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Carolyn Miguelle Ouellet
Wilfrid Laurier University

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MOTHERS' EXPERIENCES OF THE CARE PROVIDED TO THEIR CHILD WITH A LIFE-LIMITING ILLNESS

BY

Carolyn Miguelle Ouellet

Honours Bachelor of Arts, University of Ottawa, 2003
Bachelor of Education, Lakehead University, 2006

THESIS
Submitted to the Faculty of Social Work
in partial fulfillment of the requirements for the Master of Social Work degree
Wilfrid Laurier University

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ABSTRACT

The purpose of this study was to examine mothers’ experiences of the care provided to their child with a life-limiting illness. This study explored mothers’ experiences in finding, accessing, and providing care for their children and their perceptions of gaps, barriers, and strengths in care for their children. As a secondary focus, this study looked at how these mothers understand pediatric palliative care. A qualitative descriptive design was used to explore the experiences of six mothers caring for children with life-limiting illnesses in urban areas of Ontario and Quebec. Mothers shared their experiences through in-person interviews.

Findings revealed that the experience of caring for a child with a life-limiting illness was overwhelming in nature for mothers in terms of finding, accessing, and providing care. Mothers expressed the overwhelming nature of the experience around three themes: (1) realizing the strengths and barriers of the health care system, (2) long-term caregiving and coping, and (3) advocacy. Experiencing the gaps and barriers and having to advocate for their own children led mothers to want to make change and give back so that other families would not have to face the same gaps and barriers as they had. Findings also revealed that mothers had diverse understandings of pediatric palliative care that had developed through their understanding of their own child’s illness and lifespan; adult palliative care; professionals’ communication about pediatric palliative care; and other experiences with pediatric palliative care, such as interacting with other families with a child with a life-limiting illnesses. Recommendations for change are made and areas for future research are identified.
ACKNOWLEDGEMENTS

I would first of all like to thank all of the mothers who participated in the study for allowing me into their lives for a brief time and for the candour with which they shared their stories. It was an honour to meet you and your children.

I would also like to thank my thesis advisor Dr. Susan Cadell for her encouragement, support and guidance throughout the research process, and my committee members Dr. Cheryl-Anne Cait, Dr. Nancy Freymond, and Dr. Juanne Clarke for their feedback and support.

Finally, I would like to thank my family and friends who supported me in my journey through the research process.
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CHAPTER 1: INTRODUCTION

Children with life-limiting illnesses deserve the best care possible. Care for these children involves both life-sustaining care and pediatric palliative care depending on how pediatric palliative care is understood and implemented. It is not clear how well the health care system is meeting the needs of these children in terms of the care provided. Mothers who are caring for a child with a life-limiting illness are in a unique position to assess how care, including pediatric palliative care, is meeting their child’s needs. Moreover, mothers are often themselves key providers of care to their child with a life-limiting illness. Because of their direct and intimate experience in finding, accessing and providing care for their children, it is critical that mothers’ perspectives be examined in order to better understand both what is working and what is not in terms of care for their children. As a result, this study aims to explore mothers’ experiences of the care provided to their child with a life-limiting illness in order to identify areas for improvement in care provided to these children. As well, because of the potential for these children to receive pediatric palliative care and the potential impact of mothers’ understandings on the type of care they access, this study also aims to explore mothers’ understandings of pediatric palliative care.

Mothers

Mothers were chosen to be the focus of this study for a number of reasons. Mothers of children with life-limiting illnesses play an important and active role in the care that their children receive. They deal first-hand with the health care professionals (i.e. doctors, nurses, social workers) who are involved with providing information regarding care, including pediatric palliative care, and who recommend and administer such services. As well, mothers often play a significant role in providing care to their children who are ill. As a result,
mothers are keenly aware of the needs of their children and have a unique understanding of the services their children are receiving. While fathers are clearly an important part of these children's lives and sometimes take on a caregiving role, literature shows that women continue to be the parent who primarily take on the role of caregiver when a child or adult has a life-limiting illness (Sawatzky & Fowler-Kerry, 2003).

Definitions of Terms

Before entering an exploration of mothers' experiences, it is important to delineate a number of terms. *Life-limiting illness* refers to a disease that is severe, progressive, and life-threatening, in which it is expected that the child with the illness is “not expected to live into full adulthood” (Cadell, Research Proposal, p.12d). For example, cancer, HIV/AIDS and muscular dystrophy are all considered life-limiting illnesses. For the purposes of this study, *care* is used to describe any care received by the child with the life-limiting illness, including life-sustaining care and pediatric palliative care. Throughout this study, the terms *health care providers* and *professionals* will be used interchangeably to represent all formal (paid) workers involved with the child’s care, including social workers, personal support workers, educational assistants, nurses, and physicians.

