Program she had 14 people in her house in one week. This mother’s recommendation was that there should be respite parents on the eligibility screening committee so that a more realistic picture is presented of what it is really like to care for these children at home. Another mother’s primary recommendation for improving the Program involved better communication between the Consultants and the nurses. In her opinion, there needed to be more supervision of the nurses in the homes to ensure that the nurses were competent to perform the technical skills required to provide safe care for the children. Another suggestion offered by this mother was that there should be regular team meetings with all the nurses involved in the child’s care to share issues and management concerns. This same mother felt that policy makers did not think out the full implications of their programs prior to its implementation phase, meaning that the responsibility for coordination of care fell on the families. In her words:

More and more kids are living...and [there are] a lot more of these problems.... How are they [referring to the policy makers] going to manage them?... It’s always just sort of been the parent’s responsibility...and I think it’s a whole community responsibility.... The medical [profession]...it’s their decision too. They’re the ones that saved these kids.... I think there needs to be more people involved in the decision-making process.... Families being involved with the professionals...I think their [parents’] input is so important.... When you deny their input, I think you’re denying any solutions to problems and to programs.
As well as dealing with the added stress of caring for their technology-dependent children, several mothers expressed frustration that the coordination of services fell on them. These mothers felt strongly that there needed to be a case manager involved in the children’s care because they were coping with enough already. One mother describes her situation like this: “Well, managing [my son] and all of his care providers...it was just like a small business.... It was incredible.”

A number of mothers expressed frustration that there was a lack of other respite options for their children. Mothers who had used a long term care facility complained that their children’s emotional needs were neglected, and that their children regularly came home with respiratory infections after staying at these facilities for any length of time. One mother had to cut her vacation short because her son’s leg was broken while he was staying at a live-in respite facility. Generally, mothers felt that there needs to be more suitable respite options available to them, because they could never leave their children for a holiday; or even for a weekend away.

Summary

The stories told by these ten mothers provide evidence of a rocky road as they progress through the various stages of Learning to Manage the System. However, all of the mothers admitted that without the Program, they would be unable to care for their children at home. Over the course of 18 months (the data collection period), nine of 10 mothers moved through the four phases of Learning to Manage the System. There was only one instance of a mother who seemed unable to move through all four of these phases. At the time of the third interview she seemed to be moving back and forth between Losing Control and Taking Charge. Initially, mothers had high expectations about the Program, and the majority of the mothers anticipated their children’s arrival home with excitement and positive feelings. Only one mother was extremely worried about how she was going to manage her son’s care at home. During the Taking In phase, mothers were learning a great deal about their children’s illness and about the services which were available to them in the community once their technology-dependent children were ready to come home. At this time, mothers were in the Blindly Trusting phase of their relationships with the health care professionals. They blindly trusted these professionals to take care of their children’s and their
own needs, and felt the Nursing Respite Program would enable them to cope effectively with the responsibilities involved in their children’s care.

For the majority of mothers, as the time came closer to the anticipated discharge date, they began to realize that the Program’s assessment criteria did not tell the whole story of the responsibilities involved with technology-dependent children at home. Mothers were losing trust in the system and the health care professionals who enforced the B C Nursing Respite Program’s rules. This second phase of *Learning to Manage the System* was conceptualized as *Losing Control*. The degree that mothers lost control varied considerably based on a number of important variables, including the degree of uncertainty they were dealing with, how smooth the transition progressed from hospital to community-based services, how well the Nursing Respite Consultants were able to meet their individual respite needs, and the extent to which the nurses were competent, reliable, and dependable. Other studies investigating how well nursing respite is meeting families’ needs have reported that the nurses were not caring and did not meet the developmental needs of the children (Scharer & Dixon, 1989; Stevens, 1994). In our study, this was not a concern for the mothers, as all of them commended the nurses for being very caring and sensitive. *Losing Control* in this grounded theory analysis seemed to be closely related to the degree of *Program, Professional, Illness* and *Daily Uncertainty* in these mothers’ lives. The greater the stress from uncertainty, the more these caregivers reported that they were *Losing Control*.

The third phase of *Learning to Manage the System* was conceptualized as *Taking Charge*. *Taking Charge* for these mothers involved a number of strategies to increase their control over the situation and increase the predictability in their daily lives. Strategies used to gain control were very similar to coping skills used by mothers in the chronic illness and uncertainty literature. The coping strategies used by these mothers included *learning the rules of the Program, taking it one day at a time, focusing on the positive, taking control, just getting on with it*, and *seeking social support*. By *Taking Charge*, mothers felt more in control of their situations and better able to handle the uncertainty and the other aspects of their lives which were beyond their control. Mothers very soon realized that even though there were numerous problems with the Nursing Respite Program, they
needed the Program in order to continue to care for their children at home, rejecting the alternative of returning their children’s care to the structure of the acute care hospital environment as unthinkable.

