

**Evaluating the Utility of the Adaptive Tasks Framework for Assessing
Parental Needs when Providing Primary Care for their Child with a
Chronic Health Condition**

by

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ABSTRACT

The purpose of this study was to evaluate the utility of the Adaptive Tasks Framework for assessing parental needs when providing primary care for their child with a chronic health condition. A qualitative descriptive methodology framed the study and two methods were employed to collect data: a secondary analysis of existing interview data from seven parents of children with chronic health conditions and interviews with four parents who were currently providing primary care for their child with a chronic health condition. The data was analyzed using content analysis, whereby interview data was explored to determine if it fit into one or more of the eight adaptive task categories. Parents reported needs in all of the eight adaptive tasks categories, with the need for information regarding their child's chronic health condition being the foremost concern among parents. The need for caring, empathetic, and patient health care professionals who are sympathetic to the informational needs of parents, while at the same time acknowledging their expertise, was the second need expressed by the parents in this study. Implications of these findings for nurses is that the Adaptive Tasks Framework provides a useful tool for assessing parental needs when managing their child's chronic health condition, and for determining areas in which the parents may require support.

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CHAPTER ONE: INTRODUCTION

The parents of children with chronic health conditions are a unique group as they are often assigned the double role of both parent and primary caregiver to their child. A chronic health condition can be described as a health condition that is expected to last three months or longer (American Academy of Pediatrics, 1993). Last, Stam, Onland-van Nieuwenhuizen and Grootenhuis (2007) state that it is estimated that “approximately 15-20% of children between the age of 0 and 18 years are growing up with a chronic illness” (p. 101). Children with a chronic health condition often receive treatment for their condition in a multitude of settings, such as acute care hospital, family doctor’s office or clinic specific to their health condition. However they usually require supplementary care in the home, and consequently the parents become their primary caregivers.

Hodgkinson and Lester (2002) described how raising a child with a chronic health condition such as Cystic Fibrosis is “stressful” (p. 378), and that it has implications for all members of the family especially the primary caregiver. Barrera, Chung and Fleming (2004), Barnett, Clements, Kaplan-Estrin and Fialka (2003), Fletcher and Clarke (2003), George, Vickers, Wilkes, and Barton (2007), Hatton, Canam, Thorne and Hughes (1995) and Santacroce (2002) described the role of the parental primary caregiver to a child with a chronic health condition as stressful. Hauenstein (1990) described how the onset of childhood chronic health conditions profoundly affected personal and family life of the parental primary caregiver of the child. The author described how the family of the child with the chronic health condition may have to become intensely involved in the child’s care and maintenance which often caused parental distress due to the dramatic changes in family life experienced post diagnosis.

In my practice as a nurse at a pediatric oncology outpatient clinic, parents have often described the additional role of primary caregiver to their child as being “highly stressful”. This has led me to question what the needs of the parents of children with a chronic health condition may be when they are providing ongoing care for their child with a chronic health condition.

The Study Framework

Canam’s (1993) Parental Adaptive Tasks Framework was chosen for this study, as it was proposed that this framework can have a role in assessing parental needs when managing their child’s chronic health condition. Canam’s adaptive tasks include:

- Accepting the child’s condition, so that the family can move forward and continue with their life, and avoid a situation where the child’s illness becomes the main focus of life, upsetting the balance in the home.
- Managing the child’s condition on a daily basis encompasses gathering as much information as necessary to be able to take care of their child’s daily needs. The family must find ways to incorporate the health care system into their lives and view health care professionals as a positive resource for their daily care giving tasks.
- Meeting the child’s developmental needs, whereby the parents are able to incorporate the child’s chronic health condition into their daily lives, so that the focus remains on the child moving through normal developmental stages, rather than focusing on the effects of the chronic health condition.

- Meeting the needs of the other family members, where the parents are able to provide equitable amounts of time to themselves, their marital relationship, and the lives of the siblings, as they provide primary care to the child with the chronic condition.
- Managing ongoing stress and periodic crises, where the parents are able to deal with the daily stress of caring for their child, and not let the stress build to a crisis point in their lives.
- Assisting family members to manage their feelings, where the parents are able to manage their own feelings, as well as assist their children including the child with the chronic health condition, and their spouse and extended family members to manage their feelings about living with a chronic health condition.
- Educating others about the child's condition, is the way in which parents are able to expand their own knowledge about the child's chronic health condition so that they are able to educate others about it.
- Developing and utilizing resources, where the parents establish a support system for themselves and their family, in order to help them cope with being the caregiver to a child with a chronic health condition.

Problem Statement

Despite the overwhelming evidence that points to the stress of being in the dual role of both parent and primary caregiver to a child with a chronic health condition, there is a lack of in-depth exploration into the needs of the parents relating to managing family life and the child's condition, and how health professionals can more effectively support parents in this primary caregiver role.

Purpose of the Study

This study will explore the usefulness of Canam's adaptive tasks framework in assessing parental needs when managing their child's chronic health condition, and in determining areas in which the parents may require support.

Research Question

How well do parents' descriptions of their needs related to managing family life when they are the primary caregiver for a child with a chronic health condition, fit with Canam's Adaptive Tasks Framework?

Significance of the Study

If the Adaptive Tasks Framework is shown to be useful in capturing the needs of parents who are providing primary care for their child with a chronic health condition, it has the potential to provide health care professionals, and nurses in particular, with a tool for assessing parental needs and identifying areas in which they require further support.

Summary of Chapter One

Chapter one discussed evidence of the stressful nature of being in the dual role of both parent and primary caregiver for a child with a chronic health condition. The lack of exploration of the needs of parents in relation to managing family life and the child's condition, and ways in which health care professionals can more effectively support parents in this primary caregiver role were also discussed. Canam's Adaptive Tasks Framework was introduced, as a potential tool for assessing parental needs when they are the primary caregiver to a child with a chronic health condition. The purpose of the study is to explore the usefulness of the framework in assessing parental needs and determining areas in which the parents may require support. The research question and potential significance of the study were also discussed.

In chapter Two a review of the literature relevant to the potential sources of stress and needs of parents who are the primary caregivers for their child with a chronic health condition is explored, as well as an examination of supportive interventions available.

CHAPTER TWO: LITERATURE REVIEW

Numerous studies have explored parents as primary caregivers for their child with a chronic health condition. Carnevale, Alexander, Davis, Rennick and Troini (2006), describe the political shift in Canada towards community care, where sending a child with a chronic health condition home from the hospital is seen as “the most desirable option” (p. 48). This shift towards homecare was described by Hewitt-Taylor (2005) who observed that medical professionals believe children who require long- term care would have better outcomes if they received their treatment on an outpatient or community focused basis and were not brought up within the walls of an acute care hospital. The author described how prolonged hospital care has deleterious effects on children’s “psychological, developmental and social needs” (p. 42). Kirk (2001) illustrates how medical advances have led to the survival of more children with chronic health conditions, and explains how government policies in the UK have changed to shift the care of these children from the hospital to the home. Kirk goes on to describe how this relocation of care has led to many parents becoming proficient at complex nursing care for their own children.

Shifting Roles for Parents

The relocation of children with a chronic health condition from acute to community care has led to a “blurring of boundaries” between professional and parental primary care-giving roles (Kirk, 2001, p. 594). In a qualitative study involving a mix of both parents and professionals, Kirk (2001) used in-depth interviews to establish that many parents felt they took on the role of primary caregiver out of a feeling of obligation

to their child. The parents described feeling pushed into this role by the professionals, who assumed that they would want to take over their child's care in the home. In a grounded theory study of 24 British parents who are primary caregivers for their technology dependent children at home, Kirk, Glendinning and Callery (2005) found that most of the parents in their study were not entirely comfortable with the combined role of parent and nurse. What these mothers and fathers really wanted was for their children to see them as parents first. In a literature review by Sullivan-Bolyai, Sadler, Knafl and Gilliss (2004) it was found that parents who took on the role of primary caregiver had to become proficient in many areas that were typically seen as the domain of professional caregivers, which was found to be very stressful for these parents.

Sources of Stress and Parental Needs

Farmer, Marien, Clark, Sherman and Selva (2004) conducted a Family Needs Survey where 83 mothers of children with chronic health conditions filled out questionnaires related to child and family functioning. These researchers found that parents of children with chronic health conditions are at "risk for emotional distress and poor adjustment to the demands of caring" (p. 355) for their child's chronic health condition. The mothers in their study described how the new role of primary caregiver brought their families stress associated with the "daily hassles of the [new] medical regimes, social isolation, role restriction, and financial strain [as well as] difficulty navigating the complex system to obtain needed medical... and social services" (p. 355). Similarly, Kirk, Glendinning and Callery (2005) described how parent caregivers often

suffer from stress, anger, depression and a sense of overwhelming anxiety when they have to provide care that inflicts pain on their own children.

Ray (2003) conducted a secondary analysis of qualitative interviews completed with 30 families living in a large Western Canadian city, who were raising children with a chronic health condition. Ray examined the challenges inherent in parental primary care giving and found that the parents in the study reported that their increased stress levels could be related to a variety of factors such as a heavy level of bureaucracy when trying to organize outside care for their child. They also cited that the inconsistencies and inefficiencies in the medical team's care had often caused unnecessary problems for their family. Overall the three main challenges for the parents providing primary care to their child with a chronic health condition in this study, were observed to be related to the severity of the child's chronic condition, the personal resources of the caregiver, as well as how demanding the parents' care-giving tasks were.

Sloper (2000) studied parents of children diagnosed with cancer to investigate levels of psychological distress they experienced at six and eighteen months post-diagnosis. Sloper was interested in the parents' coping strategies and whether their distress would lessen over this time period. Data were collected by using questionnaires which were distributed to 68 mothers and 58 fathers of the children with cancer. It was found that for 51% of the mothers and 40% of the fathers the distress level remained high for both the short and medium term. Despite children's treatment and illness status having changed at the two time periods, many of the parents remained at a similar high level of distress, and some parents whose children had even finished treatment were no less distressed than parents of children who were still on treatment or whose disease had

relapsed. Sloper postulated that this could be due to the fear the parents had that their child's illness may recur. The parents who felt distressed described how they thought they had not received enough preparation and support for the problems that they had sometimes encountered post treatment. Sloper suggested that it is important for health professionals to investigate parental perceptions of "their feelings about the demands of the illness and their confidence in their ability to deal with these demands" (p.88) in order to be able to provide them with ongoing support throughout their child's illness trajectory.

There are a few studies that explored the needs of parents who were acting as their child's primary caregiver. Perrin, Lewkowicz, Martin and Young (2000) described the results of a study of 123 children with chronic health conditions who were treated in a primary care facility in Massachusetts. Through the analysis of survey data from both parents and primary care pediatricians, the investigators found that parents most often had a need for information about the child's medical condition, treatment, and the long-term implications of their child's chronic condition. It was noted that most parents also reported a need for family support and counselling. Tak and McCubbin (2002) conducted a secondary analysis of data from a longitudinal study of 92 families of children who had congenital heart disease and noted that if perceived social support was high it would help parents cope with being caregivers to their child with a chronic health condition.

Parents' perceptions of their needs when caring for a child with Cystic Fibrosis (CF) were explored by Hymovich and Dillon Baker (1985) who conducted an exploratory study using questionnaire data with 161 parents of children with CF. The researchers found that there were a few key areas where the parents felt they needed the

most help. Over half of the parents (mother and father sets) wanted help with informational needs about their child's condition, physical and emotional development of their children, and managing behaviours in their child. In terms of past coping strategies, when asked where they had gone for informational needs about their child's condition, 92% of the parents stated they had asked a doctor, and 88% had asked a nurse involved in their child's care. Nineteen percent of the parents belonged to a CF association, and of those 35% regularly attended support meetings. The researchers explained that the findings about the parent's informational needs were noteworthy, as it proved how health care professionals should be aware of the parents' need for information and be readily available to provide it to these parents.

Garwick, Kohrman, Wolman and Blum (1998) used qualitative in-home semi-structured interviews to collect data from 63 families representing three cultures to explore the parents' ideas about improving the services they received for their child's chronic health condition. They found that the parents overwhelmingly supported centralized care in the community as decentralized care often left them feeling unsure of where to turn next to get help. The parents thought that health care professionals should be well educated in ways to provide supportive and sensitive care, and suggested that the parents of children with chronic health conditions should be "actively involved in training physicians" (p. 445). The parents in this study suggested that there should be more information hotlines available and that more health services should be provided in the community rather than the hospital. The need for information, and to have parents included in planning and service delivery seemed to be the most commonly cited factors

that helped parents to increase coping when taking on the role of primary caregiver to their child with a chronic health condition.

When it came to having a child with a chronic health condition admitted to hospital there were some potential needs that parents described. Balling and McCubbin (2001) completed a retrospective, cross-sectional, descriptive correlational study looking at the care-giving needs of fifty parent care-givers of children with a chronic health condition who had been hospitalized. The purpose of their study was to “describe parents’ desired degree of participation in the care of their child with chronic illness when the child was hospitalized and to determine how parents perceive their expertise to be valued by health care professionals” (p. 111). The researchers found that the parents described being happiest when they were able to participate and have some control over their child’s care while the child was hospitalized, and also had adequate amounts of information shared with them by the health care professionals. It was also found that of all the health care professionals the parents’ dealt with daily, they felt that the nurses and doctors valued their expertise the most. Overall, it was stated that because nurses are held in a highly esteemed position by parents, that they are in the prime position to help parents with their needs while their children are hospitalized.

Supportive Interventions

A parental supportive care needs assessment for parents of children with cancer was undertaken by Kerr, Harrison, Medves, Tranmer, and Fitch (2007), who found that there were six main areas that the parents expressed needs. These areas encompassed

- informational

- emotional
- psychosocial
- physical
- spiritual
- practical

The researchers found that the majority of the parents expressed needs in the areas of information and emotion, but that all of the six areas were reported as important to the parents in this study. The researchers suggested that it is important to assess “the full constellation of needs” (p. 290) when planning appropriate interventions for these parents.

Ogden Burke, Kauffmann, Costello, Wiskin, and Harrison (1998) performed a meta-analysis using the content analysis method, on qualitative literature from the years 1990-94, on the topic of stressors and tasks for families of a child with a chronic health condition. This was done in order to confirm the components of their Burke Framework for clinical use. The researchers described how parents of children with a chronic health condition were living in a “world with new priorities and unique norms” (P. 73), they went on to describe how these parents were presented with unique stressors, tasks challenges and concerns. They observed that even though these stressors do exist, not all of the families would experience each stressor. They contended that a nursing assessment and intervention should only focus on the family’s “current” (p. 74) stressor, for more positive family outcomes. The researchers customized their Burke Stressors and Tasks Framework, so that it would be useful for families of children with chronic health conditions. The Burke stressors and tasks include:

- Gaining and interpreting knowledge, skills and experience to manage child's health problem,
- Acquiring and managing physical resources and services to manage child's health problem (other than child and health care),
- Acquiring and managing financial resources to care for child's health problem,
- Establishing and maintaining effective social support,
- Rearing a child with a chronic or life-threatening condition,
- Developing beliefs, values and philosophy of life incorporating child's health problems and way family copes,
- Managing the burden of care for the child,
- Identifying and managing sibling issues,
- Maintaining spousal, parental, and nuclear family relationships,
- Maintaining health of other family members
- Maintaining effective relationships with health-care system and other sources of care (p. 87).

The researchers posit that their Burke Framework identified all of the critical stressors for families of a child with a chronic health condition, and through its use, nurses could provide effective interventions based on the specific stressors that these families displayed.

Mazurek Melnyk and colleagues (2001) conducted a literature review of studies that pertained to strategies and interventions for coping in parents who have a chronically ill child. An overview of stressors for these families, a summary of instruments available

to assess parental coping in this population and also a review of the intervention studies available that enhance coping in these parents was provided. The researchers found that the major stressors for these parents uncovered in the literature were focused around:

- diagnosis of the chronic illness in the child
- uncertainty surrounding the child's diagnosis and illness
- stressors around the developmental transitions of the child
- chronic sorrow experienced by the parents
- ongoing care provided by the parents
- financial burden parents experience
- exacerbations and hospitalizations
- uncertainty and fear about the future

Mazurek Melnyk, Fischbeck Feinstein, Moldenhouer and Small (2001) further discovered that there were a variety of instruments available to assess parental coping with a chronic health condition, but suggested that due to the “complexity of childhood chronic illness and parents’ coping responses” (p. 550), the nurse should try to use multiple techniques, including sensitive interviewing with the parents, rather than relying only on assessment instruments. The researchers found that even though there were many studies available that describe the stressors these parents face, there was a lack of intervention studies available to help increase coping in this population. They concluded that “further studies to enhance coping outcomes in parents of chronically ill children are urgently needed” (p.555).

Clements, Kaplan-Estrin and Fialka (2003) conducted a literature review of current research focusing on parent and child functioning in families of a child with a

chronic health condition. Their study outlined an intervention “designed to promote parent and child well-being by focusing on parental adaptation to their child’s condition” (p. 184). The researchers described how even though the role of being a primary caregiver to a child with a chronic health condition was found to be stressful for parents, the majority of parents in their research were found to be quite resilient and able to cope with the demands of the care. The researchers found that many of the parents reported high satisfaction with the role of primary caregiver and enjoyed their role.

The above authors propose using parental group support as an intervention to encourage positive adaptation among a larger number of families in the position of primary caregiver to a child with a chronic condition (p. 185). The researchers describe how some parents had difficulties adapting to their new role, whereas others found a way to work through it. It was discovered that the feelings of grief may continually reappear for the parents. The goal of the group intervention the researchers proposed was to “help parents understand the ongoing challenges of raising a child with special needs and to develop the confidence and tools needed to adapt not only in the present but to anticipate future change and adapt accordingly” (p. 190). While the intervention had not yet been evaluated, the researchers expected that it would be effective because it “targets and changes parental adaptation to their child” (p. 194).

Canam (1993) identified eight common adaptive tasks facing parents of children with chronic health conditions, from a synthesis of the “theoretical, research and clinical literature on family coping with a child’s chronic illness or disability” (p. 46) and developed a framework for assessing parental coping based on these adaptive tasks. The framework was utilized by students in both an undergraduate and graduate nursing

courses to test its usefulness in assessing parental coping with a child's chronic health condition. It was found that the tool was an effective way of assessing parental coping and of identifying areas in which parents needed support to develop more effective coping strategies to meet the adaptive tasks (C. Canam, personal communication, June 27, 2007). Subsequently, Canam developed, implemented, and evaluated a parent education program based on the adaptive tasks, hypothesizing that parents would cope effectively with their child's chronic health condition if they were provided with the knowledge and skills needed to meet the adaptive tasks. Results of the study showed a significant increase in the use of effective coping strategies after completion of the program (Canam, 2001), supporting the original hypothesis.

Summary of the Literature

In summary, there is a great deal of evidence that supports specific stressors evident in the lives of parents who provide primary care for their child with a chronic health condition in the home, but there is a lack of research evidence about how to best deal with these stressors. A few studies were reviewed that described the stress parents experienced when caring for their chronically ill children, but there were not many studies that explored the needs of parents in detail or evaluated interventions to assist parents in developing more effective coping strategies for the dual role of parent and primary caregiver.

CHAPTER THREE: METHODOLOGY

A qualitative, descriptive, research design was chosen as an approach to the study. Two methods were used, a secondary analysis of existing interview data from parents of children with chronic health conditions and current interviews with parents of children with chronic health conditions.

The secondary analysis component of the study was carried out on seven interview transcripts from an original qualitative study of parental coping with their child's chronic health condition after participation in a parental education program. The educational program consisted of "eight two hour group sessions based on the common adaptive tasks facing parents whose child has a chronic condition" (Canam, 2001, p. 362). To expand on the evaluation data from the quantitative findings, in-depth interviews were conducted with a sample of participants who completed the educational program, to evaluate the extent to which the program had assisted parents in meeting the adaptive tasks related to providing primary care for their child with a chronic health condition. The participants were asked open-ended questions about what had changed for them, in relation to the adaptive tasks, since taking the program and what aspects of the program contributed to the changes.

Four additional interviews were conducted with parents who are currently providing primary care for their child with a chronic health condition. The purpose of these interviews was to further assess the fit of the adaptive tasks framework with the described needs of parents' who did not participate in the education program. It was expected that interviewing parents who are the primary caregiver for a child with a chronic health condition would provide additional data in relation to the usefulness of the

adaptive tasks framework in assessing parental needs when managing family life while being the primary caregiver to a child with a chronic health condition. Another purpose for interviewing parents was to account for socio-cultural changes that may have occurred since the original data was collected, that may have influenced parents' perceptions of their needs, in relation to the adaptive tasks. A semi-structured interview guide was used to explore parents' perceived needs in relation to providing primary care for their child. Questions relating to managing family life while being the primary caregiver to a child with a chronic condition and what type of issues they encountered, and what was helpful to them during this time were explored.