*Pediatric palliative care* is also a focus in the current study. A number of terms are often used to describe aspects of this type of care: end-of-life, terminal care, and hospice. These terms are intertwined, but are separate concepts (Benini, Spizzichino, Trapanotto, & Ferrante, 2008, & Nuss, Hinds & LaFond, 2005).

*Pediatric palliative care* is a multidisciplinary approach to caring for a child with a life-limiting illness that involves improving quality of life by “allieviat[ing] [the] child’s physical, psychological, and social distress” through “the active total care of [that] child’s
body, mind and spirit,” as well as the provision of support to the child’s family (WHO, 1998, WHO Definition of Palliative Care for Children). Children with life-limiting illnesses require pediatric palliative care during the course of their illness – in fact, the World Health Organization (2007) indicates that palliative care should start when the child receives the diagnosis of a life-limiting illness. While Nuss et al. (2005) indicate that pediatric palliative care continues until either cure or death, there is growing recognition that pediatric palliative care should continue even after the child’s death, through continued support to the child’s family (Clarke & Quin, 2007; Heller & Solomon, 2005). This type of care can be delivered through a variety of care providers, such as hospitals, home care services, hospices, and community agencies and resources, and should be provided whether or not the child is also receiving treatment for the illness (WHO, 1998). In fact, palliative care does not require that curative treatment is exhausted or stopped before it is implemented; palliative care can and should be provided in concert with curative therapies in order to improve the quality of life of the children and families throughout the child’s illness (American Academy of Pediatrics, 2000; Liben, 2000; Sourkes et al., 2005; WHO, 1998).

Steele, Derman, Cadell, Davies, Siden, Straatman (2008) outline the distinctions between the terms *palliative care* and *hospice* and identify that “palliative care refers to the philosophy behind the care and the whole range of services offered, while hospice means a specific structure where children and their families receive care and a wide range of services including not only end-of-life care, but also respite and bereavement services” (p.5). Pediatric palliative care also differs from *end-of-life* or *terminal care* in that *end of life* or *terminal care* involves care that is provided “during a time closely related to [the child’s] death (within weeks, days, or hours)” (Benini et al., 2008). In other words, “care is focused
on preparing for an anticipated death” and involves symptom management and provision of support to the child and family (Nuss et al., 2005, p.126). End-of-life or terminal care is but one element of pediatric palliative care (Benini, et al., 2008; Nuss et al., 2005).

The Researcher’s Social Location

It is also important before going any further, to disclose my social location. I am a relatively young, middle class, Caucasian female from an English-speaking and French-speaking family with extended family in both Ontario and Quebec. The area of research of life-limiting illness and pediatric palliative care may not seem an evident choice for research for me, at least on the face of it: I am single with no children and am an outsider to the experience of both caring for a child with a life-limiting illness and pediatric palliative care. Coming to the decision to do research in this area, however, was influenced in part by my recent experiences in assisting with research related to parents caring for children with life-limiting illnesses. I was struck by the need for such research, particularly in exploring the experiences of parents themselves. As well, while I do not have children of my own, I have an extensive background in working with children and families as an educator, a social work student in placement, and as a volunteer. Through these experiences, I have developed a strong commitment to the health and well-being of children and their families. In conducting this research in this area, I am hopeful that the findings will help support the health and well-being of the children and families affected by life-limiting illnesses. While being an outsider to the experience may have some limitations, it can also be a benefit in terms of allowing a different viewpoint to emerge and in having an open mind with fewer preconceived notions.
CHAPTER 2: LITERATURE REVIEW