Mothers during the Taking Charge phase of Learning to Manage the System realized that in order to continue to care for their children at home they needed to work cooperatively with the health care professionals involved in the Nursing Respite Program. The final phase of Learning to Manage the System has been conceptualized as Managing Effectively Within the Constraints of Inflexible Rules. During this phase mothers were Establishing Working Relationships with the professionals involved in the Program. For most of the mothers, the transition to this phase occurred quite smoothly: after receiving nursing respite for a year, these caregivers had accepted the limitations of the Program, and had spent their time and energy focusing on the positive aspects of the Program and the situations in their daily lives which they were able to control.

In this final phase of Learning to Manage the System, mothers’ coping and stress levels continued to fluctuate because they were still facing daily uncertainty in many aspects of their lives. Therefore, as confirmed in other research on chronic illness and its impact on family functioning, mothers were constantly adapting to change and living with uncertainty. However, the majority of the mothers in this study at the time of the third and final interview were managing effectively, and attributed their positive coping abilities to the Nursing Respite Program. There was only one mother who continued to suffer from exhaustion, feelings of losing her mind, and whose daily life could potentially be considered to be in a state of chaos and disorganization.

A number of mothers sent a clear message to the policy makers and government funding bodies. Their caregiving responsibilities should not include organizing and coordinating community services and resources they needed. There were enough sources of stress and uncertainty in their lives, and they felt they should not have to take on a job which they believed was the professional’s responsibility. One mother in particular felt that there needed to be better regulations in place in the Program to ensure the competency levels of the nurses who were working outside of a health care agency. Another of her recommendations was that the nurses
should to be able to validate their decisions with the Consultants, especially when they were providing care at night. Her fear was that the nurses, knowing how much the parents needed their sleep, would be reluctant to wake them if a safety concern arose, or if they needed to validate their decisions. Finally, several mothers believed there needed to be alternative respite programs in place, so that they would not be left without respite if their children were no longer eligible for the Nursing Respite Program.
CHAPTER FIVE
SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS
AND IMPLICATIONS FOR NURSING

Summary

Understanding the issues facing primary caregivers caring for their technology-dependent children at home is of significance to nurses support of families in the shift toward home care. While governments are being forced to look at alternatives for expensive hospital care for increasing numbers of children with long-term health conditions, care decisions are being made without comprehensive understanding of the impact that the increased responsibility for home care has on primary caregivers and the family unit. Technology-dependent children often have 24 hour a day care needs, an impossible task for one care provider to assume. The current research, while sparse, indicates that registered nurses are often the only individuals in whom parents can confidently entrust the care of their children with medically fragile conditions. Due to the level of knowledge and skill required to manage the children’s equipment safely at home, the majority of parents are unwilling to leave their children in the care of family or friends. By definition, respite care is intended to provide temporary relief for caregiving responsibilities while contributing to a positive and rewarding experience for the child (Canadian Association for Community Care, 1996).

Although, programs similar to British Columbia’s Nursing Respite Program are being implemented in the United States and in several provinces in Canada, there has been minimal research that evaluates how well these programs are meeting the families’ needs. Hayes and McElheran (1993b) were the first researchers to receive external funding to evaluate this province’s Nursing Respite Program. Hayes and McElheran’s study included both qualitative and quantitative goals. The purpose of the qualitative component was to generate theory about the families’ experience of commencing and continuing with respite services. Grounded theory was chosen as the method to explore the qualitative research question, a method best selected when little is known about the phenomenon under study. Qualitative data were gathered by trained research assistants and the co-principal investigators using an unstructured interviews approach. Interviews lasted
between one to one and a half hours and explored the parents’ and other family members’ perceptions of the process of using and adapting to pediatric nursing respite care in their homes.

The research question asked in this masters’ thesis arose from early coding of Hayes and McElheran’s (1993b) data, when I joined the research team and became familiar with the grounded theory evolving in the major study, I assumed responsibility for a question of interest to me: How do mothers who are primary caregivers of their technology-dependent children view the role of nursing respite in managing their stress and increasing their coping?

Out of the total sample of 27 families in the major project, there are only 17 families where there is a complete set of three transcribed interviews. My sample included 10 families out of these 17. A decision to focus on only the primary caregivers’ views was based on a preliminary literature review which supports that in most families, the mother is the primary caregiver (Stevens, 1990, 1994).

Grounded theory was the method of choice to explore mothers’ perceptions of how well the program assisted in decreasing stress levels and increasing these primary caregivers’ abilities to cope. The unstructured interview format encouraged them to share whatever was significant for them. The non-directive, free flowing, family centred interview style allowed mothers to express their feelings and perceptions candidly, thereby increasing the likelihood that the data would represent an accurate picture of their reality. The constant comparative method of simultaneous data collection and analysis was conducted following the steps outlined by Strauss and Corbin (1990). Open coding began with the reading of the first transcribed interview and naturally progressed through the other analytic stages of axial and selective coding. Proceeding with this process, I looked for verification that the emerging concepts or categories identified in previous data were present in each subsequent piece of data. Relevant concepts emerged and were eventually condensed into categories and their properties and dimensions delineated. Finally, the relationships between the relevant categories were determined, and the constant comparative method of data collection and analysis continued until there was saturation of all the relevant categories.
With a focus on mothers' stresses concerning their children's care demands and the role nursing respite played in assisting their coping, a core category of *Learning to Manage the System* emerged. Mothers need to learn how to manage their children's care within the constraints of the health care system in order to receive maximum benefits from this nursing respite service. Consistent with the grounded theory method, this core concept (for this component of the analysis for the larger study) draws together a number of concepts or categories which explain these mothers' perceptions about the role of nursing respite in decreasing their stress and increasing their abilities to cope. In this study, these explanatory concepts were *Taking In, Losing Control, Taking Charge,* and *Managing Effectively within the Constraints of Inflexible Rules.* Mothers were also simultaneously going through four phases in their development of working relationships with the Nursing Respite Consultants and the other health care professionals in the system. The four stages have been called *Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships,* and the *Establishing Working Relationships.*