Participant Recruitment

There were two samples involved in this study, Sample A and Sample B. Sample A consisted of seven interviews chosen from a pool of fifteen interviews from parents of a child with a chronic health condition, who had completed a parent education program, and participated in an in-depth interview in their homes, three to six months after completing the program. They were recruited by having them indicate on the final evaluation of the program if they were interested in participating in a follow up interview. The majority of parents did agree, and fifteen were randomly selected to participate in an in-depth interview. The original sample was recruited by distributing brochures outlining the study to doctor's offices, social services agencies, community health centres, ambulatory clinics and inpatient units of the local pediatric hospital, and also putting an advertisement in the local newspaper. Parents then contacted the researcher and were screened to determine if they fit the study criteria, which consisted

of a) having a child who had been diagnosed with a chronic health condition for a minimum of six months, b) not currently receiving counselling and c) having a good command of written and spoken English (Canam, 2001). Each interview lasted approximately one hour, with twenty to twenty-five pages per transcript.

The participants for Sample B were selected from a population of parents in a specialty clinic at the local children's hospital who provide primary care for their child with a chronic health condition. The selection process for the interviews included: a family whose child was presently being treated in the outpatient clinic, with a good command of spoken English. Once the parents agreed to participate they were interviewed in a private office at the hospital site. The interviews were tape recorded with the parents' permission, and were approximately one hour in length, with fifteen to twenty pages per transcript.

Ethical Considerations and Procedure

An information letter (Appendix A), and consent to contact form were placed on the child's chart in a sealed envelope on the day that the child was expected to come into the specialty clinic, so that the letter could be given directly to the parent. The participant's consent to contact form (Appendix B) included a paragraph that explained how they could contact the researcher at any time with questions, plus a description of how the researcher would contact the parent, with their consent, within a few weeks and how if they chose not to participate their name and phone number would be discarded. An informed consent form (Appendix C) outlined the purpose and title of the study and type of information that would be gathered during the interviews. After approval by the

Behavioural Research Ethics Board, the consent form was given to the parent from sample B to review and sign before their participation in the interview. Ethics approval was received from both The University of British Columbia (Appendix E), as well as British Columbia's Children's Hospital (Appendix F).

The researcher gave a brief in-service to the Clinical Nurse Coordinator of the clinic involved in the study so that she would be able to select appropriate families for the study, and place the envelope on the charts. The Clinical Nurse Coordinator then informed the nurse who was taking care of that patient to deliver the envelope from the chart to the parent. The information letter, and consent to contact form distribution was conducted on a day when the researcher was not scheduled to work, so that there was no knowledge passed on about who refused to participate, and no possibility for coercion on the part of the researcher.

The pediatric hospital that was used as a site for data collection is viewed as a close-knit community; therefore it was crucial to ensure that the principle of privacy and confidentiality were adhered to firmly. The researcher ensured that all of the interviews remained confidential and the names and any descriptive detail that might lead to identification of the family or child removed. Sample A or the 'original interviews' that were used for the secondary analysis were also drawn from this same population, and although the transcripts were already stripped of any identifiers it was possible that the researcher would be able to recognize the original interviewees. In accordance with the principal of privacy and confidentiality the researcher used maximum care not to disclose identifying data, such as diagnosis of the original participants' children to the other

parents who were interviewed. This principle was also meticulously adhered to when reporting the study findings.

Data Analysis

The deductive process of content analysis was used to explore the data from both sets of interviews. Berelson (1952) described content analysis as a “research technique for the objective, systematic, and quantitative description of the manifest content of communication” (p. 18). The content analysis method was utilized in this research study to explore the interview data and determine if it fit into one or more of the parental adaptive tasks.

Sample A, or the ‘original interviews’, were tape recorded and transcribed. For the secondary analysis a first reading of the transcript was undertaken to become familiar with the data being discussed. A second reading was then done to begin coding the data. The data were hand coded, whereby each relevant phrase from the interview was highlighted using colour coded pens and then cut and filed into one of the eight parental adaptive task categories,

Each of the eight parental adaptive tasks was used as a different thematic category or “group of content that shares a commonality” (Graneheim & Lundman, 2004, p.107) to place the narrative data into during the analysis. This conformed to the first step in Norwood’s (2000) description of content analysis where the characteristics of the themes are defined and structured as categories into which the different pieces of data from the interviews are placed (p.379). Norwood outlined how rules must be identified for recording the different characteristics of the themes, and how “the unit of analysis”

(p.380) must be identified. A unit of analysis is described as an “activit[y], word, phrase, paragraph or the entire record” (p.380) that was used, in order to specify what type of data will “determine the occurrence of a theme” (p.380). For this study the unit of analysis were phrases pulled from the interviews and placed under the coding categories of the eight parental adaptive task themes. The last step entailed reading the interviews and “recording the frequency with which a specific content category or theme occurs” (p.380). This provided a “sense of what is in the data” (p.380), and described whether the parents’ account of their needs fit with Canam’s adaptive tasks framework.

The participants’ statements were organized under each of the eight adaptive task categories in order to get an idea of whether these tasks fit with parent’s reports of their needs. This is in keeping with Sandelowski’s (2000) description of content analysis as “the least interpretive of the qualitative analysis approaches in that there is no mandate to re-present the data in any other terms but their own” (p. 338).

In order to avoid the risk of “researcher subjectivity and inconsistency in analyzing and categorizing responses” (Norwood, 2000, p.381) coding sheets were developed that had explicit details of what phrases and key words to include under each of the eight categories. The first few interviews were coded along with a thesis supervisor in order to provide “interrater reliability” (p. 382) or validity to the findings.

Chapter Summary

In this chapter the methods for data collection, as well as a description of both Samples used in this study was provided. The ethical considerations were highlighted, and a description of the process of content analysis, which was used to analyze the interview data, was provided. The next chapter will describe the findings from both Sample A and Sample B parents.

CHAPTER FOUR: FINDINGS

This chapter is a report of the findings obtained from two samples of parents of children with chronic health conditions. The first section focuses on findings from Sample A, which were drawn from a secondary analysis of interviews conducted with parents who had participated in an education program for parents of children with chronic health conditions within the previous six months. The second section focuses on findings from Sample B, which are drawn from individual interviews with parents of children who were currently undergoing treatment for chronic health conditions. The findings are organized and discussed within Canam's adaptive tasks framework, which consists of eight adaptive tasks that parents of children with chronic health conditions need to address to cope effectively with their child's chronic health condition. The findings from both sources will then be compared and contrasted.

Findings from Sample A Participants

Seven interviews were chosen from the overall sample of fifteen available interviews, for the secondary analysis. All of the interview participants were mothers of a child with a chronic health condition, who described themselves as the primary caregivers for their child. All of the families were two-parent families, with both parents residing in the home. The children's diagnoses encompassed: asthma, chronic pancreatitis, congenital heart defect, diabetes, epilepsy, cystic fibrosis, and one unnamed disorder that was described as a severe degenerative genetic disorder. Four of the families had two children with only one child affected; one family had both children affected, and the other two families had a single child with a chronic health condition.

The children with chronic health conditions ranged in age from seven to fourteen years and the time since diagnosis ranged from one to eleven years. The siblings' ages ranged from nine to twelve years of age. There were four boys and three girls in this sample.

Accepting the Child's Condition

All of the parents discussed the difficulty they had accepting that their child had a chronic health condition and expressed various emotions, particularly those that had arisen around the time their child was diagnosed. Some of the difficult feelings they experienced at the time of their child's diagnosis included stress, uncertainty and anger. They also described a number of strategies they used to assist them in accepting their child's condition, such as expressing hope for the future and looking outwards, and realizing that their situation "could be worse".

Difficulties Parents Experienced

Stress of diagnosis. The parents spoke about accepting their child's condition as being one of the hardest things about having a child with a chronic health condition.

One parent stated:

I couldn't take that role. I just couldn't believe that I was one of those people who had to cope with a child with a horrible disease. You have to accept the fact that something like this it's always there and it never leaves and sometimes it's bad and sometimes it's not but it's always there.

For most of these families a lot of the stress centred on the initial diagnosis. For the parents who did not have a previous family history, or a suspicion that something was

different about their child, the shock was often expressed more intensely. When describing her child's diagnosis one mother put it eloquently: "You spend an hour in a doctor's office and your life is changed forever". Another mother whose child was diagnosed at just ten hours old, and who had no suspicions or family health history of the condition, spoke of how she was left wondering, "Why are we doing this? Who is God, why is he doing this to little children?"

Parents who had been noticing changes in their child's health or behaviour described diagnosis in a different way from those to whom it was a complete surprise. For example, one mother who expressed how she had had a suspicion about her child's health and "had been worrying for several years that things weren't quite right" felt that it was "more of a relief to get a diagnosis, in a way". Another parent who had been struggling to get a proper diagnosis for her child for a long time described how relief at the child's diagnosis came in a complex way. She stated: "Although I didn't like the idea that we had a problem, for me it was a relief that she didn't have to have surgery." She went on to describe how her child's eventual diagnosis was "either a nuisance or a tragedy, or somewhere in between, but it's upsetting, you cannot live just quite a normal life because of this."

A parent whose child was diagnosed at three months of age, and had a family history of the condition, spoke of how she was "always aware that there was certainly a possibility that I could be a carrier." This mother felt she knew more about her son's condition than her family doctor due to her family history, so at the time of diagnosis she was the one to suggest which tests should be done to diagnose the condition. She spoke of how she and her husband felt after the diagnosis:

Our attitude has been that he's a little kid who has CF, not a cystic who is a little kid; it's just one aspect of his life. And we've been very fortunate in having made the choice at a very early age; we've been able to follow through on it.

The above quote describes how these parents have decided to live their life since diagnosis of their son's chronic condition.

Uncertainty. Three of the seven parents spoke about uncertainty in one form or another in relation to their child's condition. This uncertainty encompassed things such as the child's future, and what it will be like to live with the chronic health condition, will the child be healthier or sicker? Will he or she die young? One mother expressed how her child's disease "never gets any better, it only gets worse, so we don't know what we are looking at in the future". Another parent spoke about this potential for ambiguity in their child's condition when she said, "uncertainty is probably the most difficult thing for a parent [with a child] with a chronic health condition to deal with, and at this point he's just like most little kids, but if his condition were to worsen there would suddenly be uncertainty".

Uncertainty about her child's future health was particularly hard for one mother. This mother had experienced a constantly changing diagnosis about the life expectancy of her child, the mother stated:

I have a very pessimistic outlook as far as he's concerned, and I have trouble being able to project what is going to happen to him in the future as far as being an architect or a doctor or graduating school etc., so G was here for a good time not a long time, he was supposed to die by the time he was eleven.

This mom later had a meeting with the doctor who changed his opinion on the child's longevity by telling her he was now going to "go on quite nicely until he's sixteen". This constant uncertainty was very hard for the mother to deal with and she spoke of feeling an incredible amount of anger due to this issue.

A family whose child has been diagnosed with a chronic health condition that seemed to "come and go" and was described as being of varying intensities, expressed how their child's chronic health condition was "just one of those strange things, it wasn't one of those normal things like a broken leg or some kind of thing that there's an obvious cause for it", and how dealing with the uncertainty about the whole condition from the medical community to the literature on the disease left them "sitting there with a question mark" about the child's future health. This suggests that uncertainty about the child's current and future health is common amongst families with a child with a chronic health condition irrespective of the diagnosis.

Anger. A heightened sense of anger in relation to their child's chronic health condition was commonly mentioned among the parents interviewed. The anger seemed to be directed at many targets such as: God, for letting this happen to their children and health care professionals for not treating the parents as well as they would like; they felt angry about the lack of information about the condition, or angry with themselves for having a sick child. One mother described how she sometimes felt angry with her child for being sick. When discussing what it was like to be the mother of a child with a chronic health condition she described how it felt to "be so bloody angry about G, about his heart condition, about everything".

The parents described how the road to acceptance could be very long. One mother spoke of how she and her husband were “still incredibly angry, it’s only been two years and we were still just completely, totally devastated that this had happened”. This same mother talked about how it was hard for her to speak with all of the health professionals she had to deal with daily at first because she was so angry about her child’s diagnosis. She described how when she went to her child’s appointments she was “so angry that I’m sure I just radiated anger when I came in the door”. Looking back on those times the mother stated how she now realized that maybe it wasn’t the health professionals she was angry at, but the diagnosis of such a devastating disease in her own child.

Strategies Parents Used to Meet the Adaptive Task

Hope. Hope was a strategy that seemed to be shared by all of the families. Parents spoke of feeling hope about their child’s future, and how despite all odds their children might get better, that perhaps there would be a cure found for their child’s condition, or that they would “be in the top twenty five percent that outgrow it.” One parent spoke of feeling hope that her child would somehow buck the odds and there would be “a medical breakthrough, or [the severity of the disease] is not going to be the same for my child”. Hope was expressed in many ways. One mother said “when we first got the compressor (for the child’s asthma treatment at home) we rented it, and it was five years ago now, and I rented it because I thought it was only going to be in the house for six months”.

Realizing it could be worse. Almost every parent interviewed mentioned how their situation was bad, but that they were aware that it could be worse. Parents spoke of how, when they heard stories of other kids with “heart problems or life threatening allergies and things like that, you have no control over that, but with this, if we look after her properly...the diabetes wasn’t as serious as a lot of things that other children have to cope with.” One mother expressed how her child’s disease wasn’t obvious if you did not know he was sick and that “it’s not like some other disorders that are so apparent to other people,” which she said gave her a certain level of comfort, and that they were able to “not make a big deal” of their child’s condition due to that fact. When speaking of going to an education session and meeting other families with children with chronic health conditions another mother stated how “it was nice to hear people with worse stories, really, mine was a pretty bad one but there are some even worse.”

Once parents got over the shock of their child’s diagnosis they could work through some of their uncertainty about the child’s future and start to express some of their feelings about their child’s condition. Comparing their children to others who had a poorer diagnosis, and realizing that maybe their situation could be worse, sometimes helped them to gain a certain level of comfort with their child’s condition and start working towards accepting it.

Managing the Child’s Condition on a Daily Basis

For most of the parents managing the child’s chronic health condition daily was something they found they eventually became proficient at no matter what their child’s

condition. Learning how to negotiate with the entire group of health care professionals who suddenly entered their lives was an adjustment for all of the parents. Most of the parents found ways to navigate this new role, whether it was by finding a way to manage the new information their child's condition required, or by working towards feeling that they had taken ownership of their child's chronic health condition.

Difficulties Parents Experienced

Dealing with health care professionals. The majority of the mothers interviewed described how after they discovered to whom they should go for information, they started to feel a bit more comfortable with the health care professionals who were providing care for their children. However, it did not always start out easily for the parents. Many of the participants described trying to negotiate their new role of primary caregiver, while trying to find information, and knowing how to approach all of the health care professionals who suddenly entered their lives upon diagnosis of a chronic health condition in their child. One mother described her first visit to the hospital for a prolonged stay and how she felt lost and confused, she said:

I didn't know what questions to ask, knowing who you can ask? When you come into a place like [the hospital] everybody's busy doing a million and three things and you want to speak to a specialist or whatever, how can you get hold of him? How can you do that?

She described how it would have been helpful if someone could have come to her at the beginning of her child's hospitalization to tell her "what questions you should ask and who you should ask and where you can go for help". She thought that "talking with the

doctors and becoming acquainted with what is available to you” was the best way to start to feel more comfortable in this situation.

Another parent was quite critical of the health care professionals’ abilities to help her deal with her child’s condition, and figured that she had better start to hone her communication skills to help her deal with the doctors in the future. She stated “some of them [doctors] are such jerks at communicating that if I get really good at it, it could be better.” She also realized that she was “going to have a long association with these people and [so I’m] trying to figure out their personalities too because it’s important that I find a way to relate to them individually”. Another mother expressed her initial discomfort with dealing with health care professionals and the hospital when she said, “that’s the hardest thing, being confronted with this great wall of professionals and hospital and all the procedures and just [trying to] understand what goes on.”

Helping their children to manage all of the necessary interactions with health care professionals was a strenuous undertaking for these families. One mother explained how difficult it was for her to watch her child continually getting poked and prodded for all of the tests and treatments necessary for her chronic health condition, and how hard it was for her child to endure. She talked about how, “having all these IV’s and blood tests and shots, it’s not one of the things that get easier after a time, it seems to get worse.” For this mother, managing her child’s condition daily was a difficult prospect, as she felt that the fact that it was chronic meant her child would have this struggle for a long time to come.

Strategies Parents Used to Meet the Adaptive Task

Acquiring Information. Acquiring sufficient amounts of information about their child's chronic health condition and learning how to deal with it on their own was a common theme for these parents. Most of the parents spoke at length about how much information was enough, how they found out about their child's condition, and how they were educated to take care of their child's daily needs. These topics generated much discussion among the parents. A mother who spoke of her child's time in the hospital after being diagnosed with diabetes explains how the health care providers took care of this distribution of information:

The reason she stayed there for ten days is that they wouldn't let her come home with us until they were sure we knew exactly what we were doing, they force fed us information, they really did, they overloaded us trying to give us all this information to start with. They gave us books and pamphlets and kits and they sat down and had discussions and brought in a dietician a couple of times and had little conferences about it. I found they were sort of reading the same information over and over again a few times, but I guess it all has to be available to you; I think they did it very well, and they were there to help us if we had any questions. The majority of the parents spoke of how they felt they were given sufficient information once the diagnosis was known. One mom explained how "I didn't have much difficulty getting information in the beginning because I knew about it before he was diagnosed". However, one mom that had a child with a very complex condition explained how her situation was very difficult because her child had "a disease that makes doctors nervous."

The parents expressed feeling more comfortable with information they received about their child, when there was more known about the child's chronic condition.

Another parent explained how she left dealing with the professionals to her husband, as he himself was a professional, so he was used to talking to people on the professional level. She felt that she was surely not assertive enough to do it on her own, and that she was so intimidated by the doctors that "they would tell me everything and then I would get home and it would be gone or I'd have it backwards or something." This mother also felt it was really important to get information in writing, especially when you are so stressed out at the time of diagnosis and "too upset to really digest it". She felt that it would be helpful to have someone to tell you all of these things in the beginning, someone who could say "this is going to happen to you, whether you realize it or not, no matter what situation you are in, or what the [child's] problem is, and [help you] realize that you are going to go through it."

Taking ownership. A mother who spent a lot of time visiting the Emergency room in the hospital with her husband and two children felt that the health care professionals were satisfied that their care of their child with a chronic health condition was competent:

They (health care professionals) know basically that we can deal with it, I think the doctors get to learn after a while that we'll follow their routine, they know that we know how to deal with the medication, and that we've got a good stable relationship and things like that, so they know that we can handle these things.

This mother felt that if you take ownership of your child's condition you could basically handle anything that comes your way. She explained how she checks in once in a while with the health care professionals, but that she and her husband basically do "most of the doctoring and nursing at home now."

Once the parents were able to accept that they were in this for the "long haul" they seemed to be able to start focusing on how they could fit the chronic health condition into their lives. Figuring out where to go to get information, and then starting to collect this information about their child's chronic health condition seemed to help the parents manage their daily routine. Forming a working relationship with health care professionals was one way that most of the parents felt they could start to manage their child's condition on a daily basis.

Meeting the Child's Developmental Needs

The parents spoke about how when you have a child with a chronic condition, it is important to let them grow up as normally as possible despite the condition. This feat was managed in a lot of different ways by each of the parents. Most of the parents tried to adapt their lives to fit into the child's illness routine, and focused on trying not to spoil their child, and adapt the level of control so that the child could participate and try to gain some control over the management of the condition.

Difficulties Parents Experienced

Age- appropriate information sharing. One of the issues the parents mentioned was how to get information about the child's condition while at the doctor's

office without upsetting the child when they were also present. One mother described her reluctance to share information with her child about her condition and how it was hard to visit the doctor, as her child was “always in the room [when the doctor is talking] and that’s a problem.” This mother felt that the information about the child’s condition was “too hard to describe to a child and it’s too scary, it’s too depressing, she would become quite depressed [knowing too much about her condition].” This mother described how she was not sure how much information was good to share with her child, but she also realized her child was “more aware [now that she’s older] and we know we’re not going to hide it from her or anything but we will just tell it to her in dribs and drabs.”

Over- protectiveness. Many of the parents described how they were worried that they might be too overprotective of their child. Some parents said they just lived their lives as they felt they normally would without a sick child, while others described how they had changed their lives out of necessity. One mother described how she tried not to change their lives too drastically since her son’s diagnosis and how she realized that might not be how all parents would approach their child’s illness routine:

I’ll let him go a little further if he’ll be going somewhere, whereby some parent would think, Oh, I wouldn’t let him out of the house. I tend to be a little less restrictive in some areas because otherwise you’re saying no to everything. She also felt she and her husband had tried to keep their lives “normal” by not treating him any differently than before diagnosis. She felt that maybe they gave in to their children more and tried to do more activities, but that she wasn’t sure if that was a change and that they probably would have “done all that anyway.”