Life-Limiting Illness and the Family

Existing studies have looked at the effects of having a child with a life-limiting illness on individuals within the family system, such as siblings, mothers, fathers, and parents as a couple (Bonner, Hardy, Willard & Hutchinson, 2007; Jones & Neil-Urban, 2003; Katz, 2002; Monterosso, Kristjanson, Aoun, & Phillips, 2007). Caring for a child with a life-limiting illness has been shown to have an impact on parents’ health (Monterosso et al., 2007), psychological well being (Bonner et al., 2007; Monterosso et al., 2007; Patiño-Fernández et al., 2008), financial status (Monterosso et al., 2007), and relationships within the family (Jones & Neil-Urban, 2003). Some studies looking at parents caring for children with severe disabilities have focused on the impacts of caregiving on parents as well, such as Murphy, Christian, Caplin, & Young (2006) who identified negative impacts on these caregivers’ physical, functional and emotional well-being. Some studies have focused on identifying parenting roles (Young, Dixon-Woods, Findlay, & Heney, 2002), coping strategies used by parents (Raingruber & Milstein, 2007; Steele, 2005), spirituality and meaning-making (Steele, 2005; Davies, Brenner, Orloff, Sumner, & Worden, 2002; Raingruber & Milstein, 2007), and parenting skills (Rempel & Harrison, 2007).

Children with Life-Limiting Illnesses and Pediatric Palliative Care

Pediatric palliative care is care that children with life-limiting illnesses may receive during their illness, depending on the approach to pediatric palliative care taken by the health care agencies and the professionals involved in the care of the child. Researchers note that the field of pediatric palliative care is one that is growing and is in increasing demand (Benini, Spizzichino, Trapanotto & Ferrante, 2008; Steele, 2002). There has been growing
recognition that adult palliative care does not adequately meet the special needs of children with life-limiting illnesses and their families (American Academy of Pediatrics, 2000; Liben, 2000; Sourkes et al., 2005; WHO, 1998): Children are diagnosed with different illnesses than adults; they are still undergoing developmental changes, which affect their needs; their illness and care directly impacts on their families; their illnesses are often prolonged; and their illness are often rare and require multidisciplinary care (Goldman, 2001; Sourkes et al., 2005). In addition to the increased understanding of the need for pediatric palliative care, the need for these services is rising. Families want and need access to different types of pediatric palliative care – such as care provided through hospitals, hospices, and the home (WHO, 1998; Liben, 2000). As well, some researchers have indicated that demand is likely to grow due to “the rising incidence of life-threatening diseases and the reduction in mortality rates, caused by advances in technology and medicine” (Steele, 2002, p.418). Benini et al. state that the “international literature indicates a prevalence of incurable disease annually affecting 10/10,000 young people from 0 to 19 years old...” (Abstract). Some researchers have identified that many of the children and families who could benefit from pediatric palliative care are not able to due to under-referral to these services (Widger et al., 2007) and a lack of access to services in their geographical location (Widger et al., 2007). Widger et al. found that in 2002, just 5-12% of Canadian children between the ages of 0 and 19 years who could have benefitted from palliative care actually received services from one of the eight pediatric palliative care programs in the country.

The Role of Social Workers

Care for children with life-limiting illnesses and their families is relevant to social work because social workers have an integral role in working with these children and their
families throughout the illness trajectory, including at end-of-life and during bereavement (Jones, 2006; Sourkes et al., 2005). Social workers are involved in providing care to children with life-limiting illnesses and their families in a variety of settings, including hospitals, hospices, home care programs, community care access centres, and private counselling agencies. They may provide care as part of a pediatric palliative care team or as one aspect of their case load. Pediatric palliative care, which can be a significant part of the care received by a child with a life-limiting illness, does not solely fall within the scope of medical professionals: it is a multidisciplinary and interdisciplinary (World Health Organization, 1998; Craig & Goldman, 2003; Sourkes et al., 2005; Benini, Spizzichino, Trapanotto, & Ferrante, 2008) and, ideally, interprofessional (Rushton, 2005) field of practice. While social workers are a key component in provision of care, including palliative care, for a child with a life-limiting illness, few studies have looked at this issue from a social work perspective. Sourkes et al. (2005) highlighted some of the key roles that social workers play in pediatric palliative care in terms of supporting children and families through practical support, assessment, psychosocial support, counselling, education, and advocacy. Jones (2006) outlined a number of roles social workers should play in pediatric palliative care in terms of assisting with pain control, helping families navigate the health care system, providing counselling and support to children and families during the illness and after the child’s death, providing companionship and bearing witness to the families’ experience, providing information, advocating for families, and providing practical support. In carrying out an exploratory study looking at social workers’ perspectives of the end-of-life needs of children with cancer and their families, Jones (2006) found that social workers identified that children “need to be free of pain, cared for, and supported in their individual experiences at the end of...
life" and that "children and families need companionship, control, and compassion" (p.786). This researcher also identified the need for research on pediatric palliative care beyond a focus on cancer and end of life, as well as for more research from the perspective of parents or children.