During the *Taking In* phase, mothers were *Blindly Trusting* that the health care personnel involved in the various community services would ensure that their own and their children's needs would be met by the Nursing Respite Program and other associated community services. The majority of the mothers had developed a good therapeutic relationship with the health care professionals who had initially taken care of their children in hospital. Based on these established relationships with physicians and nurses, mothers may have naively assumed that they could smoothly transfer their trust to the professionals involved in their children's care in the community. Early in their dealings with the Nursing Respite Consultants and the coordinators of a parallel program, the At Home Program, mothers were becoming aware that the transition home was not necessarily going to be a smooth process. In addition, when initially agreeing on home care for their children, mothers had assumed that the Nursing Respite Program would provide them with sufficient respite hours to allow them to take care of themselves as well as provide care for their special children and other family members.
As the time approached for their children to be discharged, mothers became disillusioned with the Nursing Respite Program and its Consultants. When mothers realized that that the Program would not provide them with sufficient hours of respite service, they expressed feelings of losing control over their lives. Hence, the second phase of Learning to Manage the System has been conceptualized as Losing Control. Seven of the ten mothers selected for this analysis felt that the hours of Nursing Respite they were receiving were not adequate to ensure that their own health and the needs of their children were taken care of. All ten mothers commented about the exhaustion they faced, and this affected their abilities to cope with the care demands on the days when no respite relief was available. Several mothers mentioned that some days they felt they were losing their minds. The stress of their caregiving responsibilities interfered with mothers' abilities to cope with their children. They targeted their frustration about the lack of adequate respite hours at the Nursing Consultants who are the gatekeepers for their nursing respite at home.

Simultaneously, mothers moved to a second phase in their relationships with the Consultants which was given the label of Becoming Enlightened. Mothers identified a shortcoming of the program: the Nursing Respite Program’s assessment criteria focused only on the technological needs of their children and not the caregivers’ needs. A number of mothers mentioned that they were frustrated with the way the Program was organized. The level of frustration of these mothers was related to whether respite services commenced at the time of their children’s initial discharges from hospital or after a delay. Mothers who faced delays tended to criticize the organization of the Program and the adequacy of their respite hours more than mothers whose nursing respite was in place at the time of discharge.

The mothers in this study also reported that the amount of uncertainty in their lives significantly influenced the extent to which they experienced a sense of Losing Control. Uncertainty in four domains was described by the mothers: Program Uncertainty, Professional Uncertainty, Illness Uncertainty, and Living with Daily Uncertainty. Program Uncertainty related to the services provided by the Nursing Respite Program. There was uncertainty associated with the allocation of nursing respite hours because the ongoing assessment of their eligibility for
services meant that, if the children's dependency on technology decreased or ceased, respite hours would be cut or discontinued. Mothers were afraid of losing nursing respite because they believed they would be unable to care for their children without this additional support.

Professional Uncertainty, as defined by the mothers in our study, was any professional's lack of accountability or responsibility in fulfilling her/his professional obligations to the family. Mothers' complaints included: nurses would sometimes cancel shifts at the last minute; nurses placed in their homes were not competent to care for the equipment; and nurses were not directly supervised by the Nursing Respite Consultants (or agency supervisor) in the homes. Mothers discussed at length the increased stress of dealing with these kinds of issues. Mothers believed that the Nursing Respite Consultants should be competent to take care of these problems and that it was definitely not a parental responsibility.

Due to the unpredictability associated with a chronic illness, Illness Uncertainty was a concern for all of the mothers in our study. However, during the course of the 12 months, only four of these 10 mothers experienced distressing levels of uncertainty related to their children's conditions. For example, dealing with serious infections or anticipating upcoming surgery were significant sources of stress. Experiencing high levels of Illness Uncertainty increased these women's dependence on the services of the Nursing Respite Program, because they were dealing with frightening setbacks or exacerbations in their children's conditions and therefore usually asserted that they needed additional respite hours. The inflexibility in the Program's rules do not currently allow for emergency increases in respite care.

Living with Daily Uncertainty was a source of stress and interfered with these mothers' abilities to cope. Mothers were frustrated because they no longer were able to participate in many of the activities they enjoyed prior to the onset of their children's health conditions. There was no time to do things as a couple and mothers who had other children felt they were neglecting siblings' physical and emotional needs. Some of the other repercussions of Living with Daily Uncertainty was the impossibility of holidays, or even having a weekend away from their children. Thus, they experienced a lack of spontaneity in their lives because of the unpredictability associated
with their care routines. All of these caregivers expressed feeling varying degrees of loneliness or social isolation. Mothers also expressed their needs for someone to talk to, but the majority admitted they would have no time to attend a support group.

Mothers pointed out the lack of other respite options available if home nursing respite was discontinued. Several mothers had used the respite accommodations in a Vancouver hospital for children with disabilities, and all of these caregivers were dissatisfied with the care their children had received in that facility. In the remaining interviews mothers did not mention the issue of other community respite options or if even if they would have considered using them if they were accessible and available to them.

Mothers used a number of coping strategies to regain a sense of control and organization in their lives. As mothers were attempting to regain control, they were progressing to the next phase of Learning to Manage the System, called Taking Charge. By Taking Charge of their own and their children’s lives, mothers were able to regain or maintain their sense of sanity and decrease their levels of stress and exhaustion. The coping strategies found to be most effective for these mothers were: (a) Learning the Rules of the Program, (b) Taking It One Day at a Time; (c) Taking Control; (d) Keeping a Positive Outlook; (e) Just Getting On with It; and (f) Seeking Social Support. As mothers were Taking Charge they began to realize the positive aspects of the Nursing Respite Program. All 10 mothers admitted that they would not have been able to care for their children without the Program and, so they began to accept its shortcomings and focus on the positive components. During this time, mothers accepted that they needed the support of the Nursing Respite Consultants if they were to continue to receive the services of the Program. This phase in their relationships with health care professionals has been called Seeking Effective Collegial Relationships.

None of the mothers during this phase in their relationship with health care professionals were dissatisfied with their nurses. Although some stated that they had initially experienced difficulties with the nurses’ dependability and sense of responsibility and or commitment, at the time of the final interview such problems were no longer a primary concern. Mothers did state that
when there was a change in their nurses, they experienced increased stress because of the time and energy required to train and develop a trusting relationship with their children’s caregivers. A mother who remained upset about the number of hours she was receiving, and was therefore still angry with the Consultants and Program rules, was becoming resigned to the fact that she was unlikely to receive any more hours.

When mothers were able to take control over certain aspects of their lives and felt that they had nurses who were trustworthy, dependable, and competent, they had progressed into the fourth and final phase of Learning to Manage the System: Managing Effectively within the Constraints of Inflexible Rules. In this study, all but one of the ten mothers were managing their children’s care effectively at home. Seven of these families were still receiving respite services, and at the time of the final interview, none of these mothers were experiencing problems with the Program or with the nurses providing care. In a number of families, nursing respite had been discontinued because their children were no longer eligible to receive services. In these families the children were being cared for by their fathers part of the time. Respite care was also occasionally provided by other relatives on the mother's side of the family. Such changes further stress caregivers' roles and their network of support.

Parallel to Managing Effectively within the Constraints of Inflexibility, mothers were also progressing to the fourth stage of their relationships with the health care professionals involved in the Program. As mothers accepted the shortcomings of the Program and the inflexibility built into the way the Program has been structured, they were also began to realize that they needed to maintain a good relationship with the Consultants in order to continue to advocate effectively for their own and their children’s needs. This final phase has been conceptualized as the Establishing Working Relationships. Mothers were acutely aware that there was still uncertainty associated with a chronic illness and that a setback in their children’s condition could trigger their needs for additional respite or other support.
Conclusions

1. Mothers' experiences of caring for their special children and adjusting to respite were conceptualized as moving through a four stage process of Learning to Manage the System: Taking In, Losing Control, Taking Charge, and Managing Effectively within the Constraints of Inflexible Rules.

2. Mothers simultaneously moved through four phases in their relationships with health care professionals: Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships, and Establishing Working Relationships.

3. One factor which influenced these mothers' abilities to cope and manage their stress included whether services were in place at the time of their children's initial discharge from hospital.

4. Significant degrees of uncertainty in these mothers lives kept their coping and stress levels fluctuating, and the control they had in their lives can be described as a delicate balancing act.

5. Mothers agreed unanimously that they would not consider returning their children to live-in respite or institutional care on a full time basis.

6. Mothers reported that the number of respite hours they were receiving was inadequate because they believed the decision was based solely on the care needs of the child and not the respite needs of the primary caregivers.

7. Mothers believe that they should be represented on the Screening Committee for the Nursing Respite Program so that they could provide input about what they needed in the way of respite.

8. Mothers would like the option of using a (high quality) community-based respite facility for short breaks.

9. Mothers believe that there needs to be better coordination of the services between the acute care and community settings.

10. Mothers believe that there needs to be better communication and collaboration between the professionals in the hospital and the community.
Implications and Recommendations for Nursing

Nursing Practice

It is well documented in the theoretical and research literature that significant gaps exist between the hospital and community arenas of nursing practice (Kaufman & Hardy-Ribakow, 1987; Malfair, 1992; Perrin & Ireys, 1984; Sokol, 1995; Wheeler & Lewis, 1993; Wong, 1991). In this study, mothers often criticized personnel in "the system" for not being organized and coordinated in their care delivery during the period of time when their children with special needs were ready to transfer from hospital to home. The mothers in this study faced incredible responsibilities when they receive their special children home, and were separated from the security of the hospital environment and the safety of acute care professionals’ expertise and support. This substantiates others' findings (such as Burkett, 1989) that the initial transition from hospital to community is an extremely stressful time for parents of children with complex or medically fragile conditions. It is therefore important that nurses on the front line of both acute care and community care delivery make links with each other to facilitate the establishment of trusting and empathetic relationships with children and their families during the transition and the initial at-home period. Discharge planning should begin early on in the children's hospitalization, ideally as soon as these children with ongoing special needs are born or diagnosed and admitted to the acute care unit.

The mothers in this study believed that there needed to be more high quality respite options available to them, so they could have a break (a weekend or a vacation) away from their caregiving responsibilities. Nurses working with these families (both the Nursing Consultants and the nurses providing care) are in an ideal position to advocate for these families, helping to influence the government to expand the programs and services available to these caregivers.

Another criticism the mothers voiced about the Nursing Respite Program’s structure was that the eligibility criteria did not adequately address the primary caregivers’ respite needs. The mothers believed that the number of hours they were receiving under this Program was insufficient. Technically, the eligibility criteria state that the primary caregivers’ needs for adequate
sleep are considered, although the majority of these mothers reported that they were still suffering from exhaustion. Again, the Nursing Consultants and the nurses providing care to these special needs children are in an excellent position to influence the policy makers to change the current Program’s rules so they can better meet the respite needs of these mothers.

Pediatric nurses providing care to these children in the acute care specialty units must thoroughly assess families’ home situations in order to facilitate these parents’ and children’s transitions home. Better communication between the various health care professionals in these two health care delivery settings would also serve to ensure services are coordinated between the hospital and the community. As economic pressures result in cutbacks it is important for nurses not to lose sight of the importance of a comprehensive discharge plan. A thorough discharge plan should include: (a) education, to ensure the parents are competent and confident with the their children’s care; (b) psychosocial support, to assure parents what professionals are available in case they are in need of validation of an appropriate course of intervention, or encounter a crisis; and (c) tangible support for caregiving, or the arrangement of all services, equipment and supplies parents need to assume total caregiving at home.

(a) Education. Parents are generally actively involved in their children’s care during the hospitalization and feel competent in their care skills in that setting, but to facilitate the Taking In phase of home care, they need to know the adaptations that will be necessary for the home situation and its restrictions and differences. They need to become aware of, and mentally rehearse, the differences in care logistics and the degree of parental responsibility encompassed in the anticipated home care situations that face. When the mothers are confident in their knowledge about their children’s care and how this will transfer to home, they are likely to feel less stressed when the time comes for them to take over home care. It would be helpful to have each child assigned one or two primary nurses for the duration of a hospitalization, thereby increasing the consistency in the information being given to parents. these nurses should communicate directly with the nursing respite care consultants and the agency nurses. When there is this kind of continuity and consistency, the mothers are more likely to trust and therefore will move smoothly from Blindly
Trusting to the Establishing Working Relationships with the community based health care personnel.

One possible solution to the communication and organizational problems between the hospital and community health care personnel would be to have a case manager involved with each family. A nurse with a background in pediatric intensive care, neonatology, or recent tertiary level care is an ideal person to assume this role because of her/his expert knowledge and skill with the advanced technological equipment and complex care demands needed to sustain life for this population of children. Ideally, this nurse would be employed by the regional health department in order to ensure that she is independent of the Nursing Respite Program and its Consultants. The case manager would need to work closely with both the nurses caring for the children in hospital and also with the Consultants who are assessing the children’s and families' nursing respite needs. Once the case manager has established a trusting relationship with the families, he/she could facilitate the families' working through the various phases of Establishing Working Relationships with the Consultants and nurses to assist a smooth progression. Close to the time of discharge, the case manager could make sure the primary caregivers are confident in assuming the caregiving role.

A case manager is in an ideal role to assume this responsibility to facilitate the transition of care to these children’s families. The case manager could spend time with the families prior to their initial contact with the Nursing Respite Consultants teaching about the services offered by the Nursing Respite Program and the rules for acceptance to it, so families could have advance warning of the Program’s shortcomings. Having knowledge beforehand can facilitate acceptance of its limitations. During the Taking Control phase of Learning to Manage the System, the nurses and Consultants can validate and reinforce mothers’ effective coping strategies. Further, the Nursing Consultants and nurses can teach the mothers new skills to help them manage the special child's condition and family life, and then encourage and support them as they incorporate these new coping strategies.
(b) **Psychosocial Support.** The theory generated in this study endorses the notion that mothers need to feel they are supported in their care decisions once they are alone in their caregiving responsibilities. Mothers felt isolated once they were home and would have appreciated the support of at least one professional with whom to share their feelings and concerns. The Nursing Respite Consultant could have assumed this role except that the mothers experienced numerous difficulties in these relationships. One solution to this issue may be that one of the primary nurses or the case manager could serve as an emergency contact once the child has gone home, thereby ensuring that the family has someone they trust to talk to during unforeseen stressful periods or crises. Mothers in this study also mentioned that as well as emergency support, they would have appreciated having access to a health care professional they could trust on an ongoing consultation basis; this could be the case manager. In this research, mothers' transitions through the four phases of: *Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships*, and *Establishing Working Relationships* was a bumpy process; a case manager could help make this transition progress more smoothly.

(c) **Tangible support for caregiving.** Another responsibility this case manager could assume would be to investigate the appropriate community agencies the family may need to access once their children are home. If the families were well informed about the appropriate community agencies and the kinds of services they provide prior to discharge, they will be better able to prepare themselves for what they can expect in the way of additional support in their communities. The case manager could also act as a liaison between the various community health professionals, thereby decreasing the risk of these mothers becoming disillusioned with the Nursing Respite Program professionals. Finally, there is evidence in this analysis that supports the idea that one way to decrease the risk of mothers *Losing Control* is to ensure that nursing respite will commence immediately at the time of the child's discharge.

Nursing respite should be systematically organized prior to discharge. Mothers in this study experienced added stress when there was a delay in commencement of respite care services. Ideally, the families should interview the respite nurses while their children are still in hospital, to
ensure the nurses will be comfortable with the children's care demands. Families are immensely reassured when respite care nurses have been interviewed, partly oriented, and hired prior to the child's homecoming as well. Based on the experiences of mothers in his study, it is important that the respite nurses' knowledge and skills be matched with the child's health condition. For example, a pediatric nurse who has never cared for a tracheostomy, or a seen a seizure, should not be placed in a home where these skills and knowledge are involved in the child's care. The case manager could facilitate this process by working collaboratively with the Nursing Respite Consultant and the nurses. By having the case manager involved in this Taking In phase, he/she may be able to prevent these mothers from experiencing a sense of Losing Control.

Prior to their child's hospital discharge, parents require a list of all appropriate community resources (and the type of services they offer), and a list of contacts for, and instructions on how to order, all necessary equipment and supplies. Smooth, less anxiety-producing transitions occur when all necessary supplies and equipment are in the home before the child's discharge date. The At Home Program supplies and ensures delivery of necessary equipment and supplies to the families' homes so that they can safely manage their children's technology-dependent equipment, but parents need to know this and understand the coordination required between these two sources of services.

The agency hiring respite nurses should ensure that the nurses are respectful of parents' rights to privacy and to recognize that parents are the experts in their children's care. Decisions concerning care should be mutual and collaborative between families and the nurses. Further, agencies supplying the nurses should make certain the lines of communication are kept open between all levels of professionals involved in providing care to ensure the individual needs and concerns of the parents are addressed. The Nursing Consultants need to be accountable and responsible that the nurses being placed in the families home are competent and skilled to cope with the children's care demands. In the final phase Learning to Manage the System: Managing Effectively within the Constraints of Inflexible Rules, the various health care professionals can
assist the families to cope with any unexpected unpredictable events or exacerbations in their children’s illnesses.

Nursing Education

The mandate of the Registered Nurses of British Columbia to require baccalaureate as the minimal education entry level to practice is an important step to ensuring that novice nurses have a good foundation in the issues facing our health care delivery system today. Baccalaureate nursing programs offer acute care as well as community experiences which provide beginning professionals with a broad perspective of the problems involved in our province’s trend to shift care to the community. Nursing curricula in the future need to place an increased emphasis on chronic illness, caregiver responsibilities, source of stress and effective coping strategies, and family assessment and interventions. Nursing educators have a responsibility to provide new graduates with the necessary critical thinking and problem solving skills to be able to assess and intervene in complex health care crises. Nursing theory courses need to provide beginning practitioners with theoretical frameworks such as the process of Learning to Manage the System so they can assist caregivers to deal with their daily stresses more effectively. Further, nurses need to develop skills to understand the structure of families’ relationships with health care professionals in order to be able to address concerns voiced by these children’s parents.

Due to the competency and skill level needed to safely care for these children’s fragile health condition, it would be inappropriate for the Nursing Respite Program to consider hiring new baccalaureate graduates as either Consultants or in-home nurses. Mothers in this study had some experiences with unpracticed young nurses and refused to leave their children in these nurses’ care. The care demands of these medically fragile children support that new graduates should have a minimum of one years experience working in an intensive care unit or special care nursery.

It is the responsibility of nurse educators to assist students to develop professional accountability and responsibility to ensure practitioners in the future are reliable, dependable, and committed employees. The findings of this grounded theory study reinforce the importance of health care professionals to be trustworthy, caring, and empathetic. Further, parents are much
more comfortable when they are able to develop a therapeutic relationship with only a few health care personnel. Most mothers expressed a desire to limit the number of professionals involved in care in order to minimize repetition of information and reduce confusion and disorganization with the coordination of the various health care personnel and services. It is important for the nurses providing respite care to have ongoing training sessions to ensure that their knowledge and skills are current with changing technology and care demands.

While the mothers in this study did not experience any significant difficulties with uncaring or unprofessional nurses, some of the literature reviewed for this study reveals that this has been a problem for some families. Nursing instructors in clinical settings have a responsibility to role model caring behaviours as well as facilitate students' learning appropriate caring behaviours. In the classroom, nursing educators need to provide students with a theory to facilitate understanding the concept of caring and how to apply it in their practice.

Nursing Research

If the current shift toward home care continues, it is very likely that the complexity of the issues facing parents caring for this population of children is also likely to increase. The implication of this trend is that more research is needed into the nature of caregiving for technology-dependent children. What kinds of services do these families need to ensure that the caregivers and children's needs are being adequately met? What are the primary sources of stress for these families? What do mothers perceive are the resources that would best ensure their physical and emotional well-being? What do mothers perceive would assist them to cope more effectively during the initial transition from hospital to home? Intervention studies are sorely needed.

A number of mothers believed that the Nursing Respite Program was insufficiently funded. Mothers had heard rumours that services were going to be cut and that as a result they might have their respite hours curtailed or even discontinued. This study supports that the current program is not funded to adequately meet families' needs as it is. More research is needed to evaluate what characteristics these programs need in order to serve families to the level required for optimal
family functioning. Mothers also worried about what would happen when their children no longer qualified for the Nursing Respite Program. The mother who had been able to compare this province’s program with Alberta's described that our neighbouring province had implemented a three tiered program which had better serviced her son. A number of mothers complained that their children's care demands did not match the Program’s assessment criteria and therefore described their children as "falling between the cracks". This suggests that there needs to be more exploratory research into the kinds of services and respite needs of these families have once they no longer qualify for nursing respite in their homes.

Finally, more research is needed to examine the nature of mothers’ (and families’) relationships with health care professionals. Our study interpreted these relationships to move through a four stage process. While the phases conceptualized in our study support other scholars’ work exploring this phenomenon, the research to date is still sparse. If the health care professionals involved with these families are to provide individualized care, it is imperative that they know what constitutes the important components of a therapeutic and collaborative relationship and how to maximize effective collaborative partnerships. The current research suggests that health care professionals generally do not accurately assess and prioritize what families need for quality care to be provided for their chronically ill members.

Mothers, Children with Medically Fragile or Complex Conditions, and In-Home Nursing Respite: Learning to Manage the System

The purpose of this study was to explore mothers’ (caring for technology-dependent children) views about the role of Nursing Respite in decreasing their stress and increasing their abilities to care for their children at home. Although they expressed a number of difficulties with the Program, all of these primary caregivers were ultimately very happy that this service exists. The ten mothers in this study believed that the home environment was a healthier place for their children, and remarked how well their children were thriving and catching up on developmental milestones since leaving the hospital.
Mothers were unanimous in that they would not consider returning their children to live in respite care on a full time basis, although some mothers would have liked the option of using a community-based respite facility for short-term breaks. There is only one such facility in Vancouver which will take their children for short periods of time, and some mothers found the quality or respite care there to be below optimal. The mothers in our study are sending a clear message to governments and policy makers that there is an urgent need for more respite options for these children.

Mothers also stressed that the current services offered by the Nursing Respite Program do not adequately attend to their individual families' needs. The two most pressing issues concerned the fact they felt they needed more hours in order to cope effectively and they felt there should be some flexibility in the Program's rules when they experienced an unpredictable event or their children's condition temporarily improved or deteriorated. Several mothers stated that if such services are not put in place, there is a strong likelihood that these children's primary caregivers will burn out and be unable to continue to care for their children.

In the development of this theory about *Learning to Manage the System*, this research has mapped the dimensions of "trying to have a life" while balancing the various stresses which mothers face as they carry out their caregiving responsibilities and adapt to the shortcomings of the Nursing Respite Program as it is currently structured. This theory legitimizes parents' stresses and struggles as well as outlining their coping, and the situations that challenge and enhance it. Mothers are simultaneously moving through a four stage process in their relationship with health care professionals, conceptualized as *Blindly Trusting, Becoming Enlightened, Seeking Effective Collegial Relationships* and *Establishing Working Relationships*. The discovered theory identifies that mothers are dealing with varying degrees of uncertainty which significantly contribute to their stress, and in some cases interfere with their abilities to cope.

This work can affirm for parents that they are not alone in facing the challenges of daily life and offers some alternative strategies which may assist their coping. The theory is useful for nurses when planning and intervening with these families. Finally, this research provides direction
for policy makers who are likely to plan future program incentives. Ultimately, this work will assist health care professionals at all levels of service delivery in enhancing the quality of life for parents who are making an important contribution to society by caring for children at home in the presence of significantly more demands that most parents.
REFERENCES


Appendix A:

Classifications of Children with Medically Complex Conditions

**Group I:** Children with medically complex conditions (MCC) who are periodically dependent on technological intervention (TI) and/or nursing care (NC) to meet basic needs and/or maintain survival. These children require regular, predictable patterns of nursing intervention (NI), usually related to only one medical device (e.g. a child receiving peritoneal dialysis).

**Group II:** Children with MCC who are frequently or continuously dependent on TI/NC to meet basic needs and/or maintain survival. These children require regular and PRN (as needed) patterns of NI, usually related to one or more medical devices and/or therapies (e.g. a child who is tracheostomy dependent).

**Group III:** Children with MCC who are permanently dependent on TI/NC to meet basic needs and maintain survival. These children require regular and PRN patterns of NI, usually related to a multiplicity of medical devices and/or therapies (e.g. a child who is ventilator dependent).

**Group IV:** Children with MCC who are episodically or intermittently dependent on TI/NC to meet basic needs and/or maintain survival.

**Group V:** Children with MCC who are dependent on TI/NC during the terminal phase of a progressive life threatening illness. These children require regular and/or PRN patterns of NI usually directed at managing symptoms and/or promoting comfort (e.g. a child who has leukemia refractory to further treatment).
Appendix B:

The Overall Goals of Hayes and McElheran’s (1993b) Study

Goal

The purpose of this project is to evaluate the BC Ministry of Health’s Nursing Respite Program (NRP) for families of children with medically fragile or complex conditions. Outcome measures related to costs, projected savings attributable to the program, nursing activities, and family responses will be cross-validated with qualitative analysis of parents’ exploration of the value of respite services to their families.

Objectives

In the 12-month evaluation with families new to the program, the project aims to:

1) Document the overall costs to the BC Ministry of Health for the Nursing Respite Program, and compare these with the estimated costs of out of home (i.e., institutional) respite care for children and their families. This will include parents’ assessment of their own out-of-pocket expenses.

2) Document specific care measures provided by the NRP nurses directly: a) for the ill child and b) for parents, and the nursing hours associated with these interventions.

3) Observe and document changes in the ill children’s activities of daily living for 6 and 12 months after NRP commence.

4) Observe and document changes in caregiving demands for parents 6 and 12 months after NRP services commence.

5) Assess the family system responses to receiving NRP services for 6 and 12 months.

6) Pilot test two instruments associated with the home management of a child with a challenging health condition.

7) Generate mid-range theory about the impact of all-nurse respite care for families of children with medically fragile or complex health conditions.
Appendix C

Consent/Assent to Participate in a Research Project

Project Title: Evaluation of the BC Nursing Respite Program

Purpose:
Jinny Hayes, RN, PhD, from the School of Nursing at the University of British Columbia and Pamela Otterman, RN, MSN, a nursing consultant associated with the Nursing Respite Program are conducting a study to evaluate the outcomes of the BC Ministry of Health's Nursing Respite Program (NRP) for children with complex health conditions.

Procedures:
If we agree to participate in the study, either Elsie Tan or Bev Valkenier (the nurse research assistants) will visit our home three (3) times in order to observe and talk with us about what it is like for our family to need and use nursing respite care services. We will complete seven (7) paper-and-pencil questionnaires each time: once before our family begins to receive respite services, and again six (6) months later, and six (6) months after that. Some conversations may be tape recorded and transcribed later and Elsie or Bev will also write some notes about her observations. She will also record some cost-related information from our child's in-home respite care chart, from the NRP office records, At Home Program, and In-School Support records. We are being asked to keep a diary about our experiences with the NRP and its associated costs. The timing of visits will be arranged at our family's convenience, and will last 2-4 hours each. We can ask any questions about the research at any time before, during, or after the study.

Risks/Discomforts:
Talking about our family's situation may be difficult or unpleasant at times. However, we are free to share whatever aspects of our family life we wish. We may refuse to answer any question at any time without any repercussions for our family or individual members or our child's care. Having another nursing professional in our home may present an additional threat to our privacy and will require our cooperation, but several precautions will be taken to protect our privacy and identities: All questionnaires, data summaries, diaries, tapes, and written materials are identified by a number known only to the researchers and the research assistant, not by our names. All these are kept in a locked cabinet and are only for the researchers' use. Our individual identities will not be made evident in any publication or report, and any small segments of our recorded conversations used in print will not reveal our family's identity. All of the data will be destroyed five years after the end of the study, unless we are specifically consulted and agree. We may request to be given some of the data to see or keep, such as written summaries, tapes, or questionnaires.

Benefits:
The only direct personal benefit for our family will be reimbursement of time. The information we provide will help nurses, Ministry of Health planners, and other health care providers to better understand what requiring and using respite care is like when a child has a complex or medically fragile health condition. Other families who have participated in similar research have reported that it is helpful and informative for their families to think and talk over the effects of the long-term health concern in their families.
Name of child who has received developmentally appropriate information about the study, but is not able to give his/her own consent

I consent/ do not consent   Signature of Parent

Date _______________   Signature of Child

Name of child who has received developmentally appropriate information about the study, but is not able to give his/her own consent

I consent/ do not consent   Signature of Parent

Date _______________   Signature of Child

When study results are available, I/we wish to receive a brief report. These are to be mailed to:

__________________________________________________________

Name(s)

__________________________________________________________

Street Address

__________________________________________________________

City/Town    Code