One of the parents spoke about how hard it was for her child when she was left out of things, and how she would go along with things so that she didn't feel different, but it was difficult for the parents to watch because they knew she was pushing herself too hard to keep up with the other kids. This mother said she didn't let her child do a lot of things in order to protect her, but that they would always try to have either she or her husband attend school field trips in case she needed to be carried, or have any special medical intervention. Another family had a motto of "it's the quality of life that's more important than the quantity," in order to help them keep perspective on what they would let their child do. Another mother spoke of how timing of diagnosis is important in terms of over-protectiveness. She related how she didn't think she was overprotective of her child since he was "older when he was diagnosed, and he had already formed his own personality, I think. If he had been diagnosed as a baby I think I may have [overprotected] him a little bit."

One parent spoke at length about how she felt she had overprotected her child to the point of spoiling him out of fear that he wouldn't live very long. She felt she had just let him do whatever he wanted throughout his life, with absolutely no discipline. She described how he "has been very spoiled- he's the only one we got- and the first sick child that any of the family has had to deal with and so he's been very spoiled everywhere." She said:

I'd been so weak with him... I mean he was eight years old and I still dressed him every morning, every single morning as soon as the sun came up. I was the one who put his clothes on, I was the one who took them off at night-time, I put his pyjamas on, and he had very little responsibility in his life.

She went on to describe how hard it was to deal with him presently, as he had adapted to a life of no responsibility or discipline. Now that she realized how badly she had spoiled him, she was trying to change the way she treated him, but her child was not very receptive to his routine being shifted.

Strategies Parents Used to Meet the Adaptive Task

Open communication. One of the parents had a very open style of communication when it came to sharing information with her two children about their chronic health condition. She explained how her family had “always been open with [the two kids], we’ve always been really open with them about their condition and hospitalization and everything, the communication lines have always been good.” The majority of the mothers interviewed shared this style of communicating with their children and said things like “I think R knows everything there is to know about her condition and as far as looking after herself right now she understands it,” and how they are willing to share information but that their children are too busy being kids and often “don’t care that much to know.”

Control. Some of the parents spoke of how they tried to let their children have some control over decision-making about their condition. One mom described how the child’s doctor “took some of the decision-making away from the nurses and doctors and gave some of it to [the child].” She described how once this happened she could see a “total change in her [child’s] attitude...that she has got a little bit of control and that has been really valuable”. Another mother described how she tried to let her child take

control over his medication as much as she could and would “always keep an eye out of the corner of your eye, but I don’t ask him every single night: did you?” She described how hard it was to not just jump in and control everything, but she noticed how he had made a routine for himself and had never forgotten to take his medication.

Trying to meet the child’s developmental needs within the context of a chronic condition proved to be more of a challenge to some of the families than others. Parents who had the philosophy that they should continue on with “life as normal” and tried to give their child some responsibility and control over the disease, appeared to describe their situation a bit more comfortably than those who feared they had overprotected their children to the point of “spoiling” them. These families all seemed to eventually find a way to adapt to their situation, sometimes through the help of a doctor who was willing to relinquish some control to the child, or by going along with their child on outings to give them the extra help that they needed to participate in an outside activity. No matter what the process, the outcome seemed to be that all families were able to find a way to meet the child’s developmental needs.

Meeting the Needs of Other Family Members

The parents described the difficulties they had with meeting the needs of the child’s siblings, with some parents finding that the siblings were reacting physically to the stress of being in the sibling role of a child with a chronic health condition. Some of the parents noticed both positive and negative behavioural changes in the siblings, many of the parents mentioned how their marital relationship was affected by being the

primary caregiver to their child with a chronic illness, and that sharing the care between partners was a way the parents were able to meet all of the family members needs.

Difficulties Parents Experienced

Siblings. Five of the seven parents had families with two children. In four of those five families there was one child affected with a chronic condition, and in the other family both of their children were affected with the same chronic condition. Therefore, four of the families had a sibling child who did not have a chronic condition. This sibling was often mentioned in the interviews, but interestingly it was mostly to say how understanding the sibling was of the child's chronic condition. One mother spoke of how her eleven year old, well daughter showed a lot of compassion to her seven year old sister and how she felt her daughter found it "hard to get impatient with a person who's really struggling and she is very kind hearted, she's a very motherly little girl."

Only one of the seven mothers spoke of the negative effects that the sick fourteen-year-old child's illness had on his twelve-year-old brother. This mother noticed that one of the strongest effects on her life when her son was first diagnosed was how the stress of their son's illness affected her other boy. She stated that he was "starting to have symptoms like stomach aches and all that, and we did end up on the way to a psychiatrist with him, which solved the problem fairly quickly." She explained how she and her husband didn't really notice anything different about her well son's behaviour and how he "almost behaved too well." She also described how he was a quiet child so they assumed everything was okay and that she used to think, "oh good he's all right, but he wasn't." She went on to describe how it's hard to divide the attention accordingly

between the two sons “because then the sick child’s getting all sorts of bad attention and the well one’s getting all sorts of good attention.”

The other three mothers with one child with a chronic condition and a well sibling spoke of how they felt the well child was protective of the child with the chronic condition and did a lot to help meet the needs of the sibling. One mother alluded to how her well ten-year-old daughter might find the attention that her eight-year-old brother gets unfair when she described a physio session that they had to do nightly with her son. She described how her daughter doesn’t talk a lot about how she feels but that she might in fact be jealous “because when he has physio he’s there in a one-on-one situation and he’s watching television and often she’s down here practicing piano, you think about it and which would you rather be doing?”

Marital relationship. All of the families involved spoke of how their marital relationships were affected by their child’s chronic condition. Some mothers found that they and their husbands coped differently, while others found that one parent seemed to take on more of a caregiver role to the child with the chronic health condition than the other. These issues seemed to bring on a lot of stress for the parents and were described as a daily challenge to the relationship.

One mother, who found that she took on more of an emotional load than her husband with their son, described how her husband was more “cut and dried” when it came to dealing with her son’s daily ups and downs. She described how he didn’t let things build up like she did and just dealt with the immediate problem and went on to the next issue. She described how she felt that “the mother probably is the one that ends up

with the emotional load to carry...you're sort of the one that ends up being responsible for keeping everything together."

Another parent described how "it never really occurred to me that all husbands cope by not talking in the beginning and women want to talk about it endlessly," when relating how she assumed mothers and fathers differed when dealing with their child's diagnosis. She noticed how her husband never wanted to talk about the illness and she had decided it was because talking about it made him feel worse about the situation.

Another mother related how she was the "main child-rearing person" and so she was the one that was always "enforcing the rules and regulations of the household"; this mother found it very frustrating to be the one who was always "doing the doctors and dentists appointments and giving the medicine every day, I felt like I was the one putting up with all the crap and he [husband] was going along quite nicely being his [son's] idol." This perceived unfair distribution of tasks was mentioned by a few of the mothers as being a major issue that often turned into an argument between them and their husbands.

Another parent spoke of how she accepted that her husband would likely need to be told what to do to help with her daughter's illness, and how she had to "sort of browbeat him into that [giving the shots] because it meant that I had to get up every morning and be there every morning, whereas if he learned to do it then he could take over sometimes." This mother felt that perhaps she had taken over too much of her daughter's care, and should have given her husband more of a chance to help out in the beginning.

Strategies Parents Used to Meet the Adaptive Task

Sharing the care. One mother described how her husband was very supportive and did things like splitting the physio for their son so that “he does the evening physio, and I do the morning physio.” She described how she thought he was happy with this set-up “because then he can get to watch a half hour of cartoons each night, and talk to T at the end of the day and find out how school has been because he doesn’t see him after school.” This sharing of the duties related to care giving for the child with a chronic condition was perceived as not only supportive, but also as the husband taking a certain amount of responsibility as the father of a child with a chronic health condition. Another mother described her husband as being very supportive:

I have the best husband I could possibly ask for; he’s always been not only supportive of me, but he’s very good with the kids. It’s always been an even thing as far as helping the kids. He’s up at night as much as I am...He does a hundred percent more than a lot of guys would’ve but a lot of guys would’ve walked out of the door long ago.

This same mother described how she felt she was coping better than her husband because she didn’t “look outward, I’m looking at the situation now and I just deal with it on a daily basis. I don’t dream or pre-plan anymore. So I think that helps me deal with it.” She went on to describe how even though she felt she was coping better, being the parent of a child with a chronic condition “physically takes a toll on you. Like, I get migraines, but they couldn’t give me anything for them because they say you’re so tired now you’d fall flat on your face.” Although this mother felt she was coping better than her husband, she

still described how she suffered physically and emotionally daily while caring for her two children with chronic health conditions.

The families of children with chronic health conditions, who also had siblings, often noticed how being the sibling of a child with a chronic condition had an emotional impact on the well child. Most of the family's spoke of the positive aspects of the two children's relationship, while one family noted how the sibling suffered the physical symptoms of stress that they felt was related to being the sibling of the child with a chronic health condition. All of the mothers claimed that their marital relationship was affected in some way by their role as a primary caregiver. Most of the mothers were able to find ways to share the care with their spouse in order to decrease their workload, but all of the mothers still reported they were the ones who took on the "emotional load" of caring for their child with a chronic health condition.

Managing Ongoing Stress and Periodic Crises

The parent's spoke of the difficulties they faced when dealing with the unpredictable nature of their child's chronic condition, and that they often felt unprepared to manage the level of stress that came with it.

Difficulties Parents Experienced

Unpredictability. The constant flux and lack of routine when providing care for their child with a chronic health condition was portrayed as being a barrier that was hard for these families to accept as part of their daily care. Three of the parents interviewed spoke extensively about how challenging it was to live a life where you

could never plan anything into the future, as you could never be certain how your child's condition might change. One mother described how frustrated she was with the inability to make a basic daily plan for herself:

Never knowing, never being able to plan anything in case something came up, and it seemed like you'd always make a plan and then you'd have to go into the hospital, or something would happen, so it got to the point where I would hardly be able to make a hair appointment because I'd be afraid I wouldn't be able to get to it.

Another parent described how "if you do plan something ninety-five percent of the time it's not going to happen...our ups and downs are like a roller coaster." She went on to describe how nothing in her life could become routine and that she realized "there's no guarantees in life, but actually when he was first diagnosed we flew to LA to Disneyland; we ended up there half a day and then in the hospital for three days." The families described how they were constantly trying to provide their kids with some of the fun vacations and routines their friends were having, but how they were often cut short by the intrusion of the chronic health condition.

The parents also commented on how hard it was to have much of a social life when they had to always be on alert for people who might not realize they should not visit the family when they were sick:

I just about cried sometimes when somebody would come over with their child that had a bad cold, because mine were just an open invitation, they just got everything that was ever around. To us it used to mean we're in the hospital again for three or four days.

She also described how she would have to call ahead to family dinners to make sure no one was sick, as they would have to decline the invitation if someone with a “horrible cold didn’t have the sense to stay home.”

Feeling incapable of managing stress. When describing what it is that they do to manage this ongoing stress one mother stated she “mostly has a lot of nightmares.” She described how she was sometimes at the end of her rope and felt that if “one more person needs to become emotionally dependent upon me and I’ll crack.” Another mother talked about how the only advice she had ever gotten to deal with ongoing stress when caring for her sons was to take breaks. She felt that “half the time you’re not in that state of mind” to take a break, so it was not really a good solution in her situation.

Strategies Parents Used to Meet the Adaptive Task

Care giving in a crisis. Two of the mothers described how they almost felt more comfortable when their child was in a crisis situation in the hospital. One of the moms said she felt like “the best damn mom in the whole world when he is sick- you know when he is in the hospital I am the model mom.” She described how she lives on very little sleep and is at her son’s side the whole time in the hospital, and “they don’t give him any drugs without me knowing, they don’t do nothing without me knowing. I’m there all the time and I think he really appreciates that, I handle that extremely well.” She went on to describe how her priorities changed when her son was in the hospital so that all she cared about was being with him, and when he came out of the hospital she began

to “come down on myself,” once the crisis situation was over, and she went back to caring for him at home.

The second mother who described feeling better when her son was in hospital said “I found I kind of went into almost a numbness when he was in the hospital, where you just go and you do it, and I found I almost turned off, so it was worse when he was out and free.” This mother went on to describe how when her son was out of the hospital she felt worse and this was a “funny feeling, because when he’s out he’s okay and I feel awful...in a crisis you just do what has to be done and then you fall apart after it’s all over.”

The lack of flexibility and potential curbing of their social life when providing care to their child with a chronic health condition was something the parents described as being tedious and ongoing in their daily lives. Some of the parents described a surprising feeling of relief when their child was in the hospital, followed by an inevitable crash back to daily life with a chronically ill child, when the crisis was over.

Assisting Family Members to Manage Their Feelings

Many of the parent’s spoke of the difficulties they had helping each other, as well as their children and extended family members to manage their feelings related to living with a child with a chronic health condition. Often the mothers would speak of the troubles their own parents or in-laws would have with accepting that their grandchild was “really that sick.” They also described how difficult it was to really know how their children or husbands were feeling. It was only later that they realized that their children’s behaviours were the result of unexpressed feelings.

Difficulties Parents Experienced

Understanding child's emotions. One mother described how, when the doctor was talking to her child about her condition, she was embarrassed when the child was disrespectful to the doctor, she explained:

She turned around and became very rude, which is how if she's worried or anxious or angry about something it's the way she reacts, by being rude...I was upset because I realized she was [upset]. I was also upset at her because she was suddenly being very rude and paying no attention to [the doctor] and trying to watch the television behind his back. What she was doing I think- I didn't realize this at the time, but looking back on it- what she was doing was blocking out what she had heard.

Another parent felt that she was not always sure if her child was upset, or resentful about having a chronic health condition, but she realized that his "resentment doesn't get expressed, but there probably is some." She went on to describe how when he had been at a twice-yearly visit to the clinic for a day long appointment related to his chronic health condition she felt that he was coming home stressed and "cranky, and I've finally figured out that the reason that he's reacting as he is, is because obviously that day has been a strain on him." Another mother stated how her child didn't like to talk about his condition and when he saw a program on television about his condition he wanted to be "reassured that that's not what happens to him, and I think he does kind of worry that something like that might happen." All of these mothers were able to express how they

thought their child might be feeling or reacting, but none of them reported directly asking their child about his or her feelings.

Extended family's feelings. One of the mothers described how her parents did not really have an understanding of how her family now had limitations since the child's diagnosis and how her parents "wanted life to be like it is storybook-wise, at Christmas you are supposed to do this and this, and because we can't fit into that niche, I think maybe that's one of the things that bothered them." The mother described feeling "surprised at their attitude...they've had very little to do with my kids." She felt that her parents had distanced themselves from her family since the diagnosis, as they were unable to really understand or accept that her family was now different and not as perfect as she felt her parents had hoped.

Two of the other mothers expressed a feeling that their own mothers appeared to be ashamed to be a part of a family that had a member with a chronic condition. One of the mothers described how her mother was "very difficult, she doesn't want to admit to this disease, in her generation a genetic disease is something to be ashamed of, it is a blot on the family name." She went on to describe how she found it "hopeless to get her [child's grandma] to accept this disease." This mother struggled with telling her mother too much about her daughter's condition, and eventually just gave her minimal amounts of information about her child's diagnosis as she felt "why ruin the last five years of her life, she's eighty, she's not going to live forever."

The second parent described how "with my parents, I guess it's sort of an older generation. There was a lot of denial that there was anything wrong." She found when

she tried to get some information about her family's history she "met a lot of resistance" towards genetic information sharing from her family. She was interested in knowing if there was a possibility that her child's condition was something that could be "inherited," and found it took a "lot of pushing to try to get any information" from her parents. Both of these parents described a similar feeling that their own parents appeared to be ashamed of their genetic history.

Strategies the Parents Used to Meet the Adaptive Task

Communicating with extended family. Four of the mothers talked about how hard it was to deal with their extended families' emotions related to their children's chronic health condition. One mother expressed how she was aware that it was easier for her to manage her extended family's emotions about the chronic health condition as they all lived far away and so were "not involved in the day to day." She felt it was a blessing in a way that they could just call up and show their concern "but we didn't have to deal on a day to day basis with what they were thinking, that you should be doing this, or you shouldn't be doing that, or it must be this, or it must be that." One of the other mothers explained how she felt that her in-laws really did not understand the full impact of the condition on the family, or how it was that she felt that she had to watch over her children at all times to keep their symptoms from getting out of control. They "just have no basic understanding of the situation. It's hard with asthma because when they see the kids they look fine so they can't understand what you're harping about or why they're not coming over."

Another mother explained how it was hard to find a balance with her extended family where she could “let them know what was going on, and try to keep them reassured without scaring them to death”. She said that in order to deal with this she just tried to keep the information-sharing with her relatives at a minimum because she didn’t “want to worry them...but I know myself when there’s somebody else in the family that there’s something wrong, it’s more worrisome not to know, so I don’t know why [I don’t tell them].” It appeared that this conflicting feeling of not knowing how to help their family to manage their emotions, yet wanting to reassure them with information was common among the mothers.

Another mother talked about how hard it was to deal with her own mother’s emotions around telling her about the severity of her grandchild’s diagnosis. She explained how “I didn’t know how [my mother] was going to react, and I couldn’t deal with her,” so she chose not to tell her at first. She eventually went on to tell her mother about the severity of the child’s diagnosis as she felt it was only fair that she “should tell her because she should realize it’s more serious than [just having to wear] orthopedic shoes.”

Understanding and helping to manage their family member’s feelings appeared to be a difficult task for the parents involved in these interviews. They often felt they had an idea of how their children or families were feeling, but did not describe themselves as being confident that they could help their families to manage these feelings. Some of the mothers were able to describe how their children and families were reacting, but did not appear to understand how to cope with the diverse emotions involved.

Educate Others about the Child's Condition

Some of the parents explained how they took a direct approach and were up front with people about their child's condition, while others only educated those they felt were required to know, as they came into contact with them. Some found it hard to talk to others about their child's chronic condition while others felt it was a necessary and important step to help their child "fit in" to social situations, or feel comfortable around others. The parents of children who needed to explain medications, or emergency procedures to teachers and others who came in contact with their child daily seemed to place a higher importance on this need to educate.

Difficulties Parents Experienced

Communicating with educators. One parent expressed her exasperation with trying to keep the teachers in the school educated about her child's condition:

I gave up on teachers, I tried to tell them in the beginning mainly, also so that they would know that if he had a seizure that there wasn't anything to worry about, that it would pass, and also I wanted them to tell me if he was having them because we were having to keep track of how often, and he was at school almost all the time, and I found that a few times I would go in for regular interviews and this would be three weeks later and they would say "oh a funny thing happened several weeks ago" and it would be exactly what I had described to them and yet they hadn't...so I sort of stopped. So after that I just kind of let it go.

This frustration of not feeling that their child's condition was really understood, or had the proper amount of attention paid to it in the school system was mirrored by a parent

who said she found “with the older grades whether [the teachers] are busier, but they don’t seem to have the same concerns [about the child’s chronic health condition].”

Strategies Parents Used to Meet the Adaptive Task

Educating the educators about the condition. Five of the seven parents explained how they felt it was important to explain the child’s chronic health condition to the schoolteacher. One parent explained how she didn’t tell the school right away but that she finally “decided the teacher should talk to the class about it... [as] it’s not fair to keep children in school in ignorance.” This parent related that she thought it was interesting how “uncurious” the teachers had been about her child’s condition before she educated them about it. One mother expressed how she noticed that she hadn’t “had teachers sort of feeling that he has to be treated differently...his teacher last year told me he wasn’t any different than any of the other [students].” This parent had stopped sending her son’s emergency medication to the school, as she felt he had never had the need for it, “so I didn’t see the point in sending it this year.” She had also stopped going and explaining about his condition to the school, but if the teachers ever asked for information she was always willing to share her brochures about the child’s chronic health condition with them. Another parent felt it was her duty to inform the school about her child’s chronic health condition as her child wasn’t able to participate in a lot of sports so she felt that legally they had to be informed in case something happened to her child, so that they would know how to deal with “where to send her or what to do.”

Educating other children. All of the parents explained how they felt it was necessary to educate the child's and their sibling's friends about the child's chronic health condition. Often the parents would do the educating, but one mother said her child's six-year-old sibling went around telling everyone in the neighbourhood "my sister's got something that yours hasn't." When describing how the kids in the neighbourhood react to her child's chronic condition, one mother said the kids just "take it as a matter of course." Another parent was amazed at how accepting her child's friends had been about the child's chronic health condition, without her having to provide much education to them. One of the other parents interviewed expressed how she had never done much educating with her relatives, but that "his cousins have always been-it's amazing, from being tiny- very, very aware that he is different."

Another way these parents found they were able to educate their child's peers about their child's chronic health condition was by going directly to the school. One of the parents wanted to be sure all of her child's classmates would be knowledgeable about her diabetes, and all the care it required, so she got permission to go into the classroom and test all of her child's classmate's blood for them. After this demonstration she explained how all of her child's friends thought her child was "quite a hero for doing her own shots and everything." Another mom explained how she felt "kids just have a natural curiosity, they want to know exactly what's going on," so she went to her child's school and explained all about his condition, in order to help them get their curiosity satisfied. Because she thought it was important to educate anyone who was interested to know about her child's condition; she would do things such as sending her child's friends

home with books for their parents to read to them about the condition if they asked for more information.