While few studies have been carried out from a social work perspective in relation to the care provided to a child with a life-limiting illness, social workers need continued research to assist them in their roles as care providers in understanding the issues facing families caring for a child with a life-limiting illness, and in providing, and advocating for, the best care possible for these families.

The Role of Health Care Professionals in Providing Care and Areas for Improvement: Parents’ Perspectives

In concert with mothers and other family caregivers, health care workers and social work professionals are an integral part of care for children with life-limiting illnesses. Their approaches to care and how they overcome the challenges they face in providing care can affect the experiences that families have in caring for a child with a life-limiting illness and the quality of care received by their children. As indicated above, mothers are in a unique position to assess the care that is provided to their children by health care providers.

The experiences of parents in providing care to a child with a life-limiting illness is an area that is still emerging in the research and in which there are still many gaps in our understanding in terms of the issues they and their children face. This is likely as a result of the historical bias that has tended toward privileging ‘expert’ or ‘professional’ knowledge and dismissing and marginalizing ‘non-expert’ or ‘patient’/‘client’ knowledge. Recent research has begun looking at parents’ perceptions of professionals and how these
professionals' provision of care impacts on the experiences of parents and families (Contro, Larson, Scofield, Sourkes & Cohen, 2002; Davies, Davies, & Sibert, 2003; Heller & Solomon, 2005; Hsiao, Evan, & Zeltzer, 2007; Meyer et al., 2006; Raingruber & Milstein, 2007). Davies et al. (2003) looked at parents' perceptions of sensitive versus insensitive care with respect to pediatricians' care up to, and including, the actual diagnosis of their child's illness in the United Kingdom. This qualitative study found that parents identified sensitive pediatricians as those who tried to understand families' perspectives, embraced the humanistic perspective, and had the ability to combine both technical skill (e.g. expertise) and compassion (e.g. understanding). The study revealed that insensitive pediatricians were those who lacked these characteristics and that insensitive care in some cases led to the potential of negative consequences in terms of the child's care. Davies et al.'s research, however, only examines care up to the diagnosis of the illness and does not explore sensitive care after diagnosis.

Contro, Larson, Scofield, Sourkes & Cohen (2002) carried out an exploratory study in the United States examining bereaved parents' experiences with pediatric end-of-life care. It was found that involving families in the decision-making process, having support systems and services in place for siblings, having a familiar professional deliver upsetting information in an honest and straightforward way, ensuring adequate management of the child's pain, and ensuring contact with the family after the child's death were important to bereaved parents who had accessed pediatric palliative care at a hospital. As well, distressing events, such as a disrespectful comment said by a professional or a medical error, even if they occurred only once, were reported to be remembered by parents and resulted in emotional pain long into the future.
Other studies have examined what parents feel is important in terms of communication between health care providers and families with respect to pediatric palliative or end-of-life care (Heller & Solomon, 2005; Hsiao, Even, & Zeltzer, 2007; Meyer et al. 2006). Hsiao, Evan, & Zeltzer (2007) conducted a study identifying what both parents and their children identified as helpful or hindering elements of physician communication in pediatric palliative care. They found that relationship building, sharing of information, exhibiting effort and confidence, being available, involving the parent and child, and coordinating care were significant themes identified by parents and children in terms of physician communication and quality of care. Hsiao, Evan, & Zeltzer also found that these aspects of helpful physician communication applied to other health care providers. Hindering elements included disrespect, arrogance, lack of relationship building, insensitivity, withholding information, and not informing or preparing families for changes in treatment, impaired communication and quality of care (Hsiao et al. 2007). These researchers did not examine other barriers besides communication in pediatric palliative care and they excluded families in which the child had a life-limiting illness with a prognosis of longer than three years, which excluded those families’ equally valid experiences and perspectives.

Other Quality of Care Issues

Current research has also explored other issues regarding quality of care for children with life-limiting illness, including continuity of care, caring needs, caring impacts, and barriers to pediatric palliative care. Heller & Solomon (2005) examined how bereaved parents perceived the continuity of care their children had received throughout their child’s illness, but particularly at end of life, in hospitals in the United States and found that parents identified health care worker continuity as key in ensuring that their child was being cared
for in the best possible way. They highlighted that continuity promotes relationships and caring between health care workers and families, allows health care workers to know the families and children on a more meaningful level, and creates a situation which promotes information-sharing among the workers providing care. As well, when continuity continues after the child’s death, parents indicated that health care workers can be a source of great comfort to parents. A lack of continuity, however, was both frustrating and confusing for parents during the child’s illness and at the time of the child’s death and could result in experiences that were negative for both the parents (e.g. emotionally) and children (e.g. poor quality of care) (Heller & Solomon, 2005).

Contro, Larson, Scofield, Sourkes & Cohen (2002), in their retrospective study of bereaved parents’ experiences with pediatric end-of-life care, also found that bereaved parents who have accessed care through a hospice or home care organization identified difficulties regarding care in terms of having adequate staffing, finding qualified staff in terms of caring for children and managing children’s pain, and being unable to access services offered through hospitals since they were not considered in-patients.

Widger & Picot (2008) looked at parents’ perspectives of quality of care received at the end of their child’s life, at the time of their child’s death, and following their child’s death. This study examined bereaved parents who had lost an infant, child, or adolescent within 12-24 months before the study began. In this study, parents completed a telephone or face-to-face survey (one version for parents whose child had been stillborn or had died “within 72 hours of birth” or another version for parents whose children had been older than 72 hours old) (Widger & Picot, 2008, p.54). This study was carried out with a population from an urban “eastern Canadian tertiary care center,” which served both urban and rural
communities in the area (Widger & Picot, 2008, p.54). Widger & Picot (2008) found that improvements are still needed in end-of-life care in terms of “communication, bereavement follow-up, information about autopsy and organ/tissue donation, and pain management,” as well as ensuring that parents are allowed the opportunity to “have mementos [of their child] collected at the time of death,” such as hand/foot prints and locks of hair (p.57). While this study identifies important elements for improvements in a Canadian context, it looks at only one health care centre. As well, because of the methodology used, parents were not provided much opportunity to explain their answers (all except two questions required a yes or no response), which could have provided valuable information and context on their experiences and which may have allowed a deeper exploration of the experiences of parents.

Monterosso, Kristjanson, Aoun, & Phillips (2007)’s study, discussed above, also looked at parents’ perceptions of their unmet needs in terms of pediatric palliative care in Western Australia and the impacts of these needs not being met. Parents in this study were either bereaved parents who had cared for children with cancer or non-bereaved parents caring for children with non-cancer life-limiting illnesses. Monterosso et al. reported results for these groups of participants separately as they identified that families caring for a child with cancer have access to care that is more coordinated and less fragmented than other families, because the parents of the children with cancer were bereaved, and because of the differences in “palliative care trajectories” (p.693). For bereaved parents, issues revolved around not knowing how to cope with their child’s condition and their changing levels of ability or activity, how to “maintain a normal lifestyle,” not being kept “informed about changes in child’s condition,” being unsure of who they needed to ask about their child’s care, inability to trust the health care system, and lack of information about caring for their
child at home (p. 692). In addition, unmet needs included not having enough access to specific information about their child’s disease, palliative care services, health care providers (after hours), or information about financial assistance (p. 692). For non-bereaved parents, concerns focused on receiving help with regard to medical and nutritional management of and for their child, ensuring the child was comfortable, knowing the treatment their child was getting and when it was being changed, sincerity and level of caring of the health care providers, and issues surrounding travel, day care, schooling and medication administration (p. 692). In addition, Monterosso et al. (2007) identified six themes that emerged from parents and health care providers in terms of impacts of and needs for caring for a child with a life-limiting illness: (1) “caring impact”, such as divorce, general health problems, exhaustion, and isolation; (2) “financial impact” and the need for increased funding for supports, practical aids, and “long-term accommodation for children/adolescents”; (3) need for information – information was not adequately provided, except in the case of the cancer group; (4) need for skilled ‘carers’; (5) need for service availability and accessibility; and (6) “co-ordination and workforce issues,” such as inadequate recruitment and retention practices, non-recognition of growing need for pediatric palliative care services, need for broader eligibility criteria for services (p. 692-694). Limitations of this study include the fact that the researchers separated cancer and non-cancer conditions because the cancer condition group consisted of parents who were bereaved, whereas the parents in the non-cancer condition group were not bereaved. Bereavement may have been a confounding factor in this study as the differences found between groups may have been influenced by the fact that parents were bereaved as opposed to that they had cared for children with cancer.
In terms of pediatric palliative care, Liben, Papadatou & Wolfe (2007) outlined barriers to pediatric palliative care, which included "general barriers" (e.g. emotional challenges and "lack of universal health-care coverage for all children"), "community barriers" (e.g. hospice eligibility requirements and non-reimbursement for services), "hospital barriers" (e.g. caregiver team and disruptions in care continuity) and "barriers specific to developing nations" (e.g. basic needs of children/families not met and "increasing orphan population with advanced illnesses, such as HIV") (p.4). These researchers indicated that there is sufficient knowledge for pediatric palliative care services to be improved; however, despite this knowledge, implementation of changes is not occurring (at least in a widespread way).

Parents’ and Professionals’ Understanding of Pediatric Palliative Care

Few studies have looked at parents’ understandings of pediatric palliative care. Clarke & Quin (2007) and Monterosso, Kristjanson, Aoun, & Phillips (2007) carried out such research in Ireland and Western Australia, respectively, and found that pediatric palliative care was not clearly understood by parents. Monterosso et al. (2007) examined both parents’ and health care providers’ understanding of what comprises pediatric palliative care. The researchers found that neither parents nor health care providers had a strong understanding of what pediatric palliative care involved. However, the above researchers did not outline these findings in detail nor did they report specifically on what aspects of palliative care participants did, or did not, understand. Docherty, Miles & Brandon (2007) found that most health care providers working in a pediatric acute care medical center in a U.S. medical setting, including physicians, social workers, advanced practice nurses, and a respiratory therapist, defined pediatric palliative care as an "[a]dded [d]imension in the [i]llness
trajectory" (i.e. "made clear distinctions between treatment or curative care and palliative care, seen as an added dimension at some point in the illness trajectory") (p.337). Only one physician “viewed palliative care as an ongoing philosophy of care that should begin when a child and family first begin treatment for a life-threatening illness” in which “life sustaining plan of care and the palliative plan of care work synchronously from the beginning” (p.337). These health care providers also identified that pediatric palliative care comprised “compassionate comfort,” “symptom-focused care aimed at minimizing pain and suffering” and “meeting the emotional needs of both the child and family.” They also found that health care providers tended “to define palliative care by its timing within the child’s illness trajectory. It was viewed as the critical point in the illness trajectory in which it became obvious that aggressive care was not going to be effective and the caregiving team and family needed to make a decision to transition to this different focus” (p.337). Lastly, St-Laurent-Gagnon, Carnevale, & Duval (2008) looked at physicians in one Canadian hospital providing care to children with life-limiting illnesses and found that they had a “one-dimensional definition of palliative care” in that they saw this type of care as comprising only “physical symptom relief,” that they had various feelings about when pediatric palliative care should be implemented, and that they were uncomfortable “using the term ‘palliative care’” (p.28).

The Need for Further Research

A number of studies have looked at caring for a child with a life-limiting illness (e.g. Bonner, Hardy, Willard & Hutchinson, 2007; Davies, Brenner, Orloff, Sumner, & Worden, 2002; Jones & Neil-Urban, 2003; Katz, 2002; Monterosso, Kristjanson, Aoun, & Phillips, 2007; Raingruber & Milstein, 2007; Steele, 2005); however, there remain a number
of areas which require further exploration. More research needs to be conducted from the perspectives of parents in order to ensure that parents' knowledge is utilized and shared and that their experiences are validated. Research on care, including pediatric palliative care, provided to children with life-limiting illnesses also needs to be carried out from a social work perspective because of the key roles that social workers can and do play in these situations and the need for social workers to have a base of knowledge from which to inform their practice. As well, most research on care for children with life-limiting illnesses and pediatric palliative care to date has focused on one type of life-limiting illness, such as cancer (e.g. Jones, 2006; Jones & Neil-Urban, 2003; Nuss, Illinds & LaFond, 2005; Patiño-Fernández, Pai, Alderfer, Hwang, Reilly, & Kazak, 2008; Spencer & Battye, 2001; Young, Dixon-Woods, Findlay & Heney, 2002) and on end-of-life care (e.g. Contro, Larson, Scofield, Sourkes & Cohen, 2002; Jones, 2006; Widger & Picot, 2008). Additionally, further research is needed to delineate strengths, barriers and gaps in the care for children with life-limiting illnesses and their families, including pediatric palliative care, in order to identify areas of strength that can be continued and extended and to identify areas in which improvements need to be made. The current study aims to address these gaps: The primary purpose of this study is to examine mothers' experiences of the care provided to their child with a life-limiting illness and, within this scope, aims to ask the questions: (1) What are mothers' experiences in finding, accessing, and providing care for their children? (2) What do mothers perceive as gaps, barriers, and strengths in care for their children?

While the World Health Organization (1998) defines pediatric palliative care as a multidisciplinary approach to caring for a child with a life-limiting illness that involves improving quality of life by "allievati[ing] [the] child's physical, psychological, and social
distress” through “the active total care of [that] child’s body, mind and spirit,” as well as the provision of support to the child’s family (WHO Definition of Palliative Care for Children), mothers’ understanding of pediatric palliative care is not well documented in the literature, as outlined above. The few studies that have examined this issue have been conducted outside of Canada and have found that the concept of pediatric palliative care is not well understood by parents (Clarke & Quin, 2007; Monterosso, Kristjanson, Aoun, & Phillips, 2007). As a result of this gap in the literature, a secondary focus of this study is to explore mothers’ conceptualizations of pediatric palliative care. Within this focus, the study asks the question (3) ‘How do mothers understand pediatric palliative care?’ Exploring this issue is important in order to better understand how these individuals see this type of care, identify areas of misunderstanding, or gaps in understanding, and identify areas in which more information could or should be provided to mothers. As well, mothers’ understanding of pediatric palliative care may affect their willingness to access pediatric palliative care for their child. For example, if mothers understand pediatric palliative care to be only end-of life care, or care that can only be implemented if life-sustaining or curative care is stopped, then mothers may be less willing to access pediatric palliative care for their child.
CHAPTER 3: METHODOLOGY

Introduction

This chapter (1) outlines the purpose of this study; (2) describes the paradigm and theoretical framework on which this research was based; and (3) describes the research design, including the steps taken in carrying out the research in terms of sampling, data collection, and data analysis.

Purpose

The primary purpose of this study is to examine mothers’ experiences of the care provided to their child with a life-limiting illness and, within this scope, answers the questions: (1) What are mothers’ experiences in finding, accessing, and providing care for their children?; (2) What do mothers perceive as gaps, barriers, and strengths in care for their children? As well, the secondary purpose of the study is to explore mothers’ conceptualizations of pediatric palliative care. Within this focus, the study asks the question (3) ‘How do mothers understand pediatric palliative care?’

By exploring these questions, examining mothers’ multiple realities, and identifying common themes across these experiences, this study aims to contribute to the body of knowledge regarding care and pediatric palliative care by increasing social workers’, and other health care professionals’, understanding of, and sensitivity to, the experiences and needs of families caring for a child with a life-limiting illness. Because this study is exploring the experiences of mothers who are accessing services, the knowledge gained from this research will be meaningful to both mothers navigating the health care system and professionals providing services to them.
Paradigm and Theoretical Framework

This study was carried out through the lens of the interpretivist paradigm. Interpretivism posits a number of basic beliefs: (1) research cannot reveal one truth or one reality because reality and truth are multiple and are constructed through individuals' interpretations of events and processes, (2) both the researcher and the individuals being researched are involved in learning through the research process: the researcher is not the 'expert,' (3) research is not objective nor is it neutral in terms of values, (4) research findings are linked to the time and the context in which the research was conducted and is generalizable based on individuals’ interpretations of the findings, and (5) the purpose of conducting research is to understand and describe (Westhues, Cadell, Karabanow, Maxwell & Sanchez, 1999). The theoretical framework that guided this study - that of constructivism - logically fits with this paradigm. Constructivism fits within the interpretivist paradigm in that its basic assumptions parallel those held by interpretivism. For example, there are “many realities” (Saleebey, 2001, p.179) and realities are socially constructed. These realities are created “through language and relationships” (Saleebey, 2001, p.179), the meanings or interpretations of these realities are subjective and depend on who is interpreting them, and context influences perception (Westhues et al., 1999, & Saleebey, 2001). The interpretivist paradigm and constructivist theoretical framework outlined above were chosen as the basis from which to carry out the research because these frameworks fit with the goals of the study, which are to gain a better understanding of mothers’ experiences of the care provided to their child with a life-limiting illness and to explore mothers’ understandings of pediatric palliative care. A main focus of this study is on valuing the “meanings and experiences” of mothers caring for children with life-limiting illnesses (Williamson, 2006, p.84). Mothers
usually have direct experience with their child’s care and are very much attuned to the needs of their child. Because of their first-hand and extremely personal experiences with care, they are the true experts in regards to the care required and received by their children and their voices need to be heard. In order to fully capture mothers’ experiences in a way that values their knowledge and that fits the paradigm and theoretical framework, the research is qualitative and inductive in nature.

**Overview of the Research Design**

A qualitative approach was used to examine mothers’ experiences of the care provided to their child with a life-limiting illness and their understandings of pediatric palliative care. A qualitative approach is important in that it allows the participants to share what they feel is important in terms of their experiences and allows their meanings to be heard (Creswell, 2007).

Within this broad approach, a qualitative descriptive design, as described by Sandelowski (2000), was employed. The purpose of a qualitative descriptive design is to develop “a comprehensive summary of events in the everyday terms of those events” (Sandelowski, 2000, p. 336). According to Sandelowski (2000), it is “the method of choice when straight descriptions of phenomena are desired” (p.339). This design fits the purpose of the proposed research, which is to explore individuals’ (mothers’) experiences of an event (care provided to a child with a life-limiting illness) (Sandelowski, 2000). Sandelowski delineates the features of qualitative description as independent from other qualitative research designs and states that “qualitative description studies comprise a valuable methodologic approach in and of themselves” (p.339).
Trustworthiness

A number of steps were taken to ensure trustworthiness in the study. Trustworthiness includes the concepts of credibility, dependability, confirmability, and transferability (Graneheim & Lundman, 2004). In order to achieve credibility and dependability (or validity, from the perspective of Mays & Pope, 2000), the steps taken in data collection and analysis are clearly outlined below so that the reader is aware of how the findings emerged (Mays & Pope, 2000). An explanation and example of how the abstraction process was carried out to develop themes has been included so it is clear to the reader how the abstraction process took place (Graneheim & Lundman, 2004). Care was also taken to include representative quotes from the interview transcriptions and not to exclude relevant data (Graneheim & Lundman, 2004). In addition, member checking was carried out - the preliminary analysis of the data was sent to participants to find out if they felt the analysis was accurate and reflective of their experiences and to solicit additional feedback in this regard (Chwalisz, Shah, and Hand, 2008; Mays & Pope, 1995, 2000) (see Appendix D).

Member checking was also used as a way to demonstrate confirmability. There are varying opinions on the “appropriateness of seeking agreement” since “multiple realities exist that are dependent on subjective interpretations” (Graneheim & Lundman, 2004, p.109). However, member checking in order to recognize and confirm findings is one way that can demonstrate confirmability, and this strategy was used in the current study (Graneheim & Lundman, 2004).

Lastly, Graneheim & Lundman (2004) and Chwalisz, Shah, and Hand (2008) point out that it is up to the reader to determine transferability of the findings to other contexts. In order to assist the reader in determining transferability, a clear outline of the “culture and
context, selection and characteristics of participants, data collection and process of analysis” is included in the methodology sections below and the findings chapter that follows (Graneheim & Lundman, 2004, p.110).

Participants and Sampling

Six participants were selected from a larger sample of parent caregivers of children with life-limiting illness identified through an ongoing research study by Dr. Susan Cadell (Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth). Participants were recruited for the Caregiving Parents of Children with Life-Limiting Illnesses study through posters displayed at a number of Canadian and American hospitals or through letters sent through illness-related organizations (see Appendices I-K). Posters and letters called for parents (or other caregivers, such as grandparents) who were currently caring for a child with a life-limiting illness between the ages of 0-19 and provided a number for these caregivers to call if they met the criteria and were interested in participating in the Caregiving Parents Study study. This study is based on a convenience sample of six participants who were mothers who had identified that they were currently caring for children (0-19 years of age) with life-limiting illnesses. Each participant had already completed questionnaires about stress, growth and spirituality for the Caregiving Parents study, and had indicated at that point that they were willing to be contacted for follow-up studies.

As outlined above in the introductory chapter, only mothers were selected. Foster mothers were not included in this study due to the challenges surrounding obtaining consent as foster parents are not permanent guardians of the foster child and their needs and experiences might be quite different than non-foster mothers. All participants were mothers
who self-identified as caring for a child with a life-limiting illness. A more detailed
description of the participants will be included in Chapter 4.

Three participants lived in Ontario and three lived in Quebec. Ontario and Quebec
are very similar in terms of care available for children with life-limiting illnesses. Both
provinces have large Northern populations, with major urban centres concentrated in the
south of the province. Both have similar numbers of large children’s hospitals (Ontario has
four such hospitals and Quebec has three) and they are all located in urban centres in the
southern parts of the province. Each province also has one children’s hospice and both
hospices were established fairly recently. However, as the health care systems do vary in
some ways across the two provinces, I was careful to pay attention to possible differences in
experiences as a result of provincial differences while analyzing the data.

Although the sample size is relatively small, it allowed for a variety of experