

PERPETUAL INNOVATION:  
CHILD CARE DECISIONS OF PARENTS USING PEDIATRIC IN-HOME  
NURSING RESPITE CARE

by

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### Abstract

Pediatric home care for children with medically complex conditions is a growing phenomenon made possible by parents willing and able to care for these children at home. While pediatric home care may decrease costs to the health care system, and provide social and developmental benefits to these children, their parents often have limited child care options which would enable them to rejuvenate from parenting activities and fulfill other roles and responsibilities.

To illuminate this child care dilemma, this study examines how parents of children with medically complex conditions choose to utilize in-home pediatric nursing respite care as a source of child care. This investigation constitutes one part of a larger multi-variable, pre-post descriptive design study evaluating the Nursing Respite Program in British Columbia, Canada.

To explore the process by which parents use nursing respite as child care, qualitative data from first (pre-respite service) and second (six-months after beginning service) visits with the parents from six families were analyzed using grounded theory. Interviews and accompanying field notes were audiotaped and transcribed for analysis using the constant comparative method.

Study findings indicate that parents of children with medically complex conditions choose to utilize nursing

respite as child care through a process of perpetual innovation. Throughout this process, dynamic situational factors require parents to continually modify their use of nursing respite care in relation to other forms of child care. In a cyclical manner, parents repeatedly adopt strategies aimed at creating child care situations that are mutually beneficial to both parent and child. Together, these strategies suggest a decision-making framework embedded within the process of perpetual innovation.

While literature related to these study findings is sparse, the findings are discussed within the context of research on child care, respite care, and parenting children with chronic conditions. In addition, conceptual cues which may be used to integrate study findings into the larger evaluation study are identified. Finally, policy implications of study findings are discussed in relation to pediatric respite care delivery.

## Table of Contents

Abstract .....	ii
Table of Contents .....	iv
Acknowledgements .....	viii
Dedication .....	ix
Chapter 1 .....	1
Problem Background .....	1
Child Care .....	2
Respite Care .....	3
Nursing Respite Care .....	4
British Columbia Nursing Respite Program .....	6
Research Question .....	9
Purpose .....	9
Forestructure .....	10
Assumptions .....	12
Studying Families who have Children with	
Chronic Conditions .....	13
Categorical versus Noncategorical	
Approaches .....	15
Unit of Analysis .....	15
Summary .....	16
Chapter 2 .....	17
Methods .....	17
Design .....	17
Grounded Theory .....	18

Theoretical Underpinnings of Grounded	
Theory .....	19
Sampling, Setting, and Data Collection .....	20
Data Analysis .....	23
Six Family Vignettes .....	25
The Adams .....	26
The Bentleys .....	26
The Carvers .....	28
The Darwins .....	28
The Emerys .....	29
The Fowlers .....	31
Summary .....	32
Chapter 3 .....	34
Perpetual Innovation	
Child Care for Children with Medically	
Complex Conditions .....	34
Situational Factors .....	35
Child-related factors .....	35
Parent-related factors .....	36
RN-related factors .....	37
Factors related to Nursing Respite	
Program operations .....	38
Perpetual Innovation in Context .....	40
Perpetual Innovation Strategies	
A Decision-Making Framework .....	42

Prioritizing parental activities requiring child care.....	43
Estimating the adequacy of nursing respite hours to meet parents' perceived child care needs.....	46
Weighing the advantages of nursing respite care with other forms of child care.....	48
Matching child, parent, nurse, and other situational factors to optimize child care situation.....	50
Consequences of Perpetual Innovation .....	52
Summary .....	57
Chapter 4 .....	59
Discussion .....	59
Child Care .....	61
Parenting Children with Chronic Conditions .....	63
Comprehensive Respite Care Delivery .....	65
Summary .....	68
Chapter 5 .....	69
Implications .....	69
Conclusion .....	72
References .....	74
Appendix A	
Letter to Families .....	78

Appendix B

Consent / Assent to Participate in Research Project...80



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Dedication

To Greg:

For believing in me  
and encouraging me to chase my dreams.

## Chapter 1

### Problem Background

Advances in technology, pharmacology, and medical care contribute to increasing numbers of children with medically complex conditions living at home (Cohen & Pinnick, 1989; Hobbs, Perrin, & Ireys, 1985). While these advances enable sophisticated, life-sustaining care to be delivered to these children, someone must invest time and energy to provide such care. This responsibility is usually assumed by parents.

In North America, the current trend is to keep children with medically complex conditions at home whenever possible (Cohen & Pinnick, 1989). Research suggests that the advantages of pediatric home care include social and developmental benefits to children, as well as decreased costs to the health care system (Cohen & Pinnick). Given these benefits, and the availability of sophisticated, portable technology, the trend toward high-technology home care for children with medically complex conditions is likely to increase.

When children with medically complex conditions live at home, parents assume responsibilities which exceed traditional parenting responsibilities. Yet, even when children are healthy, parenting can be a demanding, exhausting experience. For example, infant feeding schedules often interrupt parental sleep, while inquisitive

toddlers require constant parental supervision. When parents have children with medically complex conditions, the demands on parents multiply. For example, their children may require vigilant monitoring, symptom management, or technological interventions such as suctioning or dialysis.

### Child Care

According to Berns (1993), child care is "care given to children by persons other than parents during the parts of the day that parents are absent" (p. 185). It is care that parents delegate to others, rather than care that parents provide to children themselves. Child care enables parents to work outside the home, to complete household tasks, to attend school, to sustain interpersonal relationships with family and friends, or to engage in leisure activities.

To gain temporary relief from parenting activities, parents of healthy children might enlist the assistance of extended family, hire babysitters, utilize daycares, or enroll children in lessons. Such child care options enable parents to rejuvenate from parenting activities, and fulfill other roles and responsibilities. In contrast, parents of children with medically complex conditions often have difficulty finding caregivers who possess the knowledge and skill to safely care for their children (Crowley, 1990; Teague, Fleming, Castle, Kiernan, Lobo,

Riggs, & Wolfe, 1993). Given the additional child-related care demands experienced by these parents, this scarcity of child care becomes a potentially serious dilemma.

### Respite Care

Respite care is a potential source of child care for parents of children with medically complex conditions living at home. The purpose of respite care is to temporarily relieve parents from caregiving responsibilities related to their affected children. A specific form of respite, nursing respite care, is provided to these children by nurses. In British Columbia, the Ministry of Health funds in-home pediatric nursing respite care for some of these children and their families through the B.C. Nursing Respite Program (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1992).

The B.C. Nursing Respite Program is unique among respite care models. Since the 1970's, a variety of respite models have emerged, each with its own strengths and weaknesses (Ahmann, 1986; Cohen, 1982; Cohen & Warren, 1985; O'Connor, Vander Plaats, & Betz, 1992; Upshur, 1982). These models vary on attributes such as credentials and training of respite care providers, site of respite care delivery, age of individuals receiving care, and physical or developmental needs of individuals eligible to receive respite care.

Current literature identifies the need for improved quality and skill of respite caregivers providing care to individuals with medically and behaviorally complex conditions (Cohen, 1982; Upshur, 1982). In addition, the literature indicates that individuals with complex care needs are often ineligible to receive respite care services (Halpern, 1985; O'Connor, Plaats, & Betz, 1992; & Upshur, 1982). As Cohen indicates, caregiver skills matter less when the purpose of respite is to provide companionship to the recipients of care; however, specific skills are essential when recipients of respite care possess health or behavioral conditions which may require intervention by the respite caregiver. Such findings suggest that parents who have children requiring life-sustaining care, such as suctioning, may have difficulty finding individuals willing or capable of providing their children with the complex, demanding care they need.

#### Nursing Respite Care

Nurses possess both the knowledge and skill to relieve parents caring for children with medically complex conditions at home, by providing comprehensive respite care. However, few pediatric nursing respite programs discussed in the health care literature, describe these programs from the perspective of recipients or emphasize program outcomes. For example, in a discussion article, Hildebrandt (1983) describes an in-home respite program

serving the elderly and others who have chronic conditions or physical or developmental disabilities, but does not indicate if the program serves children. Furthermore, while a nurse practitioner coordinates the program, respite care is provided by a trained caregiver, and not a nurse.

In another article, Hurt, Brodsky, Gealt, and Hopper (1988) describe a registered nurse babysitting service for families of infants recently discharged from an intensive care nursery. Using a nonvalidated questionnaire which was administered to eligible users and nonusers of this service, the authors determined that all users felt more comfortable leaving their infant with a nurse than with another individual, and 71% of users would not have gone out in the absence of a nurse. While this exploratory study suggests that parents of infants who have medically complex conditions may utilize in-home pediatric nursing respite care, it does not examine how parents utilize this service in relation to other child care options.

Finally, Sherman (1995) examines the influence of in-home pediatric respite care provided by nurses over a period of six months on family stress reduction and improved quality of life. While Sherman uses a single group, pre-post test design to examine the influence of respite on these variables, 64% of 73 informants did not complete post test measures. Consequently, results should be interpreted with caution. Findings from two surveys and

one parent satisfaction questionnaire indicate that respite utilization relates inversely to psychological symptoms among children's primary caregivers; may contribute to a decrease in child hospitalizations; provides parents with opportunities to run errands, attend to personal business, and pursue relationships with spouses, other children and friends; and may provide socialization opportunities to the child.

By attempting to quantify respite outcomes related to family stress reduction and improved quality of life, Sherman's study contributes to the sparse body of knowledge regarding in-home nursing respite care for children with medically complex conditions. However, he does not examine the process by which parents choose to utilize nursing respite care in relation to other sources of care for their child. Given the demands on parents of children with medically complex conditions, coupled with the paucity of child care options, this phenomenon warrants exploration. The present study seeks to investigate the problem from the perspective of parents whose children receive in-home nursing respite care through the British Columbia Ministry of Health's Nursing Respite Program.

#### British Columbia Nursing Respite Program

The B.C. Nursing Respite Program provides in-home nursing respite to families of children age 19 and under who have medically complex conditions, or who are



technology dependent. The purpose of the program is to temporarily relieve parents from the day to day demands of caring for children with complex needs. It aims to decrease parental fatigue, prevent hospital re-admissions of children due to parental fatigue, enable parents to attend to other relationships within the home and community, as well as pursue activities other than direct child care (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1992).

Once application to the Nursing Respite Program is accepted, the child and family meet with one of seven regional nursing consultants located throughout the province. The consultant visits the child and family at home or in hospital, and assesses the child and family's respite needs. She subsequently presents this assessment to a screening committee, which determines the child's eligibility for the Nursing Respite Program. To be eligible, the child must require, in the absence of a parent, a registered nurse or licensed practical nurse as caregiver (British Columbia Ministry of Health and Ministry Responsible for Seniors, 1992).

Based on data collected by the nursing consultant, the Nursing Respite Program assigns eligible children to one of five classification groups. These groups determine the frequency, duration, and type of respite care that a child may receive. Depending on the child's condition over time,

the provision of nursing respite care might increase or decrease. Children whose conditions improve are eventually discharged from the program. When provided services are palliative, children might remain on the program until they die. The nursing consultant conducts ongoing assessments to determine the level of nursing respite care required for each child and family.

After determining the child's required level of care, the nursing consultant refers the child to a private nursing agency. In collaboration with the agency supervisor, families select and orient agency nurses to provide in-home respite care to their child. In addition, the consultant works with agency staff to develop a nursing care plan, which is approved by parents.

To summarize, the BC Nursing Respite Program provides parents who have children with medically complex conditions with a source of child care. However, little is known about the process by which parents use in-home pediatric nursing respite care to meet their overall child care needs. To illuminate this issue, I am exploring the process through which parents make decisions to integrate nursing respite care with their other sources of child care. This analysis is being conducted within the context of a larger study by Dr. V. Hayes and P. McElheran (Otterman), evaluating the BC Nursing Respite Program.

### Research Question

The analysis described in this report is directed by the following question: How do parents who have children with medically complex conditions choose to utilize nursing respite care as a form of child care? This specific question relates to an objective posed in the larger evaluation study: To generate mid-range theory about the impact of all-nurse respite care for families of children with medically fragile or complex health conditions.

### Purpose

The purpose of the following analysis is to begin generating substantive theory about the manner in which parents of children with medically complex conditions choose to utilize in-home nursing respite care to augment other sources of child care. To discover social processes involved in parents' utilization of respite as child care, data were collected and analyzed using grounded theory.

To re-emphasize, this analysis is part of a larger evaluation study being conducted by Dr. V. Hayes and P. McElheran (Otterman). Commencing in April 1994 and proceeding until May 1996, the evaluation study uses a multi-variable, one-group, pre-post-post, exploratory, descriptive design to evaluate the B.C. Nursing Respite Program. Both qualitative and quantitative data are being collected from parents at three time points: prior to the

commencement of nursing care through the Nursing Respite Program, as well as six and twelve months after initial data collection.

Within the design of this study, I am exploring how parents utilize nursing respite as child care by analyzing the qualitative data. Findings presented in this report are preliminary and reflect analysis of a representative portion of data from Hayes and McElheran's study. It is my intention to expand these findings by continuing to further analyze data from the study. The verb tense used to discuss these findings reflects the ongoing nature of this study.

#### Forestructure

My interest in this research problem emerges from my clinical experience caring for acutely and chronically ill infants and children in the hospital setting. This experience includes preparing parents for discharge of children with complex care needs such as ventilation, tracheostomy care, oxygen administration, or the use of other technologies. After discharge of their children from hospital, some parents describe difficulty finding caregivers qualified to deliver high-technology care to their children. Subsequently, they experience little relief from their caregiving responsibilities, and few opportunities to rest or pursue other activities. Such parent accounts encourage me to understand the experience

of parents caring for children with medically complex conditions at home.

To this end, I have explored through academic study theoretical and practical issues related to the experience of parenting children with medically complex conditions at home. My exposure to theoretical perspectives on health promotion and community nursing has been particularly influential in guiding me to acknowledge strengths of individuals, families, and communities, while recognizing the potential for health in situations of apparent illness or chronicity. In addition, my exposure to the work of faculty members studying children with chronic conditions and their families has sensitized me to the topic under study (Anderson, 1981; Anderson & Elfert, 1989; Canam, 1993; Hayes 1992; Robinson, 1985).

My approach to this study is further influenced by academic clinical experiences, which exposed me to a variety of respite care models designed to serve families who have children with diverse chronic conditions. This exposure includes my participation in the development of a volunteer grandparent program for families who have children with "special needs", a program which potentially provides parents with a break from parenting responsibilities.

In addition to clinical experience and academic courses, I work as a research assistant for Dr. Hayes and

Ms. McElheran on their study evaluating the British Columbia Nursing Respite Program. Since the beginning of the pilot phase of this project, I have collected both qualitative and quantitative data with families of children requiring nursing respite care, and have participated in analyzing qualitative data using grounded theory. Thus, my work as a research assistant directly influences my interest in this research question. Specifically, preliminary data suggest to me that the number and skills of potential caregivers to whom parents may delegate the care of their child who has a medically complex condition varies among parents, a phenomenon which causes me to consider how parents utilize nursing respite as a source of child care.

#### Assumptions

When conducting research, the investigator's approach implies assumptions related to methodological issues and theoretical perspectives regarding the population under study (Knafl & Deatrick, 1987). Assumptions underlying this study relate to three methodological issues described in literature examining families, or family members, who live with children who have chronic conditions. First, Knafl and Deatrick compare and contrast two approaches to studying families of children who have chronic conditions. Second, Stein and Jessop (1989), as well as Pless and Perrin (1985), debate the extent to which parents of

children with diverse chronic conditions have similar or different life experiences. Last, Thomas (1987) discusses unit of analysis in family research, and its implications. I will describe these issues and their underlying assumptions, and discuss their relevance to my study.

#### Studying Families who have Children with Chronic Conditions

According to Knafl & Deatrick (1987), researchers studying families of children with chronic conditions utilize one of two approaches, each founded on different assumptions. In describing these, Knafl and Deatrick provide a framework for organizing and interpreting existing research conceptualizing family responses to a child's chronic condition. While they use the term "family" to describe their framework, they illustrate this framework with studies based on different units of analysis. For example, study informants may be mothers, parents, siblings, the child with a chronic condition, or the family as a whole. Consequently, this framework applies to my study, in which parents are the unit of analysis.

Researchers using the Objective/Passive/Outcome Approach (OPOA) seek to measure, predict, and control the impact of pediatric chronic conditions on families (Knafl & Deatrick, 1987). Use of this approach assumes that families respond passively to the child's chronic condition; thus, strategies used by families to manage the

child's condition are not addressed. Conversely, researchers using the Subjective/Active/Process Approach (SAPA), seek to understand how families of children with chronic conditions actively manage their child's condition within the context of family life (Knafl & Deatrick). Researchers using this approach assume that living with a child who has a chronic condition is not necessarily a negative situation; rather families define their own experiences.

Together, these two approaches provide complementary views of family responses to a child's chronic condition. While the strength of OPOA lies in its ability to link potential problems or negative outcomes with at risk individuals and groups, SAPA acknowledges that families and their individual members actively define and manage chronic conditions.

In keeping with SAPA assumptions, I conducted this study assuming that parents whose children receive nursing respite care desire a break from caregiving responsibilities. Furthermore, these parents actively choose to utilize nursing respite in lieu of, or in addition to, other sources of child care to obtain relief from parenting responsibilities. Underlying these assumptions is the premise that pediatric in-home nursing respite is a form of child care.



### Categorical versus Noncategorical Approaches

While different pediatric chronic conditions present parents with diverse care issues, parents of children with different chronic conditions also face similar care issues (Pless & Perrin, 1985; Stein & Jessop, 1989). In collecting and analyzing data in this study I assume that, despite differences in the medically complex conditions of children receiving nursing respite through the B.C. Nursing Respite Program, similarity exists among parent strategies to utilize nursing respite care as a form of child care. Consequently, diversity among the medically complex conditions of children whose parents participate in this study helps elucidate universal aspects of the process by which parents of children with different conditions utilize nursing respite as child care.

### Unit of Analysis

Data collected from individual family members, dyads or other family subgroups, or the family as a whole, yield different and not necessarily congruent perspectives of family life (Thomas, 1987). Since parents are the unit of analysis in the proposed study, I am assuming that study findings will describe the parent perspective on the process by which nursing respite augments their child care options, and that the child receiving nursing respite, siblings, or other family members such as grandparents, do

not necessarily share the perspective expressed by parents. Furthermore, when parents are interviewed together, the perspective of the individual mother or father may or may not be expressed.

### Summary

Home care for children with medically complex conditions is a growing phenomenon made possible by parents willing and able to care for children at home. Potential advantages of pediatric home care may include decreased costs to the health care system, as well as social and developmental benefits to the children. Yet parents caring for these children often have limited child care options which would enable them to rejuvenate from parenting activities and fulfill other roles and responsibilities. Pediatric in-home nursing respite care represents for parents a potential source of child care for children with medically complex conditions.

To shed light on the child care dilemma faced by these parents, this study sets out a beginning conceptualization of how parents of children with medically complex conditions choose to utilize in-home pediatric nursing respite care as a potential source of child care. The next chapter describes the research methods used to examine this phenomenon.

## Chapter 2

### Methods

#### Design

Since my study is part of a larger evaluation study being conducted by Hayes and McElheran (Otterman), its design is influenced by the design of the larger study. To collect both quantitative and qualitative data, the co-investigators are using a pre-post-post exploratory descriptive design, in which data are collected from families at three, six-month time intervals. Qualitative data are being collected and analyzed using grounded theory. Grounded theory methods are congruent with exploring social processes involved in parents' utilization of nursing respite as child care. By using grounded theory to explore this phenomenon, I also avoid violating philosophical assumptions guiding data collection and analysis in the evaluation study.

A hallmark of grounded theory is theoretical sampling, which directs the researcher to seek data selectively, rather than at set time intervals, to illuminate concepts relevant to the emerging theory (Strauss & Corbin, 1990). Since the quantitative side of Hayes and McElheran's study design requires data to be collected at set time intervals, informants are being interviewed on a schedule, rather than primarily by their ability to inform specific theoretical concepts as they arise during analysis. While this

sampling plan weakens pure theoretical sampling procedures, it provided me with an opportunity to capture process by comparing parental perspectives on child care before and six months after parents begin nursing respite services.

During the course of my study, other related analyses have simultaneously been conducted with these data by members of the evaluation research team. As a member of this team, I have influenced subsequent data collection, enhanced my theoretical sensitivity, and sensitized other team members to the concept of pediatric nursing respite as a form of child care. Once thesis requirements have been met, I will continue this collaboration, incorporating future findings into the preliminary findings presented in this thesis, and weaving this work into the larger evaluation study.

### Grounded Theory

Grounded theory seeks to describe social processes through which people define and make sense of their world (Hutchinson, 1986). Theory generated by this method is "inductively derived from the study of the phenomenon it represents ... it is discovered, developed, and provisionally verified through systematic data collection, and analysis of data pertaining to that phenomenon" (Strauss & Corbin, 1990, p. 23).

Grounded theory entails simultaneous collection, coding, and analysis of data. Theoretical sampling

procedures enable the researcher to develop concepts, categories, and their associated properties and dimensions, and to identify and explain relationships between categories (Strauss & Corbin, 1990). Theoretical sampling, in combination with open, axial, and selective coding procedures, contribute to the inductive, rigorous, analytic processes of grounded theory from which empirically based theory emerges (Hutchinson, 1986; Strauss & Corbin).

#### Theoretical Underpinnings of Grounded Theory

When using grounded theory methods, the researcher relates concepts and categories emerging from the data into a conceptual framework (Hutchinson, 1986). As it emerges, this framework guides further theoretical sampling and data analysis. This approach differs from verification research, in which a selected theoretical framework guides the study (Hutchinson). The idea of an emerging framework in grounded theory misleads some into thinking that grounded theory is "atheoretical" (Chenitz & Swanson, 1986, p. 46). On the contrary, symbolic interactionism provides a foundation for the grounded theory method, and enriches interpretation of the emerging theory (Chenitz & Swanson; Hutchinson).

The symbolic interactionist underpinnings of grounded theory are congruent with examining how parents perceive nursing respite as a form of child care, and the process by which parents utilize nursing respite in relation to other

forms of child care. Symbolic interactionism focuses on the processes of social interaction through which individuals interpret their world (Blumer, 1969). Major concepts of symbolic interactionism include the self, the world, and social action (Blumer). Symbolic interactionists view the self as reflective and ever-evolving. The social world in which the individual exists and upon which the individual reflects is composed of concrete and abstract objects. The individual endows these objects with symbolic meaning; actions toward these objects reflect the meaning which they have for the individual (Blumer).

As individuals interact in the object world, they both shape and are shaped by this world (Blumer, 1969). An individual's subjective reality changes with time and context, and meaning varies among individuals. The symbolic interactionist approach enhances interpretation of parent perspectives on choosing to use nursing respite in relation to other forms of child care. Understanding parent perspectives will assist nurses to plan and deliver in-home nursing respite services which adapt to the perceived child care needs of parents.

#### Sampling, Setting, and Data Collection

Informants capable of illuminating my topic of study are being recruited through sampling procedures developed for Hayes' and McElheran's study. Over a 15 month period,

families admitted to the Nursing Respite Program are being approached to participate in the evaluation study.

Eligible informants include members of families who have not received nursing care through the B.C. Nursing Respite Program but are about to receive such care.

Once families are determined to be eligible to receive care through the Nursing Respite Program, they are sent a letter explaining the evaluation study and requesting their participation (Appendix A). A research assistant then phones eligible families to answer questions about the study and obtain verbal consent. If the family agrees to participate in the study, the research assistant schedules the first interview. Prior to this interview, informants read and sign a written consent form (Appendix B).

Families are being interviewed prior to commencement of nursing respite, and then six and twelve months later. Ongoing verbal consent is being obtained prior to second and third interviews, and families are free to withdraw from the study at any time. The evaluation study has been approved by the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects.

At the convenience of informants, members of the research team are conducting unstructured interviews in families' homes. These interviews are being audiotaped and transcribed for later analysis. In addition, researchers

are recording field notes pertaining to the interview setting, the interview process, as well as personal observations which may influence data collection and analysis. These field notes comprise additional sources of data. Once typed, interview transcripts are reviewed by all four members of the research team. After individual members code transcripts, the team meets to compare analyses and to discuss concepts and categories emerging from the data.

Early in this analytic process, I became interested in parental social support, but later came to see supportive aspects of pediatric nursing respite as part of a broader issue related to child care. I thus chose to pursue this concept of child care through further analysis. To differentiate my portion of the analysis from the main study, while recognizing the interrelationship between the two, I negotiated with the research team to analyze data that address how parents utilize nursing respite care as a form of child care. I acknowledge that data and interpretations relevant to this analysis may simultaneously relate to other categories examined by the research team. Furthermore, I recognize that my analysis should complement rather than duplicate the analytic efforts of the research team. To this end, I am communicating my findings to the research team so that my



analysis may be placed within the context of broader study findings.

### Data Analysis

As is occurring in the evaluation study, I analyzed data pertaining to child care using the constant comparative method (Strauss and Corbin, 1990). Throughout this process, I kept memos in the form of code notes, theoretical notes, and operational notes to provide a paper trail by which I, the research team, and my thesis committee could track the process of data analysis (Strauss & Corbin). As early analysis revealed concepts and categories, I directed subsequent coding to develop these ideas, as well as their properties and dimensions.

To begin capturing the process by which parents choose to utilize nursing respite as a source of child care, I analyzed qualitative data collected during first (pre-respite) and second (six-month) visits with the parents of six families. Analyzing data collected at two time points enabled me to examine the evolving nature of parent decision-making related to their use of nursing respite. Although parents had not experienced nursing respite at the time of initial interviews, their intention to utilize this service suggested to me that these interviews could provide information regarding their use of nursing respite as child care.

The decision to analyze a preselected subset of the data from the evaluation study was based on pragmatic considerations. These considerations include the availability of transcripts from first and second visits with a given family, the number and location of scheduled family visits during the analysis phase of my thesis, and the logistics of accessing data collected by another member of the research team in a timely manner.

My choice to analyze preselected data suggests that this study could be considered a form of secondary analysis (Thorne, 1994). These data evolved within the context of research questions guiding the larger evaluation study, which raises the issue of fit between these data and the research question posed in my portion of the analysis (Thorne). If these data had been collected with my more specific research question in mind, the fit between the data and my question would be stronger, and the resulting analysis denser.

While the matter of "fit" calls attention to an aspect of my study design which is characteristic of secondary analysis, other aspects of this design suggest primary analysis using modified grounded theory. For example, my involvement in data collection and analysis within the context of the evaluation study provided me with insight regarding subtle influences on the data sets, insight which is not always available to a secondary analyst (Thorne,

1994). In addition, since early data analysis conducted for the larger study sensitized me to the idea of nursing respite as social support, and subsequently child care, my topic of study "emerged" from the data, a process in keeping with grounded theory (Glaser, 1992). Furthermore, since my study is an integral part of the larger study which is currently in progress, opportunities exist within the larger study to validate, refute, and refine findings from my study.

Since haphazard use of secondary analysis may undermine the credibility of study findings (Thorne, 1994), I feel compelled to address for the reader this question of "fit". At the same time, it is important to note that grounded theory is a method in transition (Strauss & Corbin, 1994), and that the study design may reflect this fact. I raise the issue of whether or not this grounded theory study represents a primary or secondary analysis so that the reader may reflect upon how the fit between my research question and preselected data sets might influence study findings.

#### Six Family Vignettes

Prior to discussing study findings, I present six family vignettes. To protect the anonymity of individuals and families participating in this study, I have changed their names. These vignettes describe each child's medically complex condition, as well as identify sources of

child care other than nursing respite care which parents may use.

The Adams. Abby and Jim Adams are the parents of 15 year old Mona, and 17 year old Mark. Mona has end-stage renal failure, and receives overnight dialysis at home. Jim is unemployed and Abby works full-time outside of home.

Mona and Abby are the dialysis experts in the family. While Mark knows how to initiate dialysis, he views it as a chore and participates infrequently. Jim is not involved in any technical aspects of Mona's care. While Mona initiates and troubleshoots her dialysis, Abby performs these tasks when Mona is feeling tired or ill. Additionally, since Mona sleeps through the dialysis pump alarms, Abby is often up at night attending to the dialysis.

While Abby does not want nursing respite throughout the night, she feels that it is helpful when Mona is too sick to initiate her own dialysis, and the during early hours of the teenager's sleep before Abby goes to bed. They receive 16 hours of regularly scheduled respite per week and 8 flexible hours which may be scheduled at their convenience. Other sources of care for Mona never arose during our interviews.

The Bentleys. Alice Bentley is the single mother of 23 month old Eddie. An only child, Eddie has a severe seizure disorder requiring medication, is developmentally delayed,

has visual and auditory deficits, and receives total nutrition via a J-tube. Due to her son's care needs, Alice is unable to work outside the home and thus receives social assistance. Alice expects Eddie to die and has already made funeral arrangements.

Although Eddie's biological father lives in a distant town, he and Alice keep in touch by phone. Eddie's father cared for him one summer for a month, and has offered to do this again. Alice also has a boyfriend who lives nearby. While he stays with Eddie for brief periods, he is apparently frightened that Eddie may die in his care and consequently babysits infrequently.

Alice has a large extended family, most of whom do not live in close enough proximity to provide child care for her son. Although her sister sometimes helps with Eddie, she has a family of her own, and thus other responsibilities. Alice mentions only one friend who provides child care, but when Eddie seizes, Alice is uncomfortable asking her friend to babysit. Eddie receives overnight daycare twice a week in the home of a licensed daycare provider.

When Alice first heard about the Nursing Respite Program, she did not think that her child would be eligible. After Eddie's condition deteriorated, a health care provider involved in his care referred Eddie to the Nursing Respite Program. Following an eligibility

assessment, Eddie and his mother were allocated 16 hours of nursing respite per week to be used at Alice's convenience.

The Carvers. June and Jacob Carver are the parents of 11 month old twins who were born at 28 weeks gestational age. One of the twins, Hugh, has bronchopulmonary dysplasia, and his care includes the use of oxygen, feeding pumps, and medications. Both parents have children from prior marriages. June's three year old son consistently lives with them, while Jacob's 6 year old daughter lives with this family intermittently. At the time of the first interview, June was pregnant. In view of the twins' premature delivery, this pregnancy was considered high risk.

While June is a homemaker, Jacob's work involves frequent out-of-town travel. Due to June's high risk pregnancy and her husband's work schedule, June's mother helps with Hugh's care while Jacob is away. During the first interview, June expressed ambivalence about receiving nursing respite care. She wondered if it would be worth the hassle of involving strangers in Hugh's care, preferring to use family and friends for child care. Hugh and his parents receive 12 hours of respite care per week.

The Darwins. Lisa and Garth are the married parents of eight month old Kevin. Kevin is developmentally delayed and has a severe seizure disorder which intermittently causes apneic episodes. When seizures interfere with his

breathing, Kevin receives supplemental oxygen as well as medications. He also has a g-tube for feedings. Garth has paid employment while Lisa stays home to care for Kevin. Lisa's adolescent niece lives with this family.

Garth and Lisa know few people capable of caring for Kevin in their absence. While Lisa's brother sometimes helps with child care when parents are in the vicinity, he "panics" when Kevin requires medical attention. Alternatively, with the exception of seizure management, Lisa's niece understands Kevin's care needs and with supervision, assists in his care. For example, she might watch Kevin while Lisa naps, knowing that she may wake Lisa if he seizes or becomes apneic. However, neither parent wants to give this niece full responsibility for Kevin's care. Nor do they want to overburden any family member with the responsibility of caring for a child who may suddenly die.

In addition to Lisa's brother and niece, and the Nursing Respite Program, the only other source of child care which Lisa describes is monthly weekend respite at a rehabilitation centre for children. Lisa emphasizes that without nursing respite care, she would pursue bi-weekly weekend respite care at this centre. The Darwins receive 16 hours of respite per week.

The Emerys. Tina Emery is the single mother of 26 month old Ben. Ben has cerebral palsy, quadriplegia,

seizures, visual and auditory deficits, chronic renal failure, and an intermittent oxygen requirement. Tina and her son recently moved to British Columbia to live with Tina's parents. Although Tina wants to work outside the home to support herself and her son, she has been unable to make the necessary child care arrangements.

After three applications to the Nursing Respite Program and considerable personal effort by Tina, she and her son were finally allocated eight hours of nursing respite care per week, an amount which Tina feels is inadequate. After investing time and energy in securing nursing respite services, Tina fears that if her son's condition shows any improvement, her nursing respite hours might be revoked, despite the fact that an improvement in her son's condition does not reflect a significant change in his caregiving requirements.

While Tina and her son live with Tina's parents, and Tina's mother is trained to care for Ben, family members agree that Ben's care is Tina's responsibility. Although Tina is exploring and utilizing other child care options, she is concerned about the impact of these child care arrangements on her son's fragile condition. In one temporary arrangement, a caregiver did not know how to intervene if Ben became acutely ill and required oxygen. In another ongoing situation, Ben's exposure to many children and adults increases his chance of developing a



respiratory infection. When Ben becomes ill, his care needs are more complex, taxing both mother and child.

The Fowlers. Erin and Frank Fowler are the married parents of 27 month old Emily. Following the removal of a brain tumor, Emily has had hypothalamic syndrome, diabetes insipidus, an eating disorder from damage to her satiation center, a sleep disorder, and visual impairment. Her metabolic imbalance requires 24 hour monitoring and intervention. Both parents work full-time, and are involved in Emily's care.

Frank has 3 children from a first marriage. Bill, age 15 and Doug, age 9, primarily live in their father's home, while Carla, age 12 lives with her biological mother. These three siblings live together on weekends, alternating between their father's and mother's homes. Bill is capable of caring for Emily, and sometimes babysits so that the parents may run errands. Carla also babysits, but to a lesser extent. Doug often entertains Emily, but is not involved in her physical care. When Erin and Frank delegate Emily's care to siblings, they provide various levels of back-up in keeping with the knowledge and ability of siblings to manage Emily's health care needs.

Erin and Frank have hired and extensively trained a nonprofessional daycare provider who babysat Emily prior to the development of her tumor, her surgery, and subsequent metabolic complications. Since this person does not have a

health care background, the parents provide back-up for more complex caregiving responsibilities and try to schedule these activities during hours when they are home. In an emergency, this person may contact Erin at work, or Emily's physician.

Although the parents have regular child care during the week, and receive some child care assistance from Emily's older siblings, they are still up with her every night. Consequently, they primarily schedule 16 hours of their nursing respite to enable them to sleep at night. They also have 8 flexible respite hours to schedule at their convenience.

#### Summary

The information in these vignettes provides a contextual backdrop for the discussion of study findings to date. Throughout this discussion, I refer to specific individuals, but attempt to limit repetition of information presented in the vignettes. When quoting parents, I refer to the parent by his or her hypothetical name and refer to the researcher using the letter R. The sources of specific quotations are noted in brackets following each quotation. For example, S1T1P3L2 indicates study family number one (S1), visit or time one (T1), transcript page 3 (P3), and line number 2 (L2).

In the following analysis, the grounded theory approach described in Chapter 2 provided an effective means

to explore how these parents choose to use nursing respite as a form of child care, a social process about which little is known. Well suited to exploring the unknown, grounded theory is also designed to generate theory, a procedure which began with this analysis. Through constant comparative analysis, relationships between concepts and categories emerged to delineate the decision-making process of parents utilizing nursing respite as a form of child care. To begin the discussion of study findings, I describe the core category, perpetual innovation.

### Chapter 3

#### Perpetual Innovation: Child Care for Children with Medically Complex Conditions

This is a story of perpetual innovation, which describes the ongoing modifications that parents make in child care arrangements for their child who has a medically complex condition when nursing respite care is an option. These modifications enable parents to attempt to fulfill other roles, to sustain relationships with other family members and friends, to care for self, pursue leisure activities, or enhance personal development.

The term perpetual innovation captures the ongoing creativity with which parents approach the task of providing a safe care environment for their child, while enabling them to fulfill other roles and responsibilities. Parents consider competent caregivers for their child to be a finite resource. Since their child's well-being often demands caregivers to possess medical knowledge and technical skill within the realm of nursing qualifications, parents often view nurses as unique sources of child care. While nursing skills are often in demand by parents who require care for a child who has a medically complex condition, parental access to in-home nursing respite care is finite. Maximizing the use of this limited resource becomes an unending endeavor.

### Situational Factors

When using nursing respite as a source of child care, various factors influence parental engagement in perpetual innovation. These factors relate to the child, the parents, the nurses, and nursing respite program operations.

Child-related factors. The child's age, developmental level, health, and ability to provide self care influence the type of caregiving arrangement acceptable to parents. Chronologically and developmentally 15 years old, Mona Adams is the only child in this study capable of providing self care. When healthy enough, she initiates and troubleshoots her own peritoneal dialysis. If too sick to manage her own dialysis, her mother either delegates this responsibility to a nurse or initiates dialysis herself. In contrast, parents of a preschool-aged child manage their child's medical condition in all situations.

Parents also consider the stability and predictability of their child's condition, recognizing that caregivers may need to assess and manage a sudden acute change in the condition. For example, Kevin Darwin's seizures may unpredictably trigger apneic episodes. This possibility makes it difficult for parents to leave the child even briefly with a caregiver who does not know CPR. In addition, when a child's care involves specialized

equipment like that used for dialysis, oxygen administration, or suctioning, parents consider these complex needs when choosing a caregiver.

Parent-related factors. Above and beyond the physical and emotional care that parents provide to their child who has a medically complex condition, parents have other roles, responsibilities, and desires to fulfill. Many of these activities are optimized if parents can temporarily delegate caregiving responsibilities to another caregiver. Parents in this study seek child care in order to:

1. Perform household responsibilities, such as buying groceries, paying bills, washing clothes or cleaning the home;
2. Sustain interpersonal relationships with a spouse, other children, extended family, or friends;
3. Care for self, and pursue personal aspirations; or
4. Earn a living to support self and family.

In addition to care provided by nurses through the Nursing Respite Program, parents may use other forms of child care to accomplish these activities. When choosing to utilize nursing respite care or another form of child care, parents consider the level of back-up which they are able to provide potential caregivers while still accomplishing the above activities. To exemplify, when her niece is home to watch Kevin, Lisa Darwin is able to nap, knowing that if Kevin seizes or becomes apneic, she will be awakened by her

niece. However, since her niece does not know how to manage Kevin's seizures Lisa could not, for example, leave home to get groceries.

RN-related factors. While an in-depth discussion of desirable and undesirable attributes of nurses providing in-home respite care to children is beyond the scope of this report, it is noteworthy that parents perceive nursing knowledge and technical skill to set nurses apart from other potential caregivers. Parents value agency efforts to recruit nurses whose professional knowledge and skill match their child's condition and care needs. In particular, they value nurses who are familiar with their child's specific care needs and situational factors influencing those needs. For example, if a child has a seizure disorder, parents value a nurse who demonstrates effective seizure management skills which incorporate subtle management strategies specific to their child.

Drawing on professional knowledge, assessment skills, as well as problem-solving and crisis management abilities, the nurse's judgment in managing their child's medical condition is regarded by parents as an asset. Highly valued nurses also demonstrate initiative to care for the child beyond a custodial level, capitalizing on opportunities to promote the child's development and acquisition of social skills.

Factors related to Nursing Respite Program operations.

The manner in which parents use nursing respite care depends in part on Nursing Respite Program operations. For example, program eligibility criteria influence the number of hours of nursing respite care per week received by a child and his or her parents, as well as the duration in weeks or months that Nursing respite is provided. To illustrate the latter, Tina Emery discusses her inability to use nursing respite to make long-term plans in her life since an improvement in Ben's condition may result in him being discharged from the nursing respite program.

Tina: It's wonderful but it can be taken away from you as fast as you get it.... So that's extra added pressure that one has to deal with is, um, don't plan too much with your life because, um, it could end (S8T1P18L48-55).

Ultimately, Tina would like to be able to work outside the home for pay, but her desire to use nursing respite for this purpose is further stymied by the program's mission statement which precludes parental use of nursing respite time for employment.

Nursing respite program operations also influence parents' ability to schedule nursing respite at their convenience. Flexibility in scheduling, and ability of the nursing agency to provide nurses on short notice, is partly determined by the availability of individual nurses hired



by the agency to deliver nursing respite care to a particular child. While individual nurses may be more or less flexible or willing to work at the last minute, it is ultimately the agency's responsibility to meet the parent's scheduling needs. If parents are unable to schedule nursing respite care at preferred times, then the agency may negotiate work hours with individual nurses, or hire other nurses to meet parents' desired scheduling needs.

Alice Bentley discusses the importance of flexible scheduling, but simultaneously reveals that she negotiates her respite schedule around the availability of agency nurses.

Alice: The way the nursing works and stuff it's all been really good and you know they do it around my schedule and not, not theirs .... If neither of (the nurses) are available on a day then I've got, then I can just change that day or whatever, to another day.  
(S2T2P33L41-P34L3)

As a single mother home on social assistance, Alice's primary responsibility is caring for her child. Her days are unstructured, so she is able to negotiate her respite schedule with the preferred work schedules of the agency nurses. In contrast, Erin and Frank Fowler have multiple work and family responsibilities and need the nurses to accommodate parental scheduling needs. They primarily schedule nursing respite care at night to enable themselves to sleep and to minimize disruptions of having a nurse in

the house during waking hours. Since Frank's work day may begin early or late in the morning, parents try to schedule nursing respite care to correspond with the hours when parents are sleeping. To accommodate last minute scheduling requests by these parents, the nursing agency utilizes a pager system.

Erin: At one point [Frank] went on early shift which meant we were getting up at three thirty.

Frank: You know we had the freedom to change that time pretty much at will....

Erin: The nurses at the beginning thought it was a bit unusual because we were having them come at eight at night and leaving at four in the morning and it was an unusual shift but they didn't mind at all.... They did ask was this going to be forever and (laughter) we said no, its not forever....

Frank: So basically we've got to let them know at the last minute so that's convenient to be able to do that and know that there's going to be something done (S10T2P10L44-P11L40).

### Perpetual Innovation in Context

The frequency, intentionality, and extent to which parents engage in perpetual innovation when utilizing nursing respite care fluctuates to complement child care requirements as perceived by parents. The frequency of innovation may vary from low to high, the intentionality from proactive to reactive, and the extent from minor to major.

Parents who have predictable child care needs coupled with a steady, competent source of child care may proactively schedule nursing respite hours far in advance.

Such intentional planning decreases the frequency with which parents must modify child care plans.

The Fowlers provide evidence of both high and low frequency innovations, both of which suggest proactive intentionality. On one hand, the agency knows that the Fowlers require nursing respite care on specific nights of the week which translates to low frequency innovation activity by parents. On the other hand, the Fowlers require minor adjustments in the specific times when the nurse provides care on those predetermined nights. These minor innovations occur with higher frequency.

The reliability of nurses influences the intentionality of innovation by parents. If nurses cancel their scheduled shifts with a particular child due to personal illness or some other reason, parents find themselves reactively innovating at the last minute, either finding substitute caregivers or altering personal plans to provide child care themselves. Thus, even when child care requirements are predictable, planning care is a perpetual endeavor.

The extent to which parents engage in perpetual innovation also varies with the predictability of parents' perceived child care requirements, the flexibility and availability of nurses hired by the nursing agency to meet their scheduling needs, and the availability of child care options other than the nurses. Parents who perceive their

child care options to be inadequate in either quality or quantity often exert extensive effort to fortify their child care options. This effort is in reaction to the perceived inadequacy of available child care options.

In describing her extensive, frequent efforts to secure nursing respite services, Tina Emery evokes a war metaphor, using terms such as battle, fight, ammunition, and victory. Prior to receiving nursing respite services, her story of perpetual innovation suggests a reactive intentionality of major extent and high frequency.

A further illustration of intentionality is provided by the Carvers who were unsure about whether or not to utilize the nursing respite program, preferring to "leave it to family" (S4T1P10L44). However, their child care arrangements fell through coinciding with June's hospitalization with preterm labor. This left Jacob as the only caregiver competent to meet Hugh's care needs; as a result of caring for Hugh, Jacob lost his job, the family's only source of income. While the Carvers could have planned nursing respite care proactively, a sudden change in situational factors forced Jacob to utilize nursing respite care in a reactive manner.

#### Perpetual Innovation Strategies: A Decision-Making Framework

Throughout the process of perpetual innovation, parents adopt a number of strategies. As situational

factors change hourly, daily, weekly, and monthly, parents repeatedly use these strategies, thus emphasizing the cyclical nature of perpetual innovation. These strategies include:

1. Prioritizing parental activities requiring child care.
2. Estimating the adequacy of nursing respite hours to meet parents' perceived child care needs.
3. Weighing the advantages of nursing respite care with other forms of care.
4. Matching child, parent, nurse, and other situational factors to optimize the child care situation.

Together, these parent strategies suggest a decision-making framework embedded within the process of perpetual innovation. The goal of this process is to create caregiving situations that are mutually beneficial to both parent and child.

Prioritizing parental activities requiring child care.

When planning nursing respite care, parents describe many opportunities which they hope that this service will provide for them. These opportunities range from the concrete, such as sleep, household chores, and appointments, to the abstract, such as freedom, rejuvenation, and "having a life".

The different lifestyles and responsibilities of parents serve to illustrate the process through which they

prioritize their caregiving responsibilities with other personal demands and desires. For parents with few caregiving options, priorities often reflect basic personal needs such as sleep, nutrition, and personal care. For these parents, nursing respite represents a key to personal survival. For example, Tina Emery postponed some personal dental surgery until she and her son began receiving nursing respite, and has since used nursing respite time for this and other basic self care.

R: So it was respite that enabled you to get to those appointments.

Tina: Yeah, yeah, I did it during respite times and not that it was much of a break (laughs) because I was frozen and stuff but it was good and I've got to do it again and then during respite I'm going to get my hand looked after and that, otherwise I don't know what I'd do [emphasis added](S8T2P16L42-47).

Tina's situation illustrates how parents of children with medically complex conditions may subordinate their own needs to the needs of their child. Unable to find child care to enable her to attend dental appointments for herself, she put her own needs aside. Nursing respite enables Tina to perform essential activities that she otherwise would be unable to do; these essential activities take priority.

When deciding how to use their respite time, parents who have more than one child consider the needs of their other children. For example, June Carver describes how her

husband, Jacob, used respite while she was hospitalized with pre-term labor. Since Hugh's care required equipment such as oxygen and feeding pumps, family outings were difficult. Thus, Jacob viewed nursing respite as an opportunity to spend time with Hugh's siblings outside the home.

June: He would just take the kids, like I said because you couldn't, with Hugh you couldn't go anywhere .... Because the other kids were active, through my experience they were cooped up all the time so we would take off with them when the nurses come, well they were able to run in the fields or whatever ... blow off some air and you know they'd come home and they would be happy so everybody would be happy [emphasis added] (S4T2P4L38-48).

June's description suggests that fulfilling parent roles and responsibilities within the family may be a satisfying use of respite time to the extent that this time contributes to harmonious family environment. Nursing respite care for Hugh frees Jacob to perform activities with his other children in which Hugh cannot participate. In this situation, Jacob prioritizes the social and developmental needs of Hugh's siblings over other parent activities for which respite care might be used. If children are happy, then parents are happy.

Although some parents view nursing respite almost exclusively as a personal relief, others expect that nursing respite will also relieve the burden of child care

from others. For example, Erin and Frank Fowler hope that nursing respite will relieve their 15 year old son, Bill, from caring for his youngest sister Emily:

Erin: To be able to go out and feel that whoever is here could handle whatever comes up with her, I mean, the kids are excellent, [Bill] is very good about looking after her but it's one, not a fair position that he's the only one who could look after her and two, if a medical crisis happens ... it's not a fair position for him (S10T1P4L57-P5L6).

While Erin and Frank value Bill's willingness and ability to care for his youngest sister, they hope that nursing respite will provide them with other child care options, thereby freeing Bill to pursue adolescent interests. As parents, they feel that Bill's developmental growth is a factor influencing their child care decisions. Although Bill provides Erin and Frank with a source of child care which facilitates perpetual innovation, they want to fulfill parenting responsibilities to both Emily and Bill, rather than subordinating Bill's needs to Emily's.

Estimating the adequacy of nursing respite hours to meet parents' perceived child care needs. While parents may desire a certain amount of nursing respite care for their child each week, the number of hours for which they are eligible may be inadequate to meet their perceived child care needs. Lisa Darwin illustrates the challenge of setting parent priorities when the provided hours of nursing respite are finite. Since Lisa and Garth are



saving money to buy a house, her husband works long hours while she cares for Kevin. Except for nursing respite, they have few child care options. As her son Kevin's primary caregiver, Lisa uses her respite time to manage the household, attend appointments and pursue personal activities like reading, writing letters, or catching up on sleep. She feels, however, that the sixteen hours of nursing respite per week do not enable her and her husband to spend time together as a couple. Thus, she faces the choice of using nursing respite time for chores and personal rest, or spending time alone with her husband:

Lisa: I don't feel that it's enough hours due to the fact that twelve out of the sixteen hours I'm taking just for myself alone, my husband is not dealing with any of it except for four hours a week .... And that's, you know, because he's out working everyday so I don't feel that it's actually fair to both parents, for myself, sixteen hours is great for me but I don't think it would be a bad idea if they threw in an extra four hours like, you know, twenty hours a week so then the husband and wife can go out together not just four hours the one day .... We want to go out where we don't always have our son with us ... and it's not enough time for parents to be together; it's usually one parent or the other that gets more of the respite than the other one and it's both of them going through it, not just the one [S5T1 P5L51-P6L19].

For Lisa, inability to spend more time alone with her husband is clearly a compromise, but household management, sleep, and personal rejuvenation take priority. Lisa differentiates between time for herself and time with her husband, illustrating qualitative differences in her

desired use of nursing respite time. In other words, nursing respite care represents more than a break in Kevin's caregiving routine. It represents an opportunity to fulfill some personal goal like maintaining relationships with others or caring for self.

Weighing the advantages of nursing respite care with other forms of child care. After prioritizing desired parental activities, and estimating the adequacy of nursing respite hours to cover their perceived child care needs, parents may determine that their allotted nursing respite hours are inadequate. Subsequently, they consider the care situations in which nursing respite is desirable and those in which another caregiver, such as family members or day care providers, will need to suffice.

The parents of four children, Erin and Frank Fowler both work full time, and have developed elaborate child care arrangements for Emily which includes her siblings, in-home daycare providers, and nursing respite care. For example, when Erin and Frank delegate Emily's care to her siblings, these parents provide levels of back-up in keeping with the knowledge and ability of the siblings. Although care by siblings enables Erin and Frank to leave the house, they always stay in phone contact, providing siblings with a phone number where they may be reached, and calling home to check on Emily and the others. According to these parents, the time that they spend away from home

when Emily's siblings care for her is qualitatively different than the time spent away when a nurse provides Emily with respite care:

Erin: Though the kids are very good and very capable of looking after [Emily], um, you always know there could be a phone call and the times we have used the respite when [Frank] and I have gone out for an evening, I think maybe there's less likelihood of (interruption)

Frank: You can relax

Erin: You can relax a bit more

Frank: You can totally relax knowing that someone is here you know, not that they're more competent because [Bill] and [Carla] are perfectly competent people

Erin: It's a big risk, if we wanted to go out a whole eight hour evening we would phone home, you know, over the evening and [Bill's] never had a problem .... but you know we went out a couple of times (using nursing respite care) ... and were able to relax for the evening and it was ... a fair drive from here you know, and we knew short of a real medical crisis, we wouldn't have to come back and we've never had a call from the nurses so I think that way its unique as well than from the other kind of care (S10T2P20L45-P21L15).

This quotation illustrates how nursing competence may contribute to parental peace of mind, thus influencing situations in which parents schedule nursing respite in preference to using other sources of child care. Although Erin and Frank use different sources of child care, it is apparent that these sources are not directly interchangeable. Rather, different child care options are more or less suited to different situations. While greater variety in child care options may facilitate perpetual innovation by providing parents with more choice, the competence of specific child care providers influences the

types of activities which parents may pursue during child care time.

In contrast, some parents, such as the Carvers, prefer to manage their child's care without the invasion of privacy inherent in having nurses in the home. When the Carvers extended family was unable to meet Hugh's care needs on their own, June and Jacob chose to utilize nursing respite care as a last resort.

June: Because of the circumstances ... we needed the respite ... we couldn't depend on the family even if we, even if we wanted to, we couldn't.... He needed the nurses and not the love, he needed, he needed also, I mean love but he also needed the medical attention involved (S4T2P10L54-P11L3, P11L48-49).

For June, nursing respite is something to tolerate in order to provide safe care for her child. She states:

I really recommend (nursing respite care) even though it's very uncomfortable to have somebody in the home, you kind of have to grate [sic] your teeth and bear with it for your child's sake, you know, you have to, they're (the nurses are) trained (S4T2P16L32-35).

The advantages of the nursing knowledge and skill related to her child's care outweigh June's discomfort with the associated invasion of privacy.

Matching child, parent, nurse, and other situational factors to optimize child care situation. After prioritizing desired parental activities, estimating the adequacy of nursing respite hours to meet child care needs,

and weighing the advantages of using nurses or other caregivers in a given situation, parents coalesce these factors to arrange child care which is mutually beneficial to both them and their child. Ideally, both parent and child benefit from the caregiving experience.

To illustrate, Erin and Frank Fowler coordinate child care provided by daycare providers, family members, nurses, and parents to maximize parent opportunities to work, sleep, run the household, and meet the needs of their children. In addition to scheduling regular nursing respite hours at night, they originally used their flexible nursing respite hours for couple time as well as family activities in which Emily could not participate. Due to continued parental exhaustion, they later decided that flexible hours would be better used at night, indicating a shift in parental priorities:

Erin: We had eight (flexible hours), but what we did is the eight of flex, because we weren't using it consistently because we don't go out all that much ... and because [Bill] is often available to provide a few hours here and there and [Carla] when she's here sometimes that we added that onto our regular night shift. Okay, the nights were more important to us, so right now ... the initial eight flex we actually schedule like regular

R: Okay, so that gives you three nights (of nursing respite care) and then you have an additional four hours of flex.

Bill: Yeah.

Erin: ...If we find we're not using it, what they've suggested is if in a two week period I haven't used up eight hours, then in that third week I add on one more night because the nights are one of the roughest times for us. (S10T2P6L6-24)

This quotation illustrates how changing situational factors and shifting parental priorities require parents to continually modify their caregiving arrangements, underlining the importance of flexibility in Nursing Respite Program operations. It also demonstrates the perpetual nature of these innovations; while the three nights of respite are consistently scheduled, the use of flex time varies week to week.

#### Consequences of Perpetual Innovation

As stated earlier, perpetual innovation is cyclical in nature. Dynamic situational variables require parents to continually modify their use of nursing respite care in relation to other forms of child care. Successful innovations result in an effective match between parent, child, and other situational factors. An effective match enables parents to fulfill roles, responsibilities, and desires other than those involving direct child care, while simultaneously ensuring a safe child care environment which ideally enhances the child's development and socialization.

The Fowlers illustrate parents whose innovations allow them to utilize nursing respite care in a manner which complements other sources of child care while enabling parents to meet personal responsibilities at home and at work. For Erin and Frank, nursing respite care makes the difference between managing Emily's care in the context of

their busy personal and family lives, and being unable to meet their multiple responsibilities. In the following quotation, they respond to a probe by the interviewer which clarifies a comment by Erin that, of all programs involved in Emily's care, the Nursing Respite Program has had the greatest impact on "us".

Erin: Probably on us as a couple, again the kids ... they may be affected if we're really irritable because we've been up a lot with [Emily] but I think on us as a couple

Frank: Yeah I think that more

Erin: It has the most impact because we're getting sleep

R: Yeah

Erin: And you can tolerate a lot more and go through a lot more if you get a decent night's sleep.

Frank: For the first while there, we were run too much ragged and up all the time and very little sleep and disjointed anyway, you know, um, it was hard for the longest time

R: Before respite

Frank: We would wonder if we, yeah, if we were going to be able to cope with that on an extended ... somehow we have to have some help (S10T2P17L11-38).

Nursing respite care provides the Fowlers with the "help" they need to meet their multiple responsibilities, while ensuring safe care for their child. While nursing respite care has the potential to enable parents to meet both their own needs and those of their child, there are times when parents' efforts to create such mutually beneficial child care arrangements are less successful. In such cases, parents create a match in which either parents' needs, the child's needs, or both are compromised. Such a

compromise is repeatedly expressed by Tina Emery, whose fight for nursing respite care resulted in eight hours of care per week. Since she feels that eight hours is inadequate, she also uses child care arrangements which she feels places her son at risk.

Tina: I did have one lady who's not a hundred percent qualified looking after [Ben].... She was better than nothing and unfortunately ... if I want the break that I need I have to jeopardize my son in order to have that which is really too bad (S8T1P3L45-51).

Similarly, given the amount of nursing respite care which she and her son were allotted, Tina comments on her decision to enroll Ben in a child care situation which she feels threatens his health: "They've left me no choice, if I want the break and I want to stay healthy to take care of Ben I have to put him in an environment where he's not safe." (S8T1P8L9-12)

Tina expresses a philosophy on parenting which suggests the potential for nursing respite to provide parents with more than a break from caregiving, and then contrasts this with the reality of finding child care for a child who has a medically complex condition.

Tina: Kids change your life, like whenever you have a child you know, don't expect, you know, to be able to do this and this and this and this, after you have children, um, that's true. But I don't think that parents that have children like I have, um, should have to give everything up, they should still be allowed to work ... they should be able to have somebody, like I wouldn't send my normal child to a



daycare that I didn't feel comfortable with ... but I have to send my son with all his special needs to a daycare that I don't feel comfortable about .... I think that there should be more (child care options) for kids like [Ben].... Make sure these kids are taken care of because if they're 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 doorstep (S8T1P29L33-P30L2).

Tina predicts that without adequate child care, parental exhaustion may eventually overcome parental desire to care for children with medically complex conditions at home. Lisa Darwin supports this prediction by stating that in the absence of in-home nursing respite care, she would pursue weekend respite at a children's hospital despite her awareness that such care would be more expensive.

Lisa: It's pretty crazy that the government doesn't realize that like here we are. There are a lot of families out there that are trying to keep their disabled children at home and care for them themselves except for the odd hours that a nurse can come in and help them so they can rest and the government can't seem to understand ... it's cheaper (S5T2P13L36-43).

Furthermore, while applying for more nursing respite hours, Lisa states, "if I don't get those extra eight hours there will come a time when I won't be able to care for myself and I won't be able to care for him" (S5T2P33L48-50). Lisa implies that if current situational factors persist, future innovation strategies will result in a child care situation which compromises both her own needs and those of her child.

Given the encompassing nature of their caregiving responsibilities in the absence of adequate child care, it is interesting to note that both Tina Emery and Lisa Darwin describe their lives being on hold. Lisa states "I haven't really had a life since he's come home" (S5T1P4L54-55). In the following quotation, Tina echoes this sentiment.

Tina: It would be great if I could go out and get a part time job, it would be great, it would be great therapy for me, it would be good for [Ben] because I know when I worked before and I came home I was just so glad to see him and I didn't mind, you know, doing this and doing that and, um,  
R: You had a bit of a break.  
Tina: I had a life (emphasis added) (S8T1P19L2-11).

Inadequate access to nursing respite or other forms of child care severely limits the scope of parental innovation strategies. Limited child care hampers the ability of parents to provide a safe care environment for their child which simultaneously enables them to pursue activities other than direct caregiving. As a result, parents persist in caring for their child, subordinating their own needs and sacrificing a life of their own. Both Tina and Lisa predict that parental exhaustion may eventually prevent them from caring for their children. If this happens, they will be forced to consider child care options which they feel compromise their child's needs, options which may be more costly to society than nursing respite and other forms of publicly funded child care.

### Summary

To reiterate, the term perpetual innovation describes the ongoing modifications that parents make in arranging child care for children with medically complex conditions when nursing respite care is an option. This term captures the continual creativity with which parents approach the challenge of providing a safe child care environment for their child, while enabling them to fulfill other roles and responsibilities. Perpetual innovation by parents is influenced by situational factors relating to the child, parents, nurses, Nursing Respite Program operations, and sources of child care other than nursing respite. These factors influence the frequency, intentionality, and extent of parent innovations.

Strategies used by parents engaged in perpetual innovation include prioritizing desired parental activities, estimating the adequacy of nursing respite hours to meet parents' perceived child care needs, weighing the advantages of nursing respite care with other forms of care, and coalescing situational factors to optimize the child care situation. Together, these strategies outline a decision-making process through which parents continually plan and re-plan child care.

If these strategies are successful, parents utilize nursing respite care in a manner that benefits both the

child and themselves. If unsuccessful, the needs of the parents, child, or both are compromised. The child's needs are compromised when he or she is placed in a child care situation which may potentially threaten his or her well-being. Parents needs may be compromised to a point where they no longer feel that they have a life of their own.

In Chapter 4, study findings on perpetual innovation are discussed within the context of selected literature. My review of literature to date indicates that the decision-making process reflected in these findings is relatively unexplored. Since few research articles relating to this decision-making process were found, the following discussion emphasizes how study findings link with current knowledge on child care, respite care, and parenting children with chronic conditions.

## Chapter 4

### Discussion

The analysis described in Chapter 3 suggests that parents who have children with medically complex conditions choose to utilize nursing respite care through a decision-making process which considers dynamic situational factors. This process is captured in the term, perpetual innovation. The following preliminary findings provide conceptual cues which may be used to integrate this analysis into the broader theory being generated in the evaluation study:

1. Due to changing situational factors, parents make ongoing innovations in their child care arrangements.
2. Parents utilize nursing respite care in conjunction with other child care arrangements.
3. The nurse's professional knowledge, skill, and ability to handle a medical crisis are unique caregiver attributes which parents consider when planning child care.
4. Some parents believe that Nursing Respite Program eligibility requirements do not reflect the child's care needs or the parent's caregiving demands.
5. Since their child may be discharged from the program at any time, parents who want to work, attend school, or make other long-term commitments for which they need child care are unable to count on nursing respite for care.

6. Parents who feel that they are receiving inadequate nursing respite care hours may be unsure of other child care options available to them.

7. Parents want to schedule nursing respite care at their convenience. Nursing agencies which provide adequate staff and flexible scheduling on short notice meet parental needs better.

8. The availability of other child care options influences how parents utilize nursing respite care.

9. While general respite care is often described in the literature as a temporary relief from caregiving responsibilities, parents identify qualitative differences in their use of respite time. For example, time for self is qualitatively different than time spent with spouse.

10. Parents identify qualitative differences in their time away when their child's caregiver is a nurse versus a caregiver who is not a nurse.

Emerging from these findings is a framework describing the decision-making process of parents who have access to pediatric nursing respite care. As discussed earlier, respite care literature to date identifies issues in respite care such as rigid program eligibility requirements, inadequate caregiver skills, and variations in models of respite care delivery (Ahmann, 1986; Cohen, 1982; Cohen & Warren, 1985; O'Connor, Vander Plaats, & Betz, 1992; Upshur, 1982). Study findings described in

this report contribute to this body of literature in three ways.

First, while the general respite care literature identifies what current issues in respite care need attention by program planners and researchers, this study begins to illuminate how these issues influence caregiving decisions made by individuals seeking respite care services. Second, these findings contribute to the limited body of knowledge on in-home nursing respite care. Understanding how recipients use this specific type of respite care in relation to other forms of care will facilitate the planning and delivery of a range of respite care services responsive to the needs of recipients. Third, these findings highlight respite care issues specific to two populations: (a) children and (b) individuals with medically complex conditions. Findings indicate that attributes unique to children as well as those unique to individuals with medically complex conditions influence the decision-making process of parents arranging respite care.

#### Child Care

While conceptual differences between pediatric respite care (nursing or non-nursing) and child care exist, both provide parents with the ability to engage in activities other than direct care for their child. The importance of examining pediatric nursing respite care as a form of child

care is supported by Thompson's (1993) work, which explores the process through which working mothers make child care decisions when a normally healthy child becomes too ill to attend daycare.

Using a pretested interview schedule, Thompson (1993) asked 20 employed mothers to describe a recent incident in which their children were too ill to attend daycare. Questions probed informants about advantages and disadvantages of other child care options, and the mother's preferences about alternative child care arrangements. Analysis revealed that mothers consider a variety of situational factors including severity of the child's illness, relative pros and cons of available options, and the mother's job flexibility. Thompson then presents a model outlining the decision-making process used by mothers to arrange child care for their sick child.

Despite the different units of analysis (mothers versus parents), results indicate a striking similarity between the decision-making process presented by Thompson (1993), and the decision-making process describing perpetual innovation. For example, when solving child care dilemmas, parents in both studies consider (a) the availability of caregivers competent to care for their "sick" (Thompson) child, (b) the nature of the child's condition and need for medical management, (c) the congruence between the abilities of different potential

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caregivers and the child's care needs, (d) the perceived advantages and disadvantages of different care options, (e) the importance and flexibility of the parenting activity for which child care is required, (f) outcomes of prior child care decisions in similar situations, and (g) the relative importance of these outcomes for the child and parent.

Thompson's (1993) model also addresses factors to which my findings allude, but which have not been developed. These factors include the ability of potential caregivers to meet the child's emotional needs, as well as the economic impact of each child care option. In view of their importance in Thompson's study, I may direct future theoretical sampling to explore these issues for possible inclusion in this emerging decision-making framework.

#### Parenting Children with Chronic Conditions

Although there appears to be no literature specifically describing decision-making processes of parents utilizing respite or other forms of child care for children with medically complex or other chronic conditions, I would like to place my study findings within the context of research on parenting such children. As described earlier (pp. 13-14), Knafl and Deatruck (1987) developed a framework for organizing research on "family" responses to a child's chronic condition. Study findings on perpetual innovation fit in the framework category

describing the subjective/active/process approach (SAPA) of study. Perpetual innovation, the process through which parents arrange child care for children with medically complex conditions, relates to current research on parent management behaviors in the presence of pediatric chronicity. Knafl and Deatrck (1990) present a model conceptualizing family management style, and explicate a component of the model which they call management behaviors (Deatrck & Knafl, 1990).

Grounded in symbolic interactionism, the Family Management Style model incorporates (a) the family's definition of the experience of living with a child with a chronic condition, (b) management behaviors related to living with a child with a chronic condition, and (c) sociocultural context (Knafl & Deatrck, 1990). The model describes the "family" perspective on management styles in terms of averaged individual perspectives. Within this model, management behaviors are explicated in terms of the following defining attributes: (a) the goal of the behavior, (b) its underlying conceptual dimension, (c) the person implementing the behavior, and (d) the focus of the behavior (Deatrck & Knafl, 1990).

Deatrck and Knafl (1990) developed the concept of management behaviors through a review of SAPA research. For example, they incorporated (a) Krulik's (1980) work on normalizing tactics used by parents to minimize perceived

differences between their child and other siblings or peers, (b) Anderson's (1981) work on family lifestyle adjustments when a family member has a chronic condition, and (c) Deatrick, Knafl, and Walsh's (1988) work on adjustments made by families to accommodate a child's chronic condition into daily life. Given these examples, it seems plausible that perpetual innovation strategies may be understood as management behaviors used by parents of children with medically complex conditions to arrange child care benefiting both parent and child. The symbolic interactionist underpinnings of both the perpetual innovation study and Knafl and Deatrick's (1990) family management style model lends further credence to this suggestion.

#### Comprehensive Respite Care Delivery

Having placed the concept of perpetual innovation in theoretical context with literature related to parenting children with chronic conditions, this section addresses pragmatic use of study findings related to respite care delivery. On both local and national levels, projects are currently underway to examine ways to restructure the delivery of pediatric respite care services, including nursing respite care, to better serve both children and their parents. Prior to discussing their recommendations, I will briefly describe these projects.

Locally, a task force in Greater Victoria recently conducted a review of family-centered community-based support services, including the Nursing Respite Program, for families caring for children with physical or developmental "disabilities" at home (Community Respite Care Project, 1993). The Victoria task force conducted surveys and interviews with four groups of stakeholders, including families, family-serving agencies, government representatives, and the general community, on topics related to pediatric respite care service delivery and utilization in Greater Victoria. Findings from this project are limited by the instruments used to collect the survey data. Developed by the task force, these instruments were not pilot tested, and subsequently informants reported that some questions were unclear (Community Respite Care Project, 1993).

Nationally, the Canadian Institute of Child Health, the Canadian Pediatric Society, the Canadian Public Health Association, and Home Support Canada have just completed phase one of a three phase collaborative project intended to respond to the home-based care needs of children with "medically fragile" conditions and their families (Home Support Canada, 1995). Project Phase One sought to identify (a) current sources of in-home pediatric care for these children, (b) perceived gaps in services or obstacles parents confront when accessing services, (c) strategies to

improve these services. Data were collected from parents of children with medically fragile conditions as well as other key informants, using mailed surveys, telephone interviews, and targeted interviews.

Both projects identify the need for greater coordination among respite care options, greater flexibility in the delivery of respite care, as well as easier access to a range of respite care options. In addition, both studies recommend a single point of entry into the system from which parents may access a range of respite care services.

These recommendations suggest an implicit value which promotes parental ease and independence in accessing and utilizing respite care services. While my study focuses on nursing respite care, the manner in which some study parents were able to utilize this professional care in conjunction with other child care options suggests that coordinated access to a range of respite care options may facilitate the process of perpetual innovation. Offering parents a range of comprehensive respite care services would enable them to match respite care services to their specific child care needs. In response to changing situational factors influencing their child care decisions, parents could weigh the advantages and disadvantages of different respite options and choose the type of respite care which benefits both parent and child.

### Summary

Due to the paucity of related literature, it is difficult to locate study findings within existing bodies of research. Nonetheless, this discussion describes study findings within the context of research on child care, respite care, and parenting children with chronic conditions. Furthermore, it addresses how study findings providing the emic perspective may influence policy decisions regarding pediatric respite care delivery. Additional data collection and analysis within the context of the larger evaluation study will provide an opportunity to elaborate on these findings, to integrate them into the larger study, and to contribute to the scarce literature on child care decisions of parents who have children with medically complex conditions.

## Chapter 5

### Implications

Study findings presented in this thesis describe the phenomenon of perpetual innovation, namely the ongoing modifications that parents arranging child care for children with medically complex conditions make when nursing respite care is an option. A decision-making framework which describes this process has implications for the delivery of nursing respite care services for children with medically complex conditions and possibly other forms of child care services. I describe these implications acknowledging that this decision-making framework is tentative, will undergo refinement and validation within the larger evaluation study, and reflects parent decisions regarding a specific respite care model involving nurses.

First, this decision-making framework may be used to educate nurses who provide direct pediatric in-home nursing respite care about the process through which parents choose to utilize nursing respite care. This understanding will sensitize nurses to the broader context in which they provide care. Although nurses care for the child, this care is provided to enable parents to fulfill activities other than direct care of their child. Appreciating the manner in which parents schedule nursing respite in relation to other child care may enable nurses to enact their caregiving role to better complement parent activities.

Second, this decision-making framework may be used by agencies delivering nursing respite care to provide these services in a manner which better responds to respite needs of parents. For example, the framework illustrates that parents planning nursing respite care consider a variety of dynamic situational variables. Agencies need to adopt strategies which provide parents with the flexibility to utilize respite care in relation to these changing variables. Study findings reveal two agency strategies which provide parents with this flexibility: (a) a paging system, and (b) adequate nursing staff oriented to care for a specific child.

Third, in view of local and national efforts to restructure the delivery of all pediatric respite care services, this framework suggests that understanding the decision-making process through which parents utilize respite care will assist policymakers and respite care providers to structure and deliver these services in a responsive manner. Responsive delivery of respite care would be adapted to the perceived respite needs of parents rather than expecting parents to adapt to inherent limits of current respite care delivery.

Further research is required to assist policymakers and respite care providers to make informed decisions about restructuring the delivery of pediatric respite care services. Parents who utilize pediatric nursing respite



care indicate the need for services which are accessible, flexible, and adaptable to a variety of situational factors influencing their child care decisions. Furthermore, parents describe using a variety of respite care models to meet their child care needs. While parents identify how different respite care models meet their child care needs, further research is needed to examine how this input from parents might be incorporated to improve pediatric respite care services.

In addition, future research needs to focus on the extent to which different respite care models serve the child care needs of parents who have children with medically complex conditions. Such research will assist in identifying positive attributes of specific respite models, barriers faced by parents in accessing care provided within different models, and perceived gaps in pediatric respite care delivery. To augment such findings, research is needed to compare the costs and outcomes of different respite care models. While current research supports the need for community-based pediatric respite care, it is difficult to determine which respite models provide the greatest benefit to program recipients at the most justifiable cost. Given current fiscal constraints, such information would be invaluable in maximizing the delivery of pediatric respite care services while minimizing the associated costs.

Research is also needed to explore how pediatric respite care and other child care services administered by different government ministries and community organizations might be coordinated to provide parents and children with flexible access to these services. The results of such research could assist policymakers at local, provincial, and national levels in promoting the development of a comprehensive model of pediatric respite care delivery. Such a model would provide parents with the freedom to arrange respite or other forms of child care in response to dynamic situational factors influencing their child care situation. In addition, it is conceivable that better coordination of pediatric respite care services might streamline administration, thereby decreasing overall costs of pediatric respite care.

### Conclusion

Pediatric home care for children with medically complex conditions is a growing phenomenon made possible by parents willing and able to care for these children at home. Yet the dearth of nursing respite and other forms of child care available to these parents is well documented. With an increasing emphasis on community health care and fiscal restraint in British Columbia, community-based pediatric respite care may potentially represent a cost-effective service to families who have children with medically complex conditions. However, financial benefits

to the province may come at a high cost to parents investing considerable time and energy caring for these children.

This study begins theory generation in a relatively unexplored area: the decision-making process through which parents choose to utilize nursing respite as a form of child care, a process captured by the term perpetual innovation. The significance of understanding perpetual innovation, the ongoing modifications through which parents of children with medically complex conditions arrange child care, is potentially far-reaching. Health care providers have a responsibility to ensure through research that programs designed to assist these parents in their caregiving responsibilities are adequate. By understanding the process through which parents arrange child care for these children, nurses and others involved in planning and delivering respite and other child care services may create services which enable parents to achieve personal goals, while assuring a safe care environment for their child.

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## Appendix A: Letter to Families

March xx, 1994

Dear Ms & Mr. xxx and Family:

We are interested in evaluating the effectiveness of the BC Nursing Respite Program, particularly from the point of view of those who receive respite services--the families. This evaluation research is being carried out independent of the administration of the Program and the Ministry of Health. Only families new to the Nursing Respite Program this year can participate, and we would like to include your family.

One direct benefit to you will be reimbursement of your time, and indirectly, the information you provide will help nurses and Ministry of Health planners to better understand what it is like to have a child who has a complex health condition that requires respite services. Other families who have participated in similar research have reported that it is helpful for them to think about the effects of the long-term health concern in their families.

If you agree to participate, this is what would be involved:

- 1) Linda Flato, an experienced nurse researcher, would visit your home three (3) times in order to observe and talk with you about what it is like for your family to need and use nursing respite services: once before the services begin, again six (6) months later, and six (6) months after that.
- 2) Parents would complete seven (7) paper-and-pencil questionnaires each time. Two or three of these questionnaires are also available in shorter children's forms, if children wish to contribute.
- 3) Some conversations may be tape-recorded and transcribed later and Linda would also write some notes about her observations about your family's responses to nursing respite care.
- 4) Linda will record some information from your child's in-home respite care chart.
- 5) The timing of each 2-4 hour visit would be arranged at your family's convenience.
- 6) You will be asked to keep a brief record of your experiences with the Nursing Respite Program and its associated costs (in diary form).
- 7) After each of the three data collection periods in which you take part, you will receive four (4) hours extra respite care.



Your participation is entirely voluntary, and you can withdraw at any time. Refusing to participate, even in part, will in no way affect the care you and your family receive. You can ask any questions about the research at any time before, during, or after the study. All information will be strictly confidential.

Thank you for considering participation in our study. Please call one of us if you have any questions. If we don't hear from you by two weeks after you receive this letter, Linda will give you a call to obtain your decision.

Yours sincerely,

Linda Flato,BSN	Virginia Hayes,RN,PhD	Pamela Otterman, MSN
Research Assistant	Assistant Professor	Nurse Consultant
727-6081 (home)	822-7477 (office)	261-3093
		(office at home)

**Appendix B:**  
**Consent /Assent to Participate in 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 Myra Percy or Linda Flato (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 Myra or Linda 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

observation, or completion of a form at any time, without repercussions of any kind for our family.

### Consent

We will be given a copy of this consent/assent to keep.  
I/we consent to participate:

\_\_\_\_\_ Signature of Parent

\_\_\_\_\_ Signature of Parent

\_\_\_\_\_ Signature of Researcher

\_\_\_\_\_ Date

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

\_\_\_\_\_ 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

\_\_\_\_\_ 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