While all parents interviewed spoke of this need to educate, most seemed to take on the educating after it became a need for their child. Once the child reached school age, most of the parents felt it was necessary to explain their child's chronic health condition to the child's teachers. A few parents even went directly into the classroom to speak to the child's classmates. Some of the parents described how frustrating it was when they felt they were not really heard by those in the education system, while others were quite satisfied with the way the school was handling their child's needs. When it came to educating the child's or their siblings' friends, most of the parents either did the educating themselves, or observed their child's interactions with friends and intervened only when they felt it was necessary.

Developing and Utilizing Resources

All of the parents felt they needed varying levels of support in their daily lives to care for their child with a chronic health condition. The parents described how they were either aware of the supports and were not always accessing them, or were not able to find the proper amount of support for themselves in their community. They explained how sometimes their families and friends were their biggest supports, but often they did not want to burden these people with what they perceived as too much stress related to their situation.

Difficulties Parents Experienced

Unsatisfactory Support groups. Four of the families explained how they had either been a part of a support group and stopped going, or found the support group lacking in some way. One mother explained how she did go to the support group at the local hospital but she thought “maybe it was just too big, I didn’t stay with it, maybe I should have stayed...I think that maybe a small group is better because I think everybody kind of got a chance to let off a bit of steam.” Another mother explained how it wasn’t the size of the group she found intimidating but the distance she had to travel to get to it. Eventually the support group had folded, as the mother explained:

The organizers were discouraged with the turnout and they thought people just weren’t interested, but in my instance there’s lots of times I was interested but I just couldn’t drive all the way into the hospital at night when I hadn’t had any sleep for weeks on end. So it wasn’t that I didn’t want them, I just couldn’t get to them.

Another mother explained how she stopped attending her parent support group as she felt it simply “wasn’t getting anywhere.” One mother recently found a support group for she and her husband that she was satisfied with so far as she felt “there wasn’t a lot of stress behind it”, like there had been in other groups she had attended.

Taking breaks. One of the mothers described:

My husband and I went together to one session for a psychologist that was supposed to deal with chronically ill kids, just basically because we wanted to

know what other people do, how they handle the situations...and again the answer was take breaks, and for seventy five dollars an hour it just didn't fit. I haven't found any answers as far as in the outside help in that respect. So a lot of it just seems to have come from within.

This idea of taking breaks was something that a lot of the parents described as being something that was hard to accomplish. They often described how they had tried to take nights off but to no avail. One mother explained how she had tried to hire in a private nurse, but at "one hundred and thirty dollars from midnight until eight in the morning, financially it's too hard to do that." Most of the mothers explained how they didn't feel comfortable leaving their children with regular babysitters, as they felt their needs were too complicated.

Strategies Parents Used to Meet the Adaptive Task

Support from professionals. Many of the mothers felt that they could get support from health professionals such as psychiatrists, and psychologists. One mother described how she had started taking her child to a child psychiatrist, and in the end she felt that "she was the one who needed her," so she continued the visits for herself after her child had completed his course of sessions. In one case the mother described how the public health nurse kept coming to visit the family home "a lot longer than she was required," which the mother found very useful for support. This mother realized the nurse was coming in a professional capacity, but felt comfortable sharing things with her like she would with a friend.

One of the mothers was able to draw a lot of support from the children's hospital where her child was often an inpatient. She described how the hospital had been a "very positive thing, and the surroundings and the attitude to [the children] and the way they gear things for them" had been a great support for her family. This mother also described how there were "some ladies that came around and did give us information on sheets" that she found very helpful while her daughter was an inpatient. She also described how she noticed that the nurses were often very busy, so she felt it would have been helpful to have a designated person come around to the hospital inpatient rooms and tell the families a few things about their stay, she explained it by stating:

A lot of these little practical things that would be very useful to know really early on because you're very stressed about a lot of things, and sometimes going and making a cup of tea is a very normal thing to do...what you need is a clear message "look you can go do this, you can't do this here and you can't do this there, and don't go in there, that's no problem, but you can do this and that and the other- and then you have the freedom to go and do it.

Support from family and friends. Often the mothers spoke of the great support they got from their family and friends. "Thank goodness I've got the support from my husband," is how one mother described her best support system. Another mother felt that she had "a good network of friends that I can talk to, but they have other problems." Many of the mothers described a situation similar to this, where they felt they had a good group of friends for support but they were afraid they would overburden them with their ongoing concerns for their child. One of the mothers described this feeling and

how she thought it would be better to talk about these issues with somebody who wasn't as close, she described the following:

It would be better to talk to somebody who was a bit more distant, who I maybe wouldn't be seeing all the time, but who had been through it and knew as well that it's just all talk, that all you want to do is talk, and not necessarily [have them] be overly sympathetic or talking or anything.

The families mentioned how they noticed that when their child was first diagnosed they felt they had a lot of support from family and friends and how over time this support would appear to decrease in intensity. One of the moms said she felt it was "because nobody knows what's going on at first and they are just being comforting and they're just consoling and they're just being with you at first, but by the time it's gone on for a few months or years that has all changed."

This change in the level of support from family and friends was mentioned by a few of the parents. The parents said they understood, but it was hard to adjust to the fact that they had to continue to act as a caregiver to their child without the same level of support they felt when their child was first diagnosed. One mother said she found it hard not having "a lot of people for support" but that her mom would come out and stay for the summer to help her out with her child. Another mother got exasperated after looking for support in the community for years via community health nurses and the health units, and then came to the realization that she was "always looking for somebody to tell me, to give me an easy way of how to deal with this, which I've now discovered doesn't exist."

All of the parents mentioned how important they felt it was to get support for themselves and their families when providing primary care for their child with a chronic

health condition. They spoke of making various attempts to achieve this support through avenues such as: support groups, health care professionals, the hospital and family and friends. Most of the parents perceived that even though they were often able to access this support they were worried about becoming a burden to the people who were helping them. With the exception of one family, all of the mothers that had tried support groups felt they were lacking in some way and eventually discontinued their participation in the group.

Summary

Each of the eight thematic categories from Canam's Parental Adaptive Tasks Framework was explored using data from Sample A interviews in this section. The findings were thematically categorized under the eight tasks; with each of the identified themes explored and presented using the parents' own words to illustrate each theme. Although there were a few instances where the data could have fit into more than one thematic category, for this analysis only one thematic category held all of the selected information. There were no themes identified that did not fit under one of the eight adaptive tasks. The next section will focus on the information from Sample B.

Description of Sample B

The interviews for Sample B were conducted at a specialty clinic in a tertiary care children's hospital. Three of the parents who were interviewed were the mothers, and one was the father of a child with a chronic health condition under current treatment. All

parents described themselves as the primary caregiver for their child with a chronic health condition. All of the families were two-parent families, with both parents residing in the home. Three of the children were diagnosed with some form of malignancy, and the fourth child had a haematological disorder. All four of the families had two children with only one child affected. The children had been diagnosed at varying times in their lives. One of the children was diagnosed when she was two months old, sixteen years ago; the most recently diagnosed was four months ago, when the child was thirteen. The children ranged in age from seven to sixteen years, their siblings ranged in age from nine to thirteen. There were two boys and two girls in this sample.

Accepting the Child's Condition

Two of the parents interviewed described their current care-giving situation as “exhausting, difficult, and insane.” One went on to say that the “whole thing sucks really, it’s all been hard to deal with,” to describe her family’s life since the diagnosis of her child’s chronic health condition, six years previously.

Difficulties Parents Experienced

The shock of diagnosis. The diagnosis of a child with a chronic health condition is often a time of confusion for the parents. One of the parents interviewed described how upon diagnosis she wanted to get the child’s treatment “over with” right away. This parent related how she started to realize that her child’s diagnosis may be more chronic than acute when the doctor told her the treatment would last “for the rest of her life...so that definitely, that really totally obviously changed our life, so that was

probably the turning point there.” All of the parents who were interviewed described how they were shocked by their child’s diagnosis of a chronic health condition, and were only learning how to deal with it over time. One parent spoke of how he felt that in his family they were unsure of how to deal with “cancer, you know that big bad word.” Another parent described how “past the shock of diagnosis you try and figure out how to live life around it.”

Hiding the diagnosis. One of the parents interviewed described how it was hard for her family to accept her child’s diagnosis with a chronic health condition as “it’s hard with the ethnic background, because some ethnic backgrounds are very private or they feel like they have to hide for whatever reason.” This had affected the mother’s ability to talk about the child’s diagnosis with her extended family, she described:

My mother or my mother-in-law are like “oh why does she have to tell all of her friends? Does she tell everyone at school”? To them it’s none of their business so why do they have to know? They were probably more worried about what people think.

This is an important issue for the family involved as it had an impact on the mother’s ability to begin accepting the child’s condition, as she felt she had to hide the diagnosis or not fully disclose information to the grandparents to decrease their worry about being “found out” in the community.

Uncertainty. One of the parents related how he felt that “the only thing certain about this whole treatment is that it is uncertain.” Another parent who stated that her

family had decided to “play hard when we can, because we don’t know what is around the next corner,” also described this feeling of uncertainty related to her child’s diagnosis of a chronic health condition. It is interesting to note that two of the parents involved in the study were unsure of the actual name of their children’s diagnoses. One parent stated what she thought her child’s diagnosis was prefaced by the comment “he has, as far as I understand...” The other parent unknowingly used the wrong name for the child’s diagnosis throughout the entire interview. This uncertainty about something as basic as the naming of the disease provided some insight into how overwhelming a diagnosis of a chronic health condition can be for a family.

Missing the old normal. One of the parents described how her life since her child’s diagnosis has “become routine,” but how none of it was without worry. She described how, since her child had gotten older, living with the chronic health condition had become “a lot better,” but she felt that she was a lot more worried about her child’s future life with the chronic health condition, than she was when her child was younger. She described how she felt that when you have a child with a chronic health condition “you can never really escape from it; it’s just hard.” She also described how she felt that coming to the hospital “once a month and just have a normal once a month thing,” instead of having to do all of the primary care at home for her child, would be more ideal, but unrealistic for her family. Another parent was adamant that life was “never normal for us,” since their child’s diagnosis with a chronic condition. The parent went on to describe how:

I suppose it is our life, and it's been that way for five and a half years, or now almost six years, it isn't normal, no it's not normal, it's not normal to have to carry an overnight bag in your car all the time, it's not normal, it's not normal to have a bag full of medications in your purse, none of it is normal.

This parent felt that despite the family never being able to lead a "normal" life they were still able to "try and make the best of it," most of the time.

All of the four parents described how they had to give up aspects of their "normal" or old ways of life when their children were diagnosed with chronic health conditions. One parent described how "in terms of what I've had to give up [since diagnosis], there's that whole issue, my professional life, my old normal is gone." Three of the four parents, who described themselves as the primary caregivers for their children, gave up their professional or working lives when their children were diagnosed. In the fourth family the non-primary care-giving parent took a stress leave from work and the primary caregiver ran a business, so was able to be away for long periods of time to care for the child at home.

Strategies Used to Meet the Adaptive Task

Advocating for their child. Three of the parents described how they had accepted that they were now in the role of advocate for their children with chronic health conditions. One parent seemed to take on the role more readily stating "no one is going to be a stronger advocate for my child than me." This parent went on to describe how in order to supplement this role of advocate she had to become "very well read about my

son's disease." The second parent seemed a bit more reluctant to take on this role when describing how:

the hardest thing for me has been researching the disease...I feel like as the parent I should be a better advocate for my child, I should be researching more, looking at more proactive ways to deal with this treatment and prevent reoccurrence and yet every time both my husband and I get on the internet and start researching and looking for things we just have to shut it down because we can sort of handle what's on our plate right now, but looking down the calendar it's just too hard to think about what might be coming up ahead.

The third parent took on this role of advocate for his child out of necessity, as the child was diagnosed in another country and there was a need for the father to act quickly to get the child home. This parent described how he was only able to take a minute to let the diagnosis "sink in, but then the dad protectiveness kicked in quickly," and he was able to go on and secure a lot of resources to get his child safely transported back to his home hospital.

Realizing it could be worse. All of the parents stated how even though their lives were difficult since their children's diagnosis of chronic health conditions they realized that there were factors that could make it far worse for them. One parent stated how sad it was that some of the kids "that were supposed to be the ones that were going to be the long-term survivors" had passed away before her child who is the one "who is not supposed to be here" due to the severity of the diagnosis. Another parent described how "in the last few months we've had other family health issues and it's really opened

our eyes to how lucky we are, particularly here at this hospital.” Another spoke of how she felt lucky to have all the family support she had for her child’s illness as she couldn’t “imagine being a single parent and not having a dad or a mom, or just not having family and stuff would be quite hard.” Another parent explained how:

As a whole, being in this cancer family I still consider ourselves extremely lucky even though we have a daughter with cancer, there are families and parents who are far worse, that have not gone home in six months, that have no hope of going home, that we still thank God that at least we have that hope because I have seen it the other way being here, and it could be far worse. So I still am very thankful that at least with what we are going through there is a positive potential outcome, which is what we look forward to.

Despite the difficulty of the task of accepting the child’s condition, all of the parents interviewed described how they were eventually able to make strides towards this goal. For one of the parents however, dealing with her family’s inability to accept the child’s diagnosis of a chronic health condition still remained a struggle. Once they were able to digest their children’s initial diagnosis, a few of the parents realized they were now in the role of advocate for their child. There was a certain level of uncertainty with all of the parents in relation to their children’s chronic health conditions. None of the parents described normalizing their current life situation, with only one parent describing a state where the diagnosis becomes somewhat routine, but still worrisome. All of the parents described giving up aspects of their previous way of life, and all were able to imagine ways in which their current life with a child with a chronic health condition could be worse.

Managing the Child's Condition on a Daily Basis

The families often spoke of the difficulties of managing their family lives along with the child's chronic condition. Once a chronic condition was introduced into these families' lives they found they often had to try to incorporate hospital life into their daily routine. This struggle included engaging with health care professionals daily, and trying to assimilate all kinds of new information about their child's health into their life. Many of the parents found they needed to become very creative to rework their suddenly very busy schedules.

Difficulties Parents Experienced

Dealing with health care professionals. The diagnosis of a child with a chronic health condition often brings a whole new confusing system into the parents' lives that they have to try and find a way to navigate through. One parent described how, when her child was first diagnosed:

It was very, very difficult because I was very intimidated by the whole system, and we [the parent and health care professionals] didn't know each other, my questions or points that I had...I didn't have enough time to have those things answered in a non-threatening environment...points that I brought up to physicians or nurses nobody really, even research papers, things that I brought to the forefront that I really was concerned about, it was just kind of "oh crazy parent" and you are too new and you don't know the system, and you don't know how to advocate for your son or daughter, but now I [don't feel as intimidated]

and it's probably just maybe my credibility has got some merit, because I'm not stupid and I have access to some really good information.

As time went on this parent described:

There has been a shift in the last couple of years, there has been times when I felt that we were just a number, and now I feel we are family, I don't know when that shift occurred and it's not that there wasn't genuine care before it just wasn't as heartfelt, and that just mainly because we've been around longer and everyone has got to know we are not psycho...most of the time.

Strategies Parents Used to Meet the Adaptive Task

Adaptation. Not all of the parents described as much of a feeling of unease with the system in the beginning of their children's treatment. One family whose child had recently been diagnosed described how:

We have never had an issue in here [hospital]. We did have one issue once where we did have a nurse who was probably not as sensitive as she could have been, but every other person in here has been unbelievable. I cannot honest to God say anything bad about any other person that is here... the staff and the doctors and the nurses have been beyond what we could ever expect in caringness and stuff like that.

This parents' main concerns were that "everyone is sympathetic, and it's about ninety-nine percent perfect right here [in the hospital]...you people are so caring, understanding of the circumstances, which I think is the best thing, they have a true understanding" when it came to the care of the child.

Another family interviewed explained how their interactions with health care professionals had on the whole been “pretty positive, my husband jokes that it sucks that everyone is always so nice there...you wish that you could have someone that you could just hate.” The mother felt it would be easier if they had someone to hate so that they could find a place to direct their feelings of irritation towards their child’s diagnosis. This mother also described feeling that her family was happiest and most comfortable when being taken care of at the children’s hospital, as they had tried an alternate hospital in the province and found:

They (health care professionals) didn’t really know how to do it [chemotherapy routine], there was nothing major, but there were some errors made because they weren’t used to the way that it’s done here. And on the whole the doctors were great and the time they were able to give us was great, but no, I just feel I am more comfortable here.

Acquiring Information. Managing the overwhelming amount of information involved in caring for a child with a chronic health condition became a challenge for many of these families. One family realized that both of the parents were interested in differing levels of information, so were able to accept that and find ways to satisfy their own needs. The father described how:

I had read up on all the things she is going to be going through, I am aware of everything; I try to educate myself enough to learn a bit of what is to come. For my wife, she knows what is happening; she understands the basics...is it going to

make her [child] sick? That's what she cares about, what are the side effects? So to her level of comfort she gets enough information.

This parent also described how the thing that he found most impressive about the care and transference of information was how the "doctors and nurses are always on the same page...everyone seems to be doing things consistently." He explained how he found it comforting to be able to rely on having his questions answered in a consistent fashion no matter who he asked in the hospital setting.

When describing how important it was to receive information about her child's diagnosis in a "caring manner" one mom described how her doctor "would explain everything and he had so much patience, he would spend forever with you explaining something." The mom went on to describe:

It's important to have a doctor that didn't make you feel like you were just a number, just give you the information and walk away; that really can sympathize with you, because I think that really is important when they are young, because it's all so new to you and you are so overwhelmed.

This mother explained how being given information in the form of reading material had not been the best resource for her or her child, but that "sitting one-on-one [with a health care professional] is a lot more helpful than just reading stuff."

Organization. Trying to manage and organize daily life while having a child with a chronic health condition receiving active treatment was also a task requiring a lot of attention for these families. One parent described how when they were given the

information about their child's future treatment needs they developed a system to organize their lives, she explained:

We set up a spreadsheet with a schedule and filled it in with who was going to be doing what, and who was going to pick up [sibling], who was going to run to the grocery store and pick up more milk, who was going to walk the dog, and that was helpful. It helped us, we felt in control.

In order to keep their life organized another parent described how she and her husband would “trade off” when their child was in hospital. She described how her husband came in on the weekends and one night during the week so she could go home and be with the sibling, and so that “neither of us maxes more than three nights, cause we just find that gets to be too much and we want to see our other child as well.”

All of the families had some contribution to this section on managing the child's condition daily. Most felt that their interactions with health care professionals were positive overall, and the amount of information and the way they received it was basically tailored to their needs. Most of the families were able to find creative ways to organize their lives to maximize their time with both their children and their spouse.

Meeting the Child's Developmental Needs

The parents faced many difficult duties as the primary caregiver to a child with a chronic health condition. Meeting the child's developmental needs was an especially difficult task for many of these parents. Having a young child have to face his mortality was one of those challenges for the parents. Most of the children were absent from school presently due to treatment needs; with the parents unwilling to add schooling stress to the

lives of their children who were already strained by treatment related sickness. Most of the parents related that they were able to share information with their children about their illnesses, even if their child did not always appear willing to acknowledge it, and felt that was the best way for them to help their child manage the situation.

Difficulties Parents Experienced

Interrupted schooling. All of the parents interviewed spoke of how their child's schooling was either interrupted or discontinued while they were receiving treatment for their chronic health conditions. One parent described how her child "goes in when he can...I would say he's probably been there a quarter of the time." Due to the large amount of time her child spends in the hospital for her treatment, and how sick he often is from the treatment, this mom described how hard it was to ask her child to visit the hospital school or do homework in his hospital room:

He's always been in for a week at a time, and then he's usually pretty sick so he got a workbook from the teacher just yesterday but getting him to...you know we can barely get him to swallow water, forget 'do you want to do some homework now?' I don't know if I should be pushing him more or not, but I sort of feel like he is feeling pretty lousy, he doesn't even want to watch cartoons so forget it.

Another parent stated how the family hadn't been "pushing that [school] right now, because she couldn't really muster a lot of days together where she was feeling good enough and could actually say 'okay let's get some homework done'." One of the other parents interviewed spoke of how amazed they were that their child had been able to keep friends at school despite the amount of time missed by the child that year. The

parent was able to attend school with the child one day and noticed that the other children were “very excited that he was finally there,” which the parent found reassuring. This same parent had noticed that while at school her child appeared aware of his physical differences due to his treatment related alopecia, so at school his hat “doesn’t come off, he doesn’t want to be that kid [with cancer], he wants to be the normal kid.” This mother was willing to support her son’s position of seemingly hiding his condition as she had decided that there was “lots of time for therapy when we get through this.”

Child’s awareness of own future. All of the parents interviewed shared thoughts about their children’s understanding of their future lives related to their chronic health conditions. One of the parents spoke of the cruelty of having a child who is living with a potentially fatal illness when she stated:

that’s the worst thing in the world to tell a child with cancer that their friend is going to die, it’s not normal, I mean it’s hard enough for a normal child without a chronic illness to lose a friend, but to have a chronic illness and then put two and two together and realize that this could be you is just brutal.

Another parent described being faced with the reality of his child’s own mortality when the child asked him “daddy am I going to die”? He went on to describe:

I will never forget that moment, that was the most unbelievable moment cause she knew there was really something wrong, and going through the oncology department we walked in there and she could see the other children, she knew about leukemia and she could see that these other children were really sick and you could see her thinking ‘am I this sick’? So before they knocked her out I

remember her saying that, and I told her, I remember saying to her, you know sweetheart I will never let anything happen to you.

Strategies Parents Used to Meet the Adaptive Task

Information sharing. One of the parents interviewed spoke of how one of his child's only treatment-related needs were that she be kept "abreast of what's happening and that people listen to her." He therefore felt it was very important that his child's treatment schedule always be posted on the fridge and that he or his wife "constantly remind her of what's to come" when she asked. When asked about how her child deals with all of the treatment-related information another mother said that her child "doesn't want to talk about it." It seems these parents just did what they could to get their child through their treatment regimen as easily and efficiently as possible while still maintaining their child's wish of not always needing to extensively talk about it, unless they pointedly asked for information.

Sharing information about their treatment and related needs with their children was something that all of the parents felt they were able to do to some degree with their children. Some of the parents found it difficult to answer their children's questions about death, or witnessing their child coming to the realization that they may be suffering from a life-limiting condition, when they observed their peers dying. Interrupted schooling was described as the norm for these children, with parents feeling it was too hard to push their children to perform when they were not feeling well due to treatment related side-effects.

Meeting the Needs of Other Family Members

Parents described the difficulty of meeting the needs of all of their family members as well as their own needs, while providing primary care to their child with a chronic health condition. There was a lot of discussion centred on how the care of the children was split between the husband and wife, and the effect the illness had on the siblings, and the parent who was the primary caregiver.

Difficulties Parents Experienced

Managing siblings' difficult feelings. Parents noted that they felt that being the sibling of a child with a chronic health condition appeared to be difficult. One parent described how:

Our other [nine-year-old] son, he's always been the child who needed more attention, he has some learning disabilities, nothing major but he's always been the kid who has needed more time and J [child with the chronic health condition] has always been the happy go lucky, tag along to all the tutors, so this illness has totally reversed all that, and both kids are struggling with it.

This parent described feeling very guilty that it took J's diagnosis with a chronic health condition to make her realize that she needed to pay more attention to J as well as his brother.

Spousal support. Two of the parents described how they felt they would like a bit more help from their spouses but did not seem to ask for it. One mother described how when she would provide necessary daily medical support to her daughter she felt

that she was “more involved with that rather than my husband so I feel like I don’t get enough support there.” This mother described many situations where she felt she was more of a lone caregiver to her daughter, but she also felt she had a lot of support from immediate family and described herself as “lucky” to be able to get the breaks she needed.

Strategies Parents Used to Meet the Adaptive Task

Helping sibling’s manage. One parent described how the sibling seemed to find a way to cope with living with a sick sister:

My other [thirteen-year-old] daughter has basically- she’s basically put up a little bit of a wall between us. She is focused on her own life at the moment and we are very happy that she is not being affected by her sister too much. She sees her sister every day but she is not taking the brunt of the harshness of the disease, the sickness and taking care of her, she’s more focused on her own life, so we are very happy to see that.

The parent felt that even though the sibling had seemingly walled herself off from dealing with the day-to-day battle, he was happy to see her life continuing as it had before the diagnosis of her sister’s illness. This family wanted to protect the sibling and provide her with “as much normalcy as possible” throughout the sibling’s treatment regime.

Another family interviewed described how they had taken a proactive approach to helping the ten-year-old sibling deal with being in this position by enrolling the child in a hospital-based sibling support group. She stated:

I was just so thankful that F [sibling] would eat anything and we could go for dinner at someone's house and he would gobble up anything that they put out and we just couldn't believe what a non-picky eater he was, and after that first sibling's coping group, that was the first thing that changed...he suddenly started saying "I don't like that" and it was like instant within a couple of weeks of the first session he suddenly turned into a picky eater, and I thought "hmm he needs to be catered to too, that's what he's saying". So now he's doing the second session, and he really has been speaking up about what is not fair...which is hard on me, but it's very good for him to be able to say, "hey that isn't fair", and he will just flat out say it...it's good that he's expressing it.

The parent described how the sibling support group had been very helpful to the child and that she felt it was very important for him to attend, and work through his feelings, as he would have to "live with this for the rest of his life."

Marital Relationship. One family described how when providing primary care for their child with a chronic health condition they had to "split the jobs, we share the responsibility of everything." This was the way the husband and wife felt they were able to help each other through the day to "preserve our own sanity, because if we didn't split the jobs and also get a little diversity in for us we would go ape crazy I think." This method seemed to work for another family in the study. The mother described how:

We fluked out and I married well, because the best thing has just been that R and I are so on track on this and he's been he's just there so much. And that has been the best thing that I don't have to question, I don't have to ask for anything from

him. He's totally there as much as I am. And that's just made it so much easier and, not that there hasn't been any issues, there are. This is a highly stressful situation, but it's made so much easier by knowing that the weight is definitely on two people. It's not even seventy-five percent one and twenty-five percent the other, it's fifty-fifty, one hundred percent, and that's just made it a lot easier.

All of the parents interviewed were able to describe situations where they felt they were able to work through the task of meeting the needs of other family members. The parents seemed to be able to handle this task most efficiently when they shared the daily care evenly between them. An issue that received a lot of attention was the effect the child's chronic health condition had on the sibling in the family. This position was most often described as one that was very hard for the sibling to bear without some outside intervention.

Managing Ongoing Stress and Periodic Crises

Managing ongoing stress was something that the parents all described having to find a way to deal with, as they all presented a view of a world where constant stress was a component of their daily lives. Getting help from friends and family was not always an easy undertaking for these families. They explained how never really knowing what was coming next in their child's illness trajectory made it hard for them to ask for help, as they often had no idea what anyone could really do to assist them to manage this ongoing stress in their daily lives.

Difficulties Parents Experienced

Unpredictability. All of the parents mentioned the need to be very flexible when providing daily care to their child. They described situations where they couldn't plan a daily or weekly schedule, as they were never certain of what the day would bring with their child's illness. One parent described:

you have to be very flexible, even though you think your day is only going to be an hour or two [at the clinic] you commit the day because there is no way as a parent you can count on anything with this, so it takes the two of us to be home, it takes the two of us to be always ready and able to deal with every challenge.

Another parent described how she was “fortunate not to work when [my daughter] was young” so that helped her to be able to be as flexible as she needed to be in order to constantly be bringing her child into the hospital for treatment.

Stress. The parents were easily able to recall many situations where there was tremendous stress related to their care-giving efforts for their child with a chronic health condition. One parent described a situation where he couldn't imagine how anyone could really come away unscathed after hearing the things that he had been told about his child during diagnosis and treatment, he explained:

Yeah, it's stressful, to different degrees, everyone handles stress differently and in my job I tend to handle stress as a challenge and I go through it, but there are some points of stress that anybody it would break. Watching your daughter being told that she's going to pass away or she could die; being told, “you just sit here and wait while we see what we can do”. Whoa, ha ha ha. Yeah, it's like “okay”; I

couldn't even imagine if my wife had been with me, it wouldn't have been pretty; we would have had two patients.

Strategies Parents Used to Meet the Adaptive Task

Managing Stress. When describing how it was important for them to get time alone together with her partner to help manage this ongoing stress one parent commented, "I have come to realize that you have to ask friends and family for help because people don't realize 'okay they haven't been out for three months together'." This parent went on to describe how she felt they almost needed to "recruit new friends, because it's exhausting, hearing what's going on in the roller coaster ride." This parent also felt it was important to get out and talk to people, or to get some exercise as this was a good way to relieve stress when it all became too much for her to handle. Another parent described how she managed the stress by recruiting family members to accompany her and her child to the hospital for the many necessary clinic visits, so that she no longer felt like she was "all alone in this." Another parent described how it was hard for them to enlist people to help them as she felt that "people don't know, I don't think unless you live it you can really get it," when it came to living with the constant stress involved in being the primary caregiver of a child with a chronic condition.

One of the parents described how his wife's career was flexible enough to help them manage the stress of needing to be able to schedule around their child's treatment needs, he described:

I couldn't imagine if all of a sudden D didn't have the job that she had where there was still some time left and me with my work flexibility...I consider

ourselves very lucky because there are a lot of people who have to actually leave their jobs and get nothing.

Despite the difficulty of dealing with the constant stress and crises involved in providing daily care for their children, most of the parents were able to find a way to manage the ongoing stress in their lives. Many relied on friends and family to help them out, or tried to be as flexible as possible in their daily routine to avoid frustration with the constant unknowns that came with their child's treatment. Some were able to describe situations where no one really could handle the amount of stress they were subjected to without "breaking," while others just seemed to get through it by getting away from the routine for a while, so they could come back, and get back to it.

Assisting Family Members to Manage Their Feelings

The parents described situations where they felt their child was having difficulties dealing with his or her emotions related to being a child living with a chronic health condition. They were also cognizant of the sibling's feelings around the issue of the brother or sister's chronic condition, and were able to express the belief that they were not always confident that they would know how to deal with what they were observing.

Difficulties Parents Experienced

The feelings of the child with the chronic health condition. One family was very aware of how hard the chronic health condition was on their child's emotional state, the father described:

She's a twin so she watches her sister going to high school, brand new school so she's making all new friends. She's going to her first school dance and L has never had the opportunity, she's watching her sister do very well in school. That's very difficult for L. It really makes her very sad; totally depresses her. She's, I wouldn't say unmotivated, but because of the physical restrictions that she has...this mental battle I think has probably been our most difficult challenge right now.

Sibling's feelings. The families all mentioned the impact having a child with a chronic health condition had on the child's sibling. One mother observed how her twelve-year-old well child "feels bad for K [child with chronic condition] at times, she doesn't express herself, she's not a very emotional kid, but she is concerned if K is not feeling well, she just doesn't say it." In regards to sibling's emotions another mother observed how her child's condition was really hard for the nine-year-old sibling to deal with. She described how he had "really been acting out... [saying] 'you don't love us', he's tried to run away; it's been a real challenge with him." The family tried to even things out by sending the sibling away to different relatives for the summer, and "trying to make his life as much fun as we could," but in the end she noticed he just "got really burned out...and said 'I just want to come home and hang out'." This mother described how hard it was to assist the sibling with his feelings, as she wasn't always able to have a true understanding of how he was really feeling.

Strategies Parents Used to Meet the Adaptive Task

Providing small comforts. One parent observed that their child “tends not to want to buddy up with oncology kids; I mean he’s lost a couple of really good friends.” This parent felt it was important to protect the child’s feelings, so she tended not to get as involved with families who had children with a poor prognosis, as she didn’t want her child to have to go through “los[ing] another friend.” Another family decided to find small ways to help comfort their daughter, by using whatever means available to them to console her. An issue that was important for their child was that she not be seen with a feeding tube in place, so they were able to negotiate to “have her feeding tube pulled out for Christmas, even though we know she is going to need to put it back in January; if we didn’t pull it out it would devastate her.” This small measure of comfort made it so that the child could enjoy the season and “take a break” from the medical side of things for a few days. Another parent whose son had alopecia due to his treatment regime described:

I can tell where his comfort level is [by observing] whether or not he chooses to wear his hat, it’s a small thing, but it’s really symbolic. If he’s got his little tie-on skullcap he’s not comfortable with these people, but if it’s off you know he’s right at home.

Despite the observation that the child with the chronic health condition, or the sibling, was often struggling with the emotions that came along with the chronic health condition, many of the parents described how they were either unsure how, or unable to do much to help, other than provide small comforts where they felt they could. It almost appeared as if the parents felt these emotions were “par for the course” when dealing with something as all encompassing as a chronic health condition in the family.

Educating Others About the Child's Condition

All of the parents described finding ways to educate others about their child's chronic health condition. This educating was done in different ways, and with different people, but all of the parents spoke of the importance of letting others know what was going on in their family life. None of the parents mentioned anything that resembled a difficulty when describing how they met this task.

Strategies Parents Used to Meet the Adaptive Task

Educating friends and family. One of the parents was quite candid about the method her family employed to educate people about her son's condition. She stated simply "everyone is aware, we are a no secret family, we just kind of say 'this is what's going on'," when describing how she keeps her friends and family educated. Another parent described how she would not go out of her way to inform people about her child's chronic condition, but that "friends and family know because when they come over they see the pump, yup, it's not something I talk about but they see the pump and they ask and I just tell them." One of the parents described how she felt it was very important for her to educate her friends and family directly about what was happening with her child's illness to cut out the instances of "miscommunication, because a lot of that happens with people if they don't actually hear it from you they fill in between the lines." Another parent chose to communicate directly with her friends and family through an "update email as events happen and we say 'if you want to forward it to somebody go ahead'," so that people could help inform others without having to speak to them directly.

Educating the educators about the child's condition. Three of the four parents spoke of going into the school to educate the educators about the child's condition. One of the parents stated that going to the school had been a "very proactive thing for me, very big important thing," and how the school had been "phenomenal" in their understanding about her child's needs due to his chronic health condition. This parent went on to describe how she had also visited the sibling's school to meet with the counsellors and teachers to educate them about how the sibling needed support too, and how it would be helpful to him if they would focus more on his needs rather than just the child with the chronic health condition, which she understood was "a natural thing to do" under the circumstances.

Educating others about the child's condition was not something all of the parents went out of their way to do, but all spoke of the importance of this task. One of the parents waited until friends and family noticed one of her child's pieces of medical equipment before telling them, while others were quick to send out mass emails to let everyone know what was happening to minimize misinformation.

Developing and Utilizing Resources

The parents all reported being aware of and using different resources to help them in their daily lives while providing primary care for their child with a chronic health condition. One of the parents described being aware of what resources were available but admitted to not reaching out to use them yet, while another reported being involved with

a support group for many years. Some used friends and family for most of their support while others were able to develop resources for themselves outside of the family unit.

Difficulties Parents Experienced

Finances. The parents did not describe situations where their finances were severely drained, likely due to the amount of coverage for health care expenses from extended benefits and the many provincial funding programs available to the families. However, one financial drain that two of the four parents interviewed did mention was parking expenses incurred while at the hospital site, one parent stated:

The one thing that is stressful for us in a financial picture is as a patient always having to deal with simple things like parking, it's something that nobody has ever done much about but man oh man for the patients coming in if they could use some of the funds to help with that, because there is no rebate on that, you can't put it on your income tax, you just have to go and pay it, there is no recourse on that.... you are spending 150-200 bucks a month on parking.

Another parent described how she felt it was just a small thing but nonetheless she described how she thought that patients' having to pay for parking at the hospital was "brutal."

Strategies Parents Used to Meet the Adaptive Task

Support groups. One parent reported being a member of a society specific to her child's condition that she claimed was an "awesome" resource, as they were able to provide excellent information about the condition to the families by collecting and sharing hands-on information to any member who had questions about the day to day care of their child's condition. Even though the parent described being happy to be part of the society and that she found it very useful, she felt it was often "hard to get everyone together because everyone is so busy, or they just don't want to bother." She described how a lot of the parents in the group were so inundated with the daily life of living with a child with the condition that they often felt "I deal with it enough, I don't want to go to a function about it"; therefore the meetings were not always well attended. The only other parent who described being a part of a formal support group was a parent who mentioned that her son was a part of a sibling support group, which she found very useful to help the sibling cope.

Support from professionals. All of the parents described the support they got from health care professionals as adequate and often explained how they felt they knew the "support is there" in the hospital. One parent described how one of the doctors at the hospital had been "my absolute mentor through this thing," when speaking of the support he had gotten from the local hospital. When asked if she was aware of the supports in the hospital and places to go to get questions answered about her child's diagnosis, one of the parents described:

I was afraid to look a little more, I mean we haven't made use of the family resource library, you know it's funny most of the doctors and the nurses that we talk to are pretty approachable, like I know with some of the vitamins we have wanted to give him the doctors have said 'yeah that's okay', but we're not doing anything outside of the standard regular practice, so I don't know, I guess I haven't posed that question, I haven't said "where do I go for this"?

When asked what she felt was most helpful as a support to her as a primary caregiver to her child with a chronic condition one of the parents described her biggest support as "the hospital, obviously because they are great here and that has been so helpful." She described how she felt that all of the services available were a big support, especially the in-house child psychologist whom her child visited occasionally, as she "likes to talk to her." When describing what was most helpful as a support, another parent stated that the health care professionals in the hospital were the best resource as "the ability to acquire the knowledge that I need is always there, any questions I ask, any time that I have issues, they are always addressed." The parent went on to describe how the health care professionals "don't overwhelm you, but they do provide me with the knowledge I need to look forward to what's coming in the future."

When describing what the best resource had been for her since her child's diagnosis, one of the parents stated:

I think people cannot ask enough, what can I do to help you? Friends, family, health care workers, those are the sweetest words anyone can say to you, what can I do to help you? What do you need right now? Is there anything I can get you right now? But just even knowing that somebody cared enough to ask, that is

huge, and I realized that from one of the nurses on the ward, one of the CNC's [clinical nurse coordinator] who has come around every time we are in and that's the first thing that comes out; is there anything we can get you? How has your stay been? It's almost like a concierge but I know she is meaning it on a totally different level. "If you need someone to talk to, if you need to go, anything". I know she would really do anything to help us; it's sincere.

Support from other families in the same position. Two of the parents felt that it would be helpful to get support from parents who also had a child who visited the hospital's outpatient clinic. One parent described how they enjoying meeting other families with children with the same diagnosis but felt it was hard to meet up with other families in the clinic setting "because the treatment protocols and the visit times are so different it's tough to actually develop a relationship with any one person for any length of time." This parent felt it was easier to meet families in similar situations to their own on the hospital inpatient unit where "we sit there and we have coffee with the parents, and as a parent I was sitting here all day and night, you get to know the other parents." When speaking of this issue another parent interviewed felt it was "so beneficial when the patients see each other outside the hospital" and suggested how perhaps a "buddy system" for families whose children share the same diagnosis would be of interest to her. She felt that it would be helpful if "the parents could be introduced, when they are here [in the clinic], the nurse or the child life worker; having someone say 'oh, I'll introduce you two', and get emails to email each other or something."

Support from friends and family. All of the parents interviewed felt that they were able to get a lot of support from their friends and family, with one parent stating, “I couldn’t imagine doing this if I didn’t have as great a husband or as strong a marriage, it would just be a lot harder.” When it came to getting help from people outside of the family unit, however, one parent described feeling “it’s tough to get a lot of help from outside people because there is not much a lot of people can really do; they can’t take care of her in a physical way because her needs are very specific.” This parent felt that what they really needed for their child was a bit of distraction “so what we did to alleviate some of the stress and to maybe help her, we got a little puppy dog...and he has been an unbelievable help, not only for her but for the family.”

Most of the parents described things like having a “wonderful group of friends that would do anything for us,” and felt they realized “just how lucky we are in that respect” when illustrating how helpful their friends and family had been. Another parent described how her parents “would love to help more, but they are eighty,” but that alternately her brother had been “phenomenal with helping out.” Despite the fact that the parents all depicted family and friends that had been a great support, two of the parents spoke of how this help often “slows down” after a while. One of the mothers had a friend who worked for a group that saw many families in this similar situation and had advised the mother to take advantage of the things people offered, she stated:

My friend told me to take everything that everyone offers you now because it will slow down, not that they don’t mean it, not that they don’t care, but just that the

newness of it and life goes on, don't take it personally but it will slow down so take it all now; and so I think we have tried to do that.

Another parent described how when her child was first diagnosed the help from friends and family was “overwhelming, and I would say within two to three months, people kind of got into the norm, like we were trying to get into a norm, but it's never normal for us, but it's normalized for them.”

One of the parents had a friend who sent out emails to all of the family's friends saying, “these are the things that R and K are going to need, so this is what you need to do.” The parent found this very helpful, as it was a way for the family to get needed resources without having to directly contact all of their friends and family, which she felt was an extra stressor during an already very stressful time. This parent suggested that the one thing she would tell any parent who becomes involved in primary care-giving for a child with a chronic health condition necessitating many trips to the hospital was “get a parking pass, get a coffee card, and get yourself some good sweats,” in order to try and make yourself more comfortable in this situation.

All of the parents felt they had adequate support from friends and family, even though they often noted it slowed down as the chronic health condition continued. Health care professionals were depicted as being a good resource and very helpful, with two parents noting they were aware of the resources, but had not yet chosen to access them. Two of the families expressed an interest in being either “buddied” up with another family with a child with a chronic health condition, or finding a situation where families could spend more time together to help support each other during this stressful time. In terms of finances most of the families did not complain of a financial strain except for the

two families who described being unhappy with the expense of parking onsite at the hospital.

Comparisons and Contrasts

The experience of parents from both Sample A and B were similar in many respects with a few differences of note throughout the findings. The parents from both samples spoke extensively of the effect of the child's diagnosis on their care-giving efforts and the subsequent ability to begin to work towards accepting the child's chronic health condition. Participants from both samples described many instances of uncertainty regarding the child's future, or the parents' understanding of the condition and how to provide care. The parents in Sample A demonstrated more anger towards the diagnosis, or health condition, as well as the ability to express hope for the future, and that the condition might not be as severe, or long lasting as commonly expected. The Sample B parents spoke more about their efforts towards normalization, or feelings that normalization was not possible in their situation and two of the parents in B were quick to describe how they were aware that they were the child's advocate throughout the treatment of the chronic health conditions. Both groups of parents provided many scenarios that demonstrated their belief that their situation could be worse.

When speaking about managing their child's chronic health condition daily, parents from both Sample A and B described situations where they had dealt with health care professionals. There were considerably more descriptions of somewhat negative interactions in Sample A, whereas on the whole Sample B parents seemed quite satisfied with their dealings with health care professionals. Parents in both Samples described how

they sought and were able to obtain information about their child's chronic health condition, with Sample A often illustrating how information was not as easy to come by, depending on diagnosis, as compared to Sample B, who often described being satisfied with the amount of information and how they received it. Parents from both samples however, discussed their awareness of how or where to get information, but did not always choose to access it. A few of the parents in Sample B also provided ideas about how they were able to organize their lives while being the primary caregiver to their child with a chronic illness, with a few parents discussing financial issues, which did not come up in any of the Sample A interviews.

In relation to meeting their child's developmental needs, many of the Sample A parents spoke of their worry about being overprotective of their children, while only one parent in Sample B spoke of this issue, but decided that it was right to protect her child as much as she could, as she felt it was necessary in his situation. Some of the parents in Sample A spoke about control issues with their children, and how they liked to let them take a bit of control of their treatment whenever possible.

Parents from both Samples explained that they did not really like to press their children to talk about their condition, and provided them with information in small pieces when possible, with the exception of one parent in Sample A who felt it was important to share everything with her children. One Sample A parent also provided an example of how she felt that the doctors were often too explicit with information about the health condition in front of her child.

Parents in Sample B all spoke of how their children's schooling was often interrupted, while this was not an issue given much attention in Sample A, with only one

parent mentioning how her child had missed some days due to his chronic health condition. The parents in Sample B all shared their thoughts on their child's understanding of their potential future with their chronic condition, whereas this issue was not given much attention by the parents in Sample A.

The parents in both of the Samples described the effect of the chronic health condition on the child's sibling. In Sample A only one parent described how the sibling's chronic health condition had a negative impact on the sibling, while in Sample B all of the parents seemed to be aware of the potential for a negative effect on their well child. Both of the Samples had parents that described how their marital relationships had been affected by being the primary care givers, with the majority of the families describing how they were able to share duties. Those that shared the responsibilities described being able to deal with the stress of being in the caregiver role more effectively.

To deal with the ongoing stress and periodic crises that came up, both sets of parents in each sample described how flexibility is the key. Parents in Sample A often described situations where they felt they were lacking flexibility, while parents in Sample B described having to retain one's flexibility to survive. Two of the parents in Sample A provided examples where they felt they were better caregivers in a crisis situation, whereas none of the parents in Sample B mentioned feeling this way. Parents from both samples provided insight into how stressful being the primary care-giver to a child with a chronic condition was, with parents from Sample B offering more insight into how they felt they were able to manage some of the stressors.

For these parents, assisting family members to manage their feelings meant they were often left trying to interpret their child's feelings. The parents in Sample A more

often described their children's emotions as complicated and something they weren't quite sure how to interpret, whereas the parents in Sample B seemed to be able to describe their children's feelings, and provided examples of how they were able to help comfort them. The parents in Sample A often spoke of how they dealt with their extended families feelings, while Sample B spoke more of the effect the chronic illness had on the siblings.

Educating others was something that both samples of parents described as being an important task. They described speaking to the child's school, with parents in Sample A going into more detail on this issue. The parents from Sample A spoke more on the topic of the importance of educating the child's friends, while the parents from Sample B spoke more about the importance of educating their friends and family.

Parents from both Samples were able to provide examples of support groups that had been attended, with more parents in Sample A describing situations where they had started then subsequently stopped attending a support group. Only one parent in Sample B regularly attended a support group, with another describing how she sent her child's sibling to a sibling support group with great success. Both Samples described situations where they had received support from health care professionals, with Sample A describing more failed attempts at support than Sample B. Both Samples had parents that mentioned getting a lot of positive support from the hospital and support staff, with two parents in Sample B describing knowing where to get support but not feeling ready to access it. Parents in both Samples described how most of their support came from family and friends, while two parents in Sample B expressed an interest in finding a way to meet

up with families with children in the same position, to help them navigate their way through daily life while providing primary care to a child with a chronic health condition.

Summary of Findings

Overall, Canam's Adaptive Tasks Framework captured all of the major themes provided in the interviews by parents from both Sample A and Sample B in this study. With the exception of two interviews, all of the parents' comments fit within the eight adaptive tasks of the framework. The majority of the themes within each adaptive task were covered with comparative depth by both Samples, with a few minor differences in the information elaborated upon by the parents.

CHAPTER FIVE: DISCUSSION OF FINDINGS

The purpose of this study was to explore the usefulness of Canam's adaptive tasks framework in assessing parental needs when managing their child's chronic health condition, and to determine in which areas the parents might need support. Looking at the data in the form of a secondary analysis, as well as analyzing a new set of interviews using the deductive process of content analysis accomplished this goal. All of the eight adaptive task categories were fulfilled in the data analysis, which demonstrates that the adaptive tasks framework has utility in capturing the needs of the parents in relation to providing primary care for a child with a chronic health condition.

This chapter will situate the study findings within the current body of knowledge about parental needs related to managing family life when providing primary care for their child with a chronic health condition. The limitations of the study will also be presented.

Accepting the Child's Condition

Of the eleven interviews, four parents from sample A spoke of feeling they had "somewhat" accepted their child's chronic health condition, whereas the other seven from both samples, expressed that acceptance of the chronic health condition was not a stage that they felt could be reached by themselves or their families.

Canam (1993) described how during the task of Acceptance parents should "assign personally significant meaning to their child's chronic illness which allows them to accept it and carry on with their normal family patterns" (p.47). Earle, Clarke, Eiser and Sheppard (2007) interviewed mothers of children with leukemia and found that their

results “suggest that leading a normal life is very important to mothers, but is not easily achieved” (p.159). This is similar to one of the parents from Sample B who vehemently denied that her family’s life could ever return to “normal” while her child was sick. This mother’s statements align with Barnett, Clements, Kaplan-Estrin and Fialka (2003) contention that the word adaptation is more appropriate to apply to parents whose children have been diagnosed with a chronic health condition than the words “resolution” or “acceptance” as “both suggest an end point, whereas adaptation assumes an ongoing process”(p.187).

The comments of some parents involved in this study fit with the chronic sorrow model, first introduced in 1962 by Olshansky to describe how parents of “mentally defective” children suffer from a pervasive psychological reaction, that was justified by the reality faced by parents who “will always be burdened by the child’s unrelenting demands and unabated dependency” (p.191). Olshansky maintained that health care professionals tended to place stress on parental acceptance of their child’s mental deficiency, which was seen as suggesting “to the parent that he is expected to perceive his child from the point of view of the professional helper” (p.191).

While Olshansky’s terminology is clearly outdated, his views may not be. Clubb (1991) described how chronic sorrow “is not a phenomenon exclusive to families of children with impaired cognition” (p.463), and suggested that the parents do not necessarily accept the child’s condition, but rather “functionally adapt” to it. Eakes (1995) defined chronic sorrow as “pervasive sadness that is permanent, periodic, and potentially progressive in nature” (p.78).

Many of the parents' descriptions of their current family status while being the primary caregiver to a child with a chronic health condition, fit with this idea of adaptation to the situation, as described in the chronic sorrow model, rather than true acceptance of the circumstances. The parents expressed feelings such as uncertainty, anger and hope, and a feeling that their life could never really be normal again.

Eakes (1995) described the emotions commonly experienced by parents who may be going through chronic sorrow to include sadness, sorrow, anger, fear, frustration, helplessness and other emotions characteristic of grief reactions. Lindgren, Burke, Hainsworth and Eakes (1992) described how the critical attributes of chronic sorrow as:

- A perception of sorrow or sadness over time in a situation that has no predictable end.
- The sadness or sorrow is cyclic or recurrent.
- The sorrow or sadness is triggered either internally or externally and brings to mind the person's losses, disappointments, or fear.
- The sadness or sorrow is progressive and can intensify even years after the initial sense of loss, disappointment or fear. (p.31)

A study by Hobdell and colleagues (2007) that explored coping and chronic sorrow in parents of children with epilepsy found that it's not the severity of the child's health condition that dictates the intensity of chronic sorrow experienced by the parent, but rather the fact that a health condition is present at all.

Throughout the interviews the themes presented as critical attributes of the chronic sorrow model were in tune with the themes that arose during the analysis of the parental interviews. Most of the parents seemed to be describing a situation where they

were in a sort of “grief cycle” where they seemed to be going through Kubler-Ross’s (1969) grief stages of denial and isolation, anger, bargaining, depression and not quite seeming to reach the final stage of acceptance, but perhaps cycling through these stages continually as in Olshansky’s (1969) chronic sorrow model, rather than at a stage where they express that they had truly accepted their child’s diagnosis of a chronic condition and were able to carry on in a “normal family pattern” (Canam, 1993, p. 47).

George, Vickers, Wilkes and Barton (2007) concur with this idea of a grief cycle and describe some of the many possible triggers for parents of children with a chronic health condition to have feelings of chronic grief re-emerge in their life, such as “unending care giving responsibilities; the unpredictable nature of the child’s illness; the potential for complications; and uncertainty about the child’s future” (p. 230). The mother from Sample A who spoke of how her life with a child with a chronic health condition was “upsetting, you cannot live just quite a normal life because of this”, or the parent in sample B who described life “past the shock of diagnosis you try and figure out how to live life around it...it’s interesting, it is stressful all of it, it never goes away”, reflect that the chronic grief, or sorrow, of being the caregiver to a child with a chronic health condition may never really end for these parents.

Managing the Child’s Condition on a Daily Basis

The parents described how the first hurdle for them was to learn how to deal with all of the health care professionals that were necessary for their child’s care post diagnosis of a chronic health condition. The importance of parents learning how to collaborate with health care professionals who provide care for their child is reflected in

the literature by Balling and McCubbin (2001), Canam (1993), Clarke- Steffen (1997), Evans (1994), Graves and Hayes (1996), Green and Murton (1996), James et al. (2002), Looman (2004), Stewart, Ritchie, McGrath, Thompson and Bruce (1996), Sloper (1996), Svavarsdottir and McCubbin (1996), Ward-Smith, Kirk, Hetherington and Hubble (2005), Young, McMenamy and Perrin (2001). All of these authors emphasize that parents' interactions with health care professionals, and the amount of information and support they were able to obtain from these interactions, have an impact on their ability to provide primary care to their child with a chronic health condition. All of the parents in this study said they eventually found ways to deal with the health care professional's sudden involvement in their daily lives that came with the diagnosis of the child's chronic health condition.

Three of the mothers spoke of their need to have a caring, patient health care professional who would be a good communicator and spend the needed time with them in order to help them understand their child's condition and how to provide care to their child who had a chronic health condition. This was a similar finding to Green and Murton's (1996) retrospective quantitative/ qualitative study using questionnaire data obtained from parents of children with Duchenne muscular dystrophy, who found that what parents in their study most required from health care professionals was "empathy and sensitivity to parents informational and emotional needs" (p. 127). Similarly, Sloper (1996) found that what parents whose children had recently been diagnosed with cancer wanted most was "clear and comprehensive information about the disease and treatment [to] help parents to make sense of their situation and to make appropriate plans" (p. 199).

Some of the parents spoke of how they had gained a certain level of expertise in caring for their child with a chronic health condition and felt that it was valued by the health care professionals they dealt with regularly. One mother felt that she could basically do all of the doctoring and nursing of her two chronically ill children at home and described how she knew the emergency room staff at the local children's hospital reported she was competent to do so. Another parent described how she was able to gain credibility among the health care professionals who dealt with her child as she had access to good information about her child's condition. This valuing of parental knowledge and expertise about their child's condition was reflected by Balling and McCubbin (2001), who found that parents of hospitalized children living with a chronic illness also felt that their expertise was valued by some of the health care professionals they dealt with regularly, namely nurses and attending physicians. On the contrary, Ray and Ritchie (1993) found that parents who did not have their expertise in caring for their child with a chronic health condition respected by the health care professionals they dealt with, reported how they were frequently frustrated with the health care system.

One of the strategies parents used in order to meet the adaptive task of managing their child's condition on a daily basis was organization of their new life style since diagnosis of a chronic health condition in their child. This prompted many of the families to seek better ways of scheduling their lives, so that they could fit in all of the necessary tasks that became routine when providing primary care at home for their child. Consistent with this finding, Clarke-Steffen (1997) found that families reconstructed their realities and strived toward predictable routines that were reliable and comfortable for them and their families post a diagnosis of cancer in their child. Judson (2004) also

noted that a task for mothers who had a child dependent on parenteral nutrition was to find ways to organize the chaos brought to their lives by the complicated procedure of home feeding for their chronically ill child.

Once the parents were able to organize their lives adequately using computer based spreadsheets, or pre-planned “trade offs” of care with their spouse, they felt more control over their daily lives. This finding was in harmony with Clarke, Fletcher and Schneider’s (2005) qualitative study looking at the home health care work of mothers whose children had cancer. The investigators found that parenting a child with a chronic health condition such as cancer, took a lot of organization by the mother of the family. The mothers in the study stated they would organize, assess the child’s health, make arrangements for appointments and administer medications to their child on a daily basis, which was described as a full time job for the mother, with the division of labour between mother and father such as the “trade off’s” of care as described in the present study, being a necessary task to keep the families functioning.

Meeting the Child’s Developmental Needs

Many of the parents mentioned how their child’s schooling was something that often became interrupted or temporarily abandoned during treatment for a chronic health condition. Some of the parents reported worrying about pushing their child to try and study or do homework, when they were so physically sick that they couldn’t really function as they normally would. In relation to this worry that their children may fall behind, Bender (1995) studied children with asthma, and raised the question: are they educationally handicapped? The final outcome of Bender’s study was that “increased

school absence is not associated with decreased achievement among asthmatic or other chronically ill children” (p. 284). Bender found that school absence temporarily challenged the children in their achievement of new skills and knowledge, but that it did not permanently damage their overall progress through the school system. This finding may come as a relief to the parents who seemed to instinctually feel that pushing their children to achieve academically while they were experiencing treatment side effects, was not something that they were willing to do.

Many of the parents of a child with a chronic health condition expressed feeling worried that they might be too overprotective. Some parents claimed that being overprotective was their job, as their child needed protecting during this vulnerable time, while other parents claimed that they hadn’t overprotected their child. One mother felt that because her child was older when the condition was diagnosed, his personality was already formed and therefore he could basically care for himself. Another mother admitted to thoroughly overprotecting her child to the point that she had spoiled him, which she later regretted. This feeling was mirrored in a study by Johnson (2000) looking at mother’s perceptions of being the parent to a child with a chronic health condition, which found that often one regret of the mothers was that they had “babied” the child too much, or for too long. Kessner Austin (1990) concurred with this finding and described how parenting a child with a chronic health condition required specialized parental knowledge as the child is at risk for “developing poor self esteem, dependency, and behavioural problems” (p. 102). The author maintained that if parents were encouraged to do things such as fostering their child’s independence, and avoid being too

overprotective or indulgent, the child would maintain a positive outlook and develop a sense of control or competence surrounding their illness (p. 102).

The parents in the current study described the difficulties they had when their child became aware of the possibility that their future was uncertain. Two of the parents described how their children had become aware of how sick they were when one child asked if she was going to die, and another suddenly became aware that his diagnosis could be fatal, when he found out that a friend who had the same diagnosis had died. One of the parents thought that it was a “cruel” aspect of a chronic health condition that her child should have to know that there was a possibility that he may die, and another parent told his child he would never let anything happen to her, when she asked if she might die. The father’s statement to his child was contrary to what O’Halloran and Altmaier (1996) found, which was that children who had life threatening illnesses fared better when they did not have the possibility of death concealed from them, and that they should be allowed to discuss their fears surrounding their future, to help decrease their anxiety, and confusion about their diagnosis. Further, Waechter (1971) argued that anxiety in a child who had been diagnosed with a chronic illness would not be prevented by parents who used denial tactics, or that a feeling of protectiveness towards the child by the parent would not help the child cope. She suggested that the parents should be open to the concerns and questions of their child about the possibility of death, and discuss it with them to help them from feeling isolated and alienated by their parent (p. 1172).

A strategy that the parents used to attain the adaptive task of managing their child’s developmental needs was open communication and information sharing with their child. Most of the parents felt that sharing information with their children about their

chronic health condition was important, with only one mother claiming she did not share much information with her child as she felt that the condition was too depressing and scary for a young child to hear about. The parents felt that sharing the diagnosis and information about their condition with their child was an important step towards helping the child understand their health condition, but that most of the children did not seem to be too interested in the information, and often appeared “too busy being kids”. In relation to this idea about sharing the diagnosis with their child, Gallo, Angst, Knafl, Hadley and Smith (2005), found that parents of children with genetic disorders approached information sharing with their child by first assessing the child’s developmental readiness, and interest, then providing the information to their children by a process of unfolding that continued throughout their childhood (p. 273). Clarke, Davies, Jenney, Glaser and Eiser (2005) also found that children whose parents had a more open style of communication and offered their children more information about their disease may cope better because they understood what their medications were for, and felt more able to talk about their concerns with their parents and health care professionals.

An interesting approach to information sharing by the physician was proposed by Mack and Grier (2004); this approach was described as the “day one talk” (p. 564). It was illustrated as a process where on the day that the diagnosis of cancer is revealed to the family and child, the physician will include the child in the conversation where possible (after discussing the child’s inclusion with the parents beforehand). It was felt that the child could benefit from hearing the news first hand, and the parents would then be relieved of the burden of informing their child about their condition, and the health care professionals would also be assured that the child would be told. The authors

described how the unknown was more distressing to the child than anything they would learn about their condition, and their inclusion in the day one talk helped the child to know what to expect in their treatment. The authors also offered the possibility of having a separate conversation with the child to discuss diagnosis and treatment if the parents refused to have them in the room for the initial conversation (p. 564), which may appeal to the mother in the present study who felt that she would prefer her child not always be present when consulting with the doctor during her child's health visits.

Another effective strategy used by the parents was allowing the child to have some control over decision making in their treatment whenever possible. One of the mothers described how the physician had initiated giving her child some control over decision-making about her treatment, and how she felt it had given the child a more positive focus. Another parent described giving her child control over the routines of his care, such as medication administration. The idea of sharing the care with the child is similar to the findings from a qualitative study by Buford (2004) describing the transfer of the management of asthma from parents to their children. Buford found that once the mothers in the families studied were able to find ways to control their situation, they were able to begin to help their children take control over some of the management of their asthma. It was also found that in some families the mothers kept up their supervisory duties over the child's management of their asthma, while in other families they did not.

Meeting the Needs of Other Family Members

Almost all of the parents mentioned the effect the chronic health condition had on their child's sibling(s). Mostly it was to note that the siblings', who ranged in age from nine to thirteen-years-old, with a mean age of eleven, suffered from jealousy, the physical symptoms of stress, or felt that they received less attention than their sibling with a chronic health condition. Woodgate (2006) undertook a longitudinal qualitative study using the philosophy of interpretive interactionism, which found that siblings (who ranged in age from six to twenty-one-years of age with a mean age of twelve) in their study also felt this way, as they often experienced a loss of self within the family after their sibling was diagnosed with cancer. The reason these children suffered this loss of self was due to the fact that they felt less cared for by their family. These children also reported feeling jealousy, worry and anger, which the researcher summed up as a "sense of sadness about the whole experience" (p. 410).

Other parents in the current study noted how the well sibling (who ranged in age from nine to thirteen, with a mean age of eleven) was often very protective, and behaved compassionately towards their sibling, and felt that the well child was tremendously understanding of their siblings needs. This is supported by Sargent, et al. (1995) who found that siblings of children with cancer (who ranged in age from five to eighteen years with a mean age of ten) reported feeling more compassionate and caring towards their sibling with cancer,

Parents used different strategies to help their well children cope with having a brother or sister with a chronic condition. One parent chose to let the thirteen-year-old

sibling “wall herself off” from the disease, and just get on with her life as normal.

Woodgate (2006) determined that the siblings studied also perceived that they were minimally involved in their sibling’s illness or care, and that this caused them to experience “increased stress and helplessness with respect to their sibling’s symptoms” (p. 417). This was described as “troubling” by the researcher as it was also found that their lack of involvement in their sibling’s cancer experience was a contributing factor to their diminished sense of family and self, which was determined to have a potential long term impact on their social development (p. 417).

One of the mothers from the current study took a proactive approach to helping the sibling cope and described how she involved her well child in a sibling coping group based out of the hospital where her child was treated. She found that it had been very helpful for the ten-year-old sibling in working through his feelings related to having a brother with a chronic health condition. Barrera, Chung and Fleming (2004) evaluated a group intervention program designed to “reduce emotional and behavioural problems in siblings of children with cancer” (p. 21), and found that the group intervention contributed to an improvement of the families’ overall quality of life. This was achieved by helping to reduce the burden of suffering by assisting the sibling’s (who ranged in age from six to fourteen-years-old, with a mean age of ten) to increase their understanding of the impact of cancer on their ill sibling and family. The program also assisted siblings to acquire some concrete strategies to help them cope with their situation (p. 34). In response to Woodgate’s (2006) finding that the siblings often felt a loss of self related to feeling less cared for by their family, Barrera et al found that “by enrolling the sibling in the SCT (Sibling Coping Together) group, parents demonstrated their concern for

patients' siblings and made efforts to spend special time with them" (p. 34), which may have helped the siblings to feel more included by their family.

Fraley (1990) described how "besides the physical and emotional needs of a chronically ill child, this child may be a disruptive factor to a marriage, finances may be a major concern, and social activities are often substantially curtailed in many families" (p. 270). The marital relationship was something that the parents in the current study either claimed was strengthened by the help that they got from their spouse when caring for their child, or seriously strained by the uneven distribution of tasks between the couple. A few of the mothers mentioned how this unfair distribution of tasks was often the root of their arguments, while others claimed they were able to split the work evenly with their husband. One of the mothers felt she had to "browbeat" her husband into helping out with the medication administration and felt that if she had encouraged her husband to help more in the beginning, she might not have had these troubles. Quittner, Oipari, Espelage, Carter, Eid and Eigen (1998) supported this idea with their finding that "early on, fathers should be encouraged to assume greater responsibility for daily medical routines" (p. 122), to help alleviate stress between the parental caregivers of children with chronic health conditions. The researchers felt that health care professionals may be able to ease caregiver stress by helping to set a more equitable partnership between the couple at diagnosis by including the father in the education sessions about medication administration, and medical procedures done at home with the child. They went on to note that once the division of labour is set up between parents it is very hard to adjust the roles (p.122).

Hauenstein (1990) cautions health care professionals that even though the mother is often the main representative of the child, and the parent they work with most often, efforts should be made to include the father in education and training sessions about the care of their child. The parents in the current study that were able to evenly divide the tasks seemed to feel more supported by their spouse, and even though they noted how difficult it was to be in the primary caregiver role, they described being very happy to be in a relationship with someone who was so understanding and willing to help out.

Managing Ongoing Stress and Periodic Crises

Parents often mentioned feeling that their lives had become very unpredictable since the diagnosis of a chronic condition in their child. They felt it was hard to get into a routine, as it was always being challenged by appointments, unexpected hospitalizations and changes in the child's health status. Having a flexible job was stated as something that was helpful to parents who worked while providing primary care to their child. This feeling was echoed by the parents in a study by Mellin, Neumark-Sztainer and Patterson (2004) who investigated parents of adolescents with diabetes and found that thirty seven percent of the parents in their study found it hard to be away from home, because of all the preplanning necessary just to leave the house. Thirty percent of the families described how they had become less spontaneous and had to change their daily habits since their child's diagnosis of diabetes. A further thirty percent of the sample felt that the diabetes was a constant burden and responsibility for them as the parents. However, the families in the study also described the closeness they felt since diagnosis as they felt they were

sharing something, such as going to the appointments with their child, and generally being more involved in the adolescent's life.

Trying to find ways to manage the stress that comes along with the diagnosis of a chronic health condition in their child was something that many of the parents mentioned. One mother felt it was too hard to take the prescribed breaks she knew would help to decrease her stress, while one of the fathers wondered how it was that anyone was supposed to handle as much stress as he had experienced when being told that his child could potentially die from her condition. Patistea (2004) looked at parental coping in families whose child had been diagnosed with leukemia and found that, as in the present study, parents felt that they didn't have time to take a break as they felt they had "too many care tasks and responsibilities to carry out" (p.288) and therefore didn't feel like doing things for themselves. These parents felt that above all their child needed them to be there, which left them no spare time for a personal life. This feeling that there was not much time for a personal life was reflected by quite a few parents in the present study, and mostly seemed to centre around the fact that their children's chronic conditions were often too unpredictable to let the parent relax into a known routine, and take some time for themselves.

Two of the parents mentioned how they almost felt more comfortable with their child's care when the child was in a crisis situation in the hospital. The mothers described how they watched over all of their child's care while in the hospital and felt they would go on autopilot emotionally and just do what they had to do to care for them while they were there. Balling and McCubbin (2001) mentioned this phenomenon among parents of children with chronic health conditions who were hospitalized. Two similar themes

emerged from Balling and McCubbin's study, one being "higher quality of parental care" (p. 115), where the parents watched over all of the nursing interactions with their child, as they felt they were able to do a better job themselves at home. In fact, thirty three percent of the parents felt that the quality of care they gave at home was higher than that given by medical staff in the hospital. The second theme that emerged was "busy nurses" (p. 115), where thirty-three percent of the parents in the study felt that there was "an unspoken assumption that they would be available to assist in their child's care because nurses were often too busy" (p. 115). This is similar to the parents' feelings from the present study that they gave the best possible care while they were in the hospital, and that the health care professionals were not able to do anything with their child without them first knowing about it. The two parents also mentioned how once this "high" of being in the crisis situation in the hospital was over they would inevitably fall apart once they were home with their child.

Assisting Family Members to Manage Their Feelings

The task of assisting family members with their feelings was something that the parents all mentioned as being a complicated task. Many of the parents acknowledged that their child must be feeling upset or angry on some level, but they did not disclose that they felt comfortable asking their child about their feelings. The parents often mentioned that they noticed their child exhibiting unusual behaviours around the time the child was admitted to the hospital, or went for medical checkups, but none of the parents explained that they understood what was going on at the time. Most of the parents stated that they later realized that their child was perhaps reacting to stress rather than

misbehaving. This lack of understanding of the behaviours exhibited by their children was explored by Leblanc, Goldsmith and Patel (2003) who found that “children who have chronic disease have more internalizing problems [such as anxiety and depression] than healthy children” (p. 862). They went on to describe that it is often hard to detect these problems as they often occur at a sub-clinical level, which may make them difficult for even an experienced medical practitioner to identify.

The parents explained how once they were able to identify that their child was having a hard time with treatment related feelings they would try to do what they could to provide their child with small comforts wherever they could. They spoke of allowing the child to take some control and letting them slowly develop a level of comfort with things. The parents would also try to just observe their child’s behaviour and learn to interpret and work within their child’s emotional comfort zone whenever possible.

Three of the parents interviewed mentioned how their extended families had a hard time understanding some of the limitations and differences in their family since their child had been diagnosed with a chronic health condition. This could be due to the fact that the grandparents’ had not reached the state of acceptance, such as reported in a study by Baranowski and Schilmoeller (1999) whose study of mothers’ perceptions of grandparents roles in their disabled child’s life found that even “the most helpful grandparent had difficulty initially accepting that the grandchild had a disability” (p. 441). Or it could be similar to Gardner, Scherman, Mobley, Brown and Schutter (1994) findings that even grandparents who had a special bond and positive outlook for growth in their grandchildren, sometimes felt that “the nature of their grandchild’s disability

created additional tensions and reduced their patience in interacting with the grandchild” (p. 6), as a mother in the present study had reported about her parents.

Two of the parents from the present study expressed that their own mothers felt ashamed of having a grandchild who was not genetically perfect, and felt that their mothers thought it was a “blot on the family name” to have a child with a potentially inherited chronic condition. It may be that the grandparents needed some support to help them to work through their feelings about their grandchild’s chronic health condition, or perhaps did not have access to information that would help them to better understand their grandchild’s condition (Pit-ten Cate, Hastings, Johnson & Titus, 2005). This finding was also revealed in a study by Hodgkinson and Lester (2002) who found that mothers of children with cystic fibrosis felt that the grandparents would often withhold support from the parents due to fear of the needs of the affected child, and guilt over the fact that they may have had a hand in passing on the genetics of the condition. The mothers in the study often felt they were in the middle “between information needs of different generations” (p. 379) of themselves and the grandparents.

Mirfin-Veitch, Bray and Watson (1997) studied intergenerational relationships in families and found that the level of support that parents who had a child with a disability felt they received from the grandparents had a lot to do with their “relationship history” (p. 308). It was found that parents and grandparents who had always shared a close bond would continue their close relationship post diagnosis of a chronic health condition in their grandchild, and for families that were not as close, the disability did not seem to change the nature of the unclosed relationship, but that the disability would “have an impact on the level of support required by parents, and they often felt let down by the

lack of grandparent support” (p. 309). As described by some of the parents in the present study, this increased need of support post diagnosis of a chronic health condition in their child, may have been what led them to examine their current relationship with the grandparents and find it lacking. As the researchers described however, their relationship with the grandparents may never have changed, but due to their increased needs, they noticed this lack of support more, causing their feelings of unhappiness within the relationship.

Educating Others About the Child’s Condition

Many of the parents spoke about the need to educate the teachers at their child’s school about the chronic health condition. One of the parents found that the educators were very receptive and understanding about her child’s condition, while others were frustrated with a school system that didn’t really understand their child’s needs. Kliebenstein and Broome (2000) looked at school re-entry for children with chronic illnesses and found that overall the parents felt that the school should be notified as soon as a diagnosis was made in their child, and that the parents should be the ones to instruct the teachers about any care their child would need while at school. It was felt by the parents in the study that the younger children were not interested in teaching the teachers about their chronic condition, but adolescents would often do a class presentation on their condition as a way of telling their classmates (p. 6).

As in the present study, the parents often felt frustrated that the teachers seemed unaware of the needs of their child with a chronic health condition. The researchers attributed this to poor and sporadic communication with both the parents and health care

professionals, and parents who “deliberately kept the school uninformed” (Kliebenstein & Broome, 2000, p. 6). Parents in the present study who felt that open communication with the school system was a very important way to get their child’s needs known mirrored this idea. Most of the parents described situations where they went into the school themselves and took on the role of educator about their child’s chronic condition to their child’s teachers and classmates. The parents felt that this was the best way to educate the school system about their child’s needs. Interestingly, Good Andrews (1991) studied parents opinions about who should inform the schools on their child’s chronic condition and found that while all of the parents felt they should be the primary informers, the majority of the parents also felt that it was important to them that the physician who oversaw their child’s care should also become more involved in communications with the school about their child. None of the parents from the present study mentioned that increased physician communication with the school was something that they sought, although it may have been something that would have helped their frustration with the teacher’s lack of knowledge about their child’s chronic health condition.

McCarthy, Williams and Eidahl (1996) studied educators’ experiences with children with chronic conditions in their schools, and found that overall “the major resource for the teachers in the school setting was the school nurse” (p. 277), although many of the educators expressed that a school nurse was not always available. It was found that the school nurses were often depended on for emergency situations that may arise with this population of children, as well as being a resource for teaching classes about the specific health conditions, and being available to “communicate with families

for the teachers” (p. 277). The educators described preferring the school nurse to provide any educational interventions, as opposed to a specialty nurse who may have more information about the chronic health conditions present in the school, as they felt that the school nurse was more familiar to the students, and therefore would be a better resource for them. The authors suggested however that the nurses from the specialty clinics that care for children with the specific chronic health condition would have a valuable role in keeping both teachers and the school nurses informed about any planned absences and the effects of treatment regimes on the specific child, and would be able to “collaborate with school personnel to support the child’s need to stay in the classroom,” (p. 278) whenever possible.

The educators in the above study suggested that it would be important to have a pamphlet specific to the needs of the child with a chronic health condition created by the specialty nurse that they could consult if they had a child with a chronic health condition in their classroom that year. The presence of a school nurse or a nurse liaison from a specialty clinic that would be able to communicate between both the parents and the teachers is an ideal solution for the parents in the present study who were frustrated with the difficulty in keeping the educators informed about their child’s specific health needs.

Theis (1999) studied the educational implications of chronic health conditions in school children and made recommendations that school nurses along with teachers and other school personnel needed to partner with parents to identify “who will serve as the point of contact for families and providers, and coordinate efforts on behalf of a child [with a chronic health condition] within the school system” (p. 396). Olson, Seidler, Goodman, Gaelic and Nordgren (2004) suggested that as school consultants for children

with chronic health conditions in the classroom, nurses have an “important role in addressing misperceptions regarding chronic health conditions.”

Educating friends and family about their child’s chronic condition was a role that most of the parents took on themselves. Some parents waited until their friends noticed a piece of medical equipment in the house before mentioning their child’s condition, while other parents described that they had a very open communication approach, and just let people know as things happened. Mass emails seemed to be a preferred communication style for families in the present study, with parents often feeling it was easier to write down the latest information about their child’s condition once, and then let friends and family pass it on amongst themselves. Most of the parents described being amazed at how their children’s friends seemed to be very accepting of their child’s differences, and just “got on with it” and continued with life as before.

Developing and Utilizing Resources

Almost half of the parents had been involved in a formal support group at some time since their child’s diagnosis with a chronic health condition. All but one of the parents had stopped going to the support groups for various reasons, but most often because they found the support group lacking in some way. Stewart and Reutter (2001) looked at mothers of children with chronic conditions and found that even though the mothers wanted support from their peers they found it difficult to join support groups because of their busy lives, and demands of caring for their child, as well as often being too far away from the support group to travel regularly to get to it. This is similar to the feelings of the parents in the present study who felt that even if they wanted to go to an

established support group, it was often too far of a distance for them to travel on a regular basis, which often caused the facilitators to end the groups out of a perceived lack of interest from the parents. Monahan (1994) comments that in order to increase attendance at a support group meeting, location is a key factor, and a “critical decision for planning support groups” (p. 703).

One of the parents from the present study commented that she felt her support group “just wasn’t getting anywhere”. Perhaps if Monahan’s idea that a groups “composition, purpose and expected outcomes” (p. 704) had been examined before the support group had begun, some of these support groups may have met with more successful outcomes. The parents did not elaborate on what type of support group they were involved in, but according to Stewart and Reutter (2001) if a support group was run by a collaboration of both peers and professionals, the relationship between these groups led to successful outcomes for the support groups analyzed in their study.

Almost all of the parents mentioned that support from professionals was something that they relied on while providing primary care to their child with a chronic health condition. Many of the parents mentioned how the hospital itself was a great support, while others elaborated on the fact that the health care professionals they had access to were their biggest support. Many of the parents described situations where they felt supported by the health care professionals most when they were given as much information as they desired about their child and their chronic health condition. This is similar to the findings from Clarke and Fletcher (2003) who interviewed parents of children with cancer about communication issues with health care professionals, and found that one of the things the parents found important was that they be given the right

amount of information. All of the parents differed in the amount of information they wanted and how they wanted it to be relayed, but overall they were most thankful for health care professionals who were good communicators who conveyed “compassion, clarity and hope” (p. 185).

Two of the parents described how they would have found it helpful to have other parents who also have children with chronic health conditions available for support. They expressed interest in getting a system going where they could perhaps be buddied up with other families in the same situation, or at least have an informal introduction made by one of the health care professionals while they were attending a chronic health conditions clinic together. Lynam (1987) found that parents whose children had cancer “perceived themselves as a group” (p. 210) and found the other parents in the group to be most helpful when becoming familiar with hospital routines. They found that the other parents anticipated their needs better than anyone else, as they felt that the other parents already had an understanding of what they were going through. Levine (2005) found that parents of children with chronic health conditions most often wanted other parents who had been through the same things to help them out, and that they felt isolated if they didn’t know any other families “in the same boat” (p. 375).

This was also reflected in a study by Kerr, Harrison, Medves, Tranmer, and Fitch (2007) who found that mothers of children with cancer were sometimes worried that they were the only parents not able to cope with their child’s illness, and that if they had the reassurance that they were not the only ones going through this, and that there were others out there struggling as they were, they might have felt more supported. Ireys, Chernoff, Stein, DeVet and Silver (2001) looked at the outcomes of parent to parent

support groups where parents of children with chronic conditions were linked to parents of children with similar conditions who had been trained to provide “informational, affirmational and emotional support” (p.204). The researchers found that overall the parent-to-parent support groups “can decrease psychological risk” (p. 211) among the parents of children with chronic health conditions. The researchers decided to focus on parent-to-parent support situations, as they had noticed that few opportunities existed for parents to maintain contact with each other despite the fact that they reported wanting to talk to someone who was in a similar care giving situation to their own. All of these studies seem to point to the conclusion that if parents felt the support of other families who had been through the same experiences they may have felt better able to cope with being the primary caregiver to a child with a chronic health condition.

Almost all of the parents spoke of the great support they felt they had gotten from their friends and family since their child’s diagnosis with a chronic health condition. Most of the parents felt their spouse was most helpful to them, and many spoke of their parents or in-laws as good supports when needed. This was similar to Stewart, Ritchie, McGrath, Thompson and Bruce (1996) who found that mothers of children with chronic conditions in their study felt their spouses and immediate family were their front line of support when it came to help with care giving demands for their child. They also found that even though “the most crucial sources of support are intimate or close relationships” (p. 76), they can often be fraught with difficulties if the effectiveness of the support is perceived as less than expected from the primary care giving parent. A few of the parents in the present study mentioned that they had noticed that the support they had originally

been receiving from family and friends had dwindled, or was not quite at the level they would have preferred to have maintained, since their child's condition was lifelong.

Many of the parents mentioned that despite repeatedly hearing that a good way to decrease their stress was to take breaks, they often found they were not able to get adequate breaks for themselves. This was similar to findings of Neufeld, Query and Drummond (2001) who studied Canadian parents who were the primary caregivers to children with chronic health conditions that were using respite care. The researchers found that despite the fact that they were using respite care seventy seven percent of the time, parents still found they were not getting adequate breaks. None of the parents in the present study mentioned using a respite service, but a few mentioned that they were financially unable to hire trained nurses for respite in the home, and felt uncomfortable leaving their child with a regular babysitter. Mausner (1995) found that respite care had often been viewed as a "luxury rather than a necessity" (p. 97) in history and had been arranged by health care professionals only after the families of children with chronic health conditions showed "significant stress" (p. 97). Neufeld, Query and Drummond (2001) agreed with these findings and found that parents often ran into difficulties when trying to access respite, as they didn't know where to get help, felt reluctant to leave their child with strangers and felt there was a lack of quality services, and that the services were too expensive for the families.

Two of the parents mentioned that things such as parking on site at the hospital was a financial drain on them that could not be recouped through their insurance or written off on their income tax. This was similar to findings from Sloper's (1996) qualitative study that looked at parents needs and responses following a diagnosis of

cancer in their child and found that of the ninety eight families that were interviewed for the study thirty-two percent found that extra expenditures from hospital visits and stays with their child had resulted in financial problems for the family. Leonard, Johnson and Brust (1993) found that one of the financial burdens experienced by parents of a child with a chronic disability was “high out-of-pocket expenses” (p. 94), such as the pay parking at hospitals, described by the parents in the present study.

Summary

This chapter explored the findings and situated them within the current body of knowledge on parental needs related to managing family life when providing primary care for their child with a chronic health condition. The next chapter will provide a summary of the study, conclusions, and implications for nurses, as well as for future nursing research.

CHAPTER SIX: SUMMARY, CONCLUSIONS, LIMITATIONS AND IMPLICATIONS

Summary

The purpose of this qualitative research study was to evaluate the utility of Canam's Parental Adaptive Tasks Framework for assessing parental needs when providing ongoing care for their child with a chronic health condition and determining in which area the parents might need support. Secondary analysis of an existing data set and analysis of data from a new set of interviews provided data for the study. The secondary analysis was of seven interviews collected from parents of children with a chronic condition who completed a parental education program (sample A). Four interviews were conducted with parents of children who attend a specialty clinic (sample B) in a local pediatric hospital. The adaptive tasks framework was used to code thematic statements from the interviews under each of the eight parental adaptive task categories. Overall, it was found that all of the information regarding parents' descriptions of their needs fit under one of the eight adaptive task categories, with no information discovered that would merit creating new categories for the data. The parents from both sample A and B were comparable in that neither sample reported anything that would suggest a bias that the parental education sessions could have introduced, such as a change in the interpretation of their needs.

Conclusions

The findings from this study uncovered many needs related to managing family life while being in the dual role of both parent and primary caregiver to a child with a chronic health condition. The overall need for information about their child's chronic health condition was expressed by all of the parents in this study. Parents reported that they needed information about how to adapt to their new life post diagnosis of a chronic health condition in their child. They also needed information about how to organize their busy lives with all of the appointments and scheduling necessary for their child's treatment. The need for information about their child's schooling was important to the parents, as many children were not able to attend school regularly or even complete homework assignments due to treatment related side effects. Some of the parents expressed a need for information about how to deal with their feelings about overprotecting their child, and finding a way to let their children gain some control and foster independence related to their condition.

Parents articulated the need for information about how to talk to their child about his/her potentially uncertain future. They also revealed a need for information about how to understand the ways their child's behaviour had changed since the diagnosis of their condition. The parents also talked about a need for information about how to help the siblings manage. The parents from Sample B all described being aware of the negative impacts that having a sibling with a chronic health condition had on their well child, while only one parent in Sample A mentioned this fact. In the past ten years there have been more studies on the impact of chronic conditions on the siblings, as well as an

increase of awareness of this issue among health care professionals, and an increase in things such as support groups for siblings, which may have influenced the increase in awareness about this issue.

In terms of the marital relationship the parents often expressed the need for information about how to maintain an equal relationship where the tasks related to managing family life were evenly distributed among the parents. Many of the parents also mentioned a need for information related to helping their extended family to understand, and feel comfortable with their child's diagnosis of a chronic health condition. The parents from Sample A often mentioned not being able to access information as easily as the parents from Sample B. Perhaps there has been a change in the last ten years, either with the popularity of the internet for accessing information, or the amount of information being distributed by the hospital or health care professionals.

The second need most often mentioned by parents was the need for a health care professional who was kind, caring and supportive, and had sufficient amounts of time to spend with the parents to discuss their child's chronic health condition. Ideally these health care professionals would be able to acknowledge the parents' expertise related to their child's care, and allow them to share control of this care when they were hospitalized. The support of health care professionals and the general hospital system were two things that most of the parents felt they needed in order to feel comfortable with being the primary caregiver to their child. Many of the parents also expressed the need for effective and accessible support groups in the community, as well as the interest in support from other parents who had children diagnosed with similar conditions, or had been through similar treatment regimes. Respite care that was accessible and affordable

was another need that parents quite frequently alluded to. A few of the parents mentioned the need for financial compensation due to high “out of pocket” expenses incurred while visiting the hospital that were not reimbursable.

Overall the needs the parents expressed were similar, no matter what the child’s chronic health condition, or whether they had undergone an education program in the past (such as the parents in Sample A). Canam’s Parental Adaptive Tasks Framework captured all of the parental needs from the interview data, and was an effective tool to highlight the needs the parents expressed. This framework would be a useful tool for nurses working with families who have children with a chronic health condition in either an inpatient or outpatient clinic setting.

Limitations

The most significant limitations of this study are the age of the data on which the secondary analysis was conducted the small sample size, and the homogeneity of the sample. The data on which the secondary analysis was conducted came from a study that was completed ten years ago, therefore a shift in health care or the social realm of parental primary caregivers since that time could limit the usefulness of the findings for parents who are currently providing primary care for a child with a chronic health condition. The small sample size may also limit the ability to extrapolate the findings to the larger population of parents in this position, which may in turn limit the extent to which the findings support the utility of the adaptive tasks framework. The parents for the current interviews were interviewed in a room on the hospital site where their children were receiving treatment, by an interviewer who was a health care professional

that was familiar to them. This may have had some impact on their descriptions of feelings of satisfaction with the health care professionals they were in regular contact with.

As one of the criteria for participation in the original study was a good command of written and spoken English, and for the current interviews a good command of spoken English, this sample is not representative of the broad cultural background of the population in which the sample is located. Also, of the eleven parents in this sample only one was a father of a child with a chronic health condition, thus the findings may not be representative of the greater population of both mothers and fathers who are the primary caregiver for their child with a chronic health condition.

Implications for Nursing Practice

If parents of children with a chronic health condition are in the position of learning to adapt to the child's chronic health condition, rather than fully accepting it, or cycling through recurring sorrow, it is important for nurses to be aware of these potentially ongoing unresolved feelings in the parent. While the chronic sorrow model fits with the parents' descriptions of their life since becoming the primary caregiver to their child with a chronic health condition, the name chronic sorrow implies a constant state of grief for these parents. I would like to reframe the term to incorporate the word recurring, given that what the parents described was not an ongoing constant daily battle with sorrow, but recurring depending on what was presently occurring with their child's chronic health condition. Although parents described never fully accepting their child's condition, they described their grief or sorrow as recurring, rather than being continually

present. If recurring sorrow is a normal process for parents to go through once their child is diagnosed with a chronic health condition, nurses should be prepared to let the parents periodically vent their feelings about the difficulties surrounding the role of being a primary caregiver to their child with a chronic health condition and be able to provide a non judgemental environment in which they can do so.

From the parent's point of view it is important that the nurse be caring, empathetic, patient, clear, comprehensive and sympathetic to the informational needs of the families that they care for. It is important to share information with the parents while at the same time acknowledging their expertise, as the parents often felt they were very knowledgeable about their child's chronic condition, and were able to perform most of the care of the child by themselves at home. An ability to share information regarding organizational tips that other parents in the same situation found helpful would be an asset for the nurse caring for the family of a child with a chronic health condition.

Many of the parents expressed feelings of worry that their child might not progress in school as they were not able to "force" them to do homework when they were suffering from treatment related side effects. It would be helpful for the nurse to let these parents know about some of the current research, such as the findings presented, which found that decreased attendance was not necessarily associated with decreased achievement in school by children with a chronic health condition. It would also be helpful for nurses to familiarize the parents with the in-hospital schoolteachers, who can help the children with their homework when they are admitted to hospital, to help relieve some of their worry about this issue.

Helping parents to find ways to keep their child's routine and discipline strategies consistent, post diagnosis of a chronic health condition may be of some importance to these parents. If the nurse is able to provide an open forum for the parents to discuss some of their difficulties with feelings of "over-protectiveness", and difficulties with discipline due to changes in normal routine, this would be beneficial to these parents.

The literature suggests a policy of open communication with a child who has been diagnosed with a chronic health condition, but this may not always be something that the parents choose to encourage with their child. It is important for the nurses caring for these families to recognize what type and how much information the child has been given, in order to be aware when there may be a discrepancy between what the nurse determines is the proper amount of information for the child, and what the parents wishes are. Perhaps if the nurse shared some of the ideas presented from the current literature about increased anxiety levels in children who are not told much about their condition, it would be helpful for these parents to evaluate their choices about level of information sharing. Ultimately it is valuable for the nurse to speak to the parents about how much information they would like shared with the child, and in what manner they would like it to be passed on. Some parents may wish to tell the child themselves, while others may choose to have a team approach, with the child included in the information dissemination.

Another implication for nurses suggested by the findings of this study is how important it is to be attentive to family situations where the sibling may be feeling left out. If a sibling coping program were available, it would be helpful to advertise it throughout the hospital to ensure the parents are exposed to the information. Currently at

the hospital site where this study took place there is a sibling coping group available, with both self, and health care professional referral options available.

With the understanding that the parents in this study preferred to have an equal distribution of tasks among themselves, it is important for the nursing staff to be aware of these findings and work towards educating each of the parents uniformly about all aspects of primary care for their child. Helping to make the parents aware of this finding starting from diagnosis onward may help to alleviate some of the stress this uneven distribution of tasks caused the parents in this study. Nurses can also encourage parents to share any information they may individually acquire related to the care of their child, with their spouse, early in the course of treatment, to help with this discrepancy of knowledge.

It is important for the nurses to be aware of the parental expertise in caring for their child at home, and acknowledge this parental expertise while the family is hospitalized. The principal of Family Centred Care views parents as “partners in care” (Dokken & Ahmann, 2006, p. 562). With this in mind the finding that parents felt they gave a higher quality of care to their child than the health care professionals makes it imperative that the nurses acknowledge the parents’ experience, and include them in the care of their child wherever possible within the hospital setting. One of the parents from the current study mentioned that she felt she did not get much respect for the knowledge about her child’s rare condition from the medical staff, so if the nurses are aware of these findings, they can help advocate for the parents during team meetings about the child’s care.

Parents may need to be given information about how children may react to the diagnosis of a chronic health condition. If parents are made aware of the possible behavioural characteristics they may see exhibited by their children, it might make it easier for the parents to understand how their child is feeling. In regards to the feelings of the grandparents, it is important for the health care professional to be aware of the relationships between family members at the time of diagnosis. It would be useful for the health care professionals to introduce ideas to the parents about how to help the grandparent's access information about the child's condition. The health care professionals can also encourage parents and grandparents to coordinate a level of support right from diagnosis that would be useful and acceptable to both parties, to reduce the incidence of miscommunication between family members that some of the parents in the present study described.

Helping parents find ways to communicate with their friends and family and also the educators at their child's school is an implication for health care professionals to be aware of when working with families whose children have a chronic health condition. The literature suggests that increased communication between the school and the physician is an important way for parents to cut down frustration with a lack of understanding by the school system. Equipped with this knowledge, nurses could help ensure the parents are able to access educational resources for the teachers of a child with a chronic health condition, as this literature is often available in the pediatric outpatient clinics of local hospitals. If a package is available that outlines the needs of a child with a chronic health condition while at school it would be a valuable resource for both the families and the school the child attends.

If a support group is to be well attended by the parental primary caregivers of children with chronic conditions it should be assured that it is be in a location central to all of the parents who are able to attend. Providing training to parents who are “experienced” and interested in working in a supportive role may be beneficial to those parents who are interested in maintaining contact with parents who are in the same situation as they are, and wish to be a part of an ongoing support group. The findings in the literature that a support group that consists of both peers and professionals may be more successful would seem to encourage collaboration amongst these groups. The parent from the present study who suggested that the thing she valued most was anyone who ever asked, “What can I do to help you”? would most likely say that a nurse who was able to assess the parents needs, or simply asks what the parents need, would be providing the best, most compassionate care to any parent in this position.

Implications for Nursing Research

The findings from this study indicate that there may be a lack of information available for parents who felt that they were “too overprotective” of their child with a chronic health condition, and found it hard to continue with their usual disciplining strategies post diagnosis of a chronic health condition in their child. It would be beneficial to have more information available for these parents in regards to how to maintain discipline in the stressful times post diagnosis. Many of the parents expressed needs in the area of telling their child about their diagnosis of a chronic health condition that may be life limiting. Nursing research exploring how parents discuss this issue with

their children and awareness about the child's developmental reactions to this type of information would be beneficial.

The findings of this study also point to a role for community health nurses, or nurses from the specialty clinics where the child receives treatment to act as a liaison between the school and the parents of a child with a chronic health condition. Many of the studies described the school nurse as having a valuable role in this, but since the school nurse was not always available, and may not have been an expert in the particular child's diagnosis; more research about this role for nursing is needed in this area.

Many of the parents in this study described being unhappy with the support groups they had attended, or found that they stopped attending due to the distances they had to travel, causing the group to fold due to poor attendance. With some of the findings of this study suggesting that it would be beneficial to have both peers and health care professionals involved in a leadership role in the support group, it would be beneficial for more research into the area of successful support groups, in order to continue offering this type of support to these parents in the future.

Overall Summary

The findings from this study can contribute to nursing's knowledge base in relation to assessing and supporting parents who are the primary caregivers for their child with a chronic health condition. Overall the parents in this study expressed similar needs, despite having children with differing chronic health conditions, and it was found that the Adaptive Tasks Framework was a useful tool for capturing the needs of parents and identifying areas in which they could benefit from supportive interventions.

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APPENDIX A: PARTICIPANT INFORMATION LETTER

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

Participant Information Letter

Title of Research Study: Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition

Dear Parents,

My name is Valla Sahraei and I am a student in the Master of Science in Nursing Program at the University of British Columbia. Over the past seven years I have worked as a registered nurse in the specialty of Pediatric Oncology. For my Master's thesis I am conducting a study exploring the needs of parents who are the primary caregiver for a child with a chronic health condition.

The purpose of this study is to gain an understanding of what the needs of parents are in relation to being both parent and primary caregiver to a child with a chronic health condition. You are being invited to participate in this study as it is anticipated that your experiences will assist nurses and other health professionals to better understand the needs of parents in this dual role and how to more effectively support them.

Participation in the study involves one interview of approximately one to one and a half hours in which you are asked about your experiences of managing family life and being the primary caregiver for your child with a chronic health condition. The interview will take place at British Columbia's Children's Hospital at a time prearranged to fit your schedule. In order to obtain an accurate record, the interview will be tape-recorded and transcribed.

Your participation in this study is entirely voluntary. If you agree to participate you may withdraw from the study at any time. You are also free to refuse to answer any questions that you do not wish to answer, or have the tape stopped at any time during the interview.

Non-participation or withdrawal from this study will not jeopardize your care or the care of your child with any agency or health care professional. A summary of the findings will be provided to you at the end of the project at your request.

Strict confidentiality will be maintained at all times. Your name and any identifying information will not appear on the written report of the study. All data will be securely stored in a locked filing cabinet for five years, at which time they will be destroyed. You are under no obligation to participate, but if you wish to you will be asked to sign a consent form before the interview takes place.

If you are interested in participating in the study or wish to discuss it further please put your name and contact information on the attached Assent Form and place it in the designated box and I will contact you within two weeks. You can also contact me Valla Sahraei at 604 684 8491 and leave a message if I am not in. My faculty advisor, Dr. Connie Canam 604 822 7494, is also available to answer any questions that you might have.

Thank you for your time and consideration.

Valla Sahraei RN BN

APPENDIX B: CONSENT TO CONTACT

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

Consent for Permission Allowing Study Personnel to Contact You

Title of Research Study: Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition

Introduction: You have been provided with an Information Letter and this Consent Form that explains more about the above titled project. In order for you to have time to think over whether or not you wish to participate in the study, we ask that you take the Information Letter home to read carefully. After reading the documents if you have any questions or would like to discuss what you have read with the study personnel, please call Valla at 604 684 8491.

Consent to Contact: You understand that, in signing this document, you are consenting only to being contacted by study personnel. You also understand that you are only providing contact information for yourself so that I may call you within the next week or two to answer any of your questions and find out whether or not you would like to participate in this study. If you choose not to participate in this study, this information will be destroyed.

Contact Information

Printed Name _____

Date _____

Signature _____

Address _____

Telephone Number (Daytime) _____

Telephone Number (Evening) _____

Best hours to call between _____

APPENDIX C: CONSENT FORM

THE UNIVERSITY OF BRITISH COLUMBIA



School of Nursing
T201- 2211 Wesbrook Mall
Vancouver, B.C. Canada
V6T 2B5

Tel: (604) 822-7417
Fax: (604) 822-7466

Participant Consent Form

Title of Research Study: Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition

Principal Investigator: Connie Canam RN PhD
Assistant Professor
UBC School of Nursing
Telephone: 604 822 7494

Co-Investigator: Valla Sahraei RN BN
Graduate Student
UBC School of Nursing
Telephone: 604 684 8491

Purpose: The purpose of this study is to gain an understanding of what the needs of parents are in relation to being both parent and primary caregiver to a child with a chronic health condition. It is anticipated that your experiences will assist nurses and other health professionals to understand the needs of parents in this dual role and how to more effectively support them.

Study Procedures: Participation in the study involves one interview of approximately one to one and a half hours in which you are asked about your experiences of managing family life and being the primary caregiver for your child with a chronic health condition. The interview will take place at British Columbia's Children's Hospital at a time prearranged to fit your schedule. In order to obtain an accurate record, the interview will be tape-recorded and transcribed.

Strict confidentiality will be maintained at all times. Your name and any identifying information will not appear on the written report of the study. All data will be securely stored in a locked filing cabinet for five years, at which time it will be destroyed.

The overall findings of the study may be published or presented at conferences to share the new knowledge and understanding with other health care professionals. A summary of the findings will be provided to you at the end of the project at your request.

Participant Consent: Your participation in this study is entirely voluntary. If you agree to participate you may withdraw from the study at any time. You are also free to refuse to answer any questions that you do not wish to answer, or have the tape stopped at any time during the interview. Non-participation or withdrawal from this study will not jeopardize your care or the care of your child with any agency or health care professional.

You understand your rights when participating in this study and that you may contact Valla Sahraei or Connie Canam at the above phone numbers if you have any questions. You understand that you may contact the University of British Columbia Research Services at the University of British Columbia (phone 604 822 8598) if you have any concerns about your rights as a research participant. You have received a copy of the participants' information letter and the consent form. Your signature below indicates that you consent to participate in this study.

Name of Participant (Please Print) _____

Signature of Participant: _____

Date: _____

APPENDIX D: INTERVIEW GUIDE

Title of Research Study: Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition

The following questions are sample questions only. Not all questions will necessarily be asked during the interview. Probing questions may be used to elicit more detailed information, and for clarification where necessary.

Preface: Introduce self; explain the purpose of the interviews and the study; have the participant sign the consent form and ask if they have any further questions about it; give the participant a copy of the consent form. Explain that interview is being audio taped and how they may choose not to answer certain questions or stop the interview or audiotape at any time. Explain that there are no right or wrong answers and that all comments, both positive and negative are welcome.

Preamble: For my Master's thesis I am conducting a study exploring the needs of parents who are the primary caregiver to a child with a chronic health condition. The purpose of this study is to gain an understanding of what the needs of parents who are caring for a child with a chronic health condition on a daily basis might be. Sharing your description of your experiences and needs related to managing family life may help nurses and other health professionals to develop and/or improve health care interventions that will assist other families in managing their child's chronic condition. With that in mind I would like to ask you some questions to explore your ideas about being the primary caregiver to your child with a chronic health condition.

1. What is your child's diagnosis?
2. How long ago was your child diagnosed with this condition?
3. What has it been like for you in terms of managing family life and being the primary caregiver for your child with a chronic condition?
4. Have there been particular issues that have been difficult to deal with?
5. What has been most helpful for you in managing family life and being the primary caregiver for your child with a chronic condition?
6. What would have been helpful?
7. What has it been like for you to interact with health care professionals when seeking care for your child's condition?

8. Have you met any other families who are caring for a child with a chronic health condition, and if so has it been helpful to you?

APPENDIX E: UBC APPROVAL FORM

Page 1 of 1



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - MINIMAL RISK

PRINCIPAL INVESTIGATOR: Connie Canam	INSTITUTION / DEPARTMENT: UBC/Applied Science/Nursing	UBC BREB NUMBER: H07-01679
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution Children's and Women's Health Centre of BC (incl. Sunny Hill) Other locations where the research will be conducted: N/A	Site Children's and Women's Health Centre of BC (incl. Sunny Hill)	
CO-INVESTIGATOR(S): Valla Sahraei		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition		

CERTIFICATE EXPIRY DATE: November 23, 2008

DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: November 23, 2007	
Document Name	Version	Date	
Protocol:			
Thesis Proposal	N/A	September 11, 2007	
Consent Forms:			
Consent to Contact	N/A	September 11, 2007	
Consent	N/A	November 22, 2007	
Questionnaire, Questionnaire Cover Letter, Tests:			
Interview Guide	N/A	September 11, 2007	
Letter of Initial Contact:			
Information Letter	N/A	November 22, 2007	
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.			
Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:			
<div style="text-align: center;"> Dr. M. Judith Lynam, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair </div>			

APPENDIX F: BCCH APPROVAL FORM



**CHILDREN'S & WOMEN'S HEALTH
CENTRE OF BRITISH COLUMBIA**

Research Review Committee

Room 202, 950 West 28th Avenue
Vancouver, BC V5Z 4H4
Phone: 604-875-3103
Fax: 604-875-2496

Nov 27 2007

Certificate of Approval

PRINCIPAL INVESTIGATOR Strahlendorf, Caron	DEPARTMENT Pediatrics	NUMBER CW07-0209 / H07-01679
CO-INVESTIGATORS: Sahraei, Valla;		
C&W DEPARTMENTS, PATIENT BASED PROGRAMS AND ADMINISTRATIVE JURISDICTIONS IMPACTED BY THIS STUDY: Oncology/Hematology/BMT; Medical Specialties and General Pediatrics;		
SPONSORING AGENCIES:		
TITLE Evaluating the Utility of the Adaptive Tasks Framework for Assessing Parental Needs when Providing Primary Care for their Child with a Chronic Health Condition		
APPROVAL DATE: Nov 27 2007		TERMS OF APPROVAL: Nov 27 2007 -Nov 22 2008
<p>CERTIFICATION:</p> <p>The protocol for the above-named project has been reviewed by the Research Review Committee and has been found to be appropriate with respect to ethics, methodology, patient impact and availability of C&W resources</p> <p style="text-align: center;">_____ <i>Approval of the C&W Research Review Committee</i> Dr. M. Levine, Chair Dr. M. Bond, Associate Chair</p> <p>This Certificate of Approval is valid for the above term provided there is no change in the research protocol</p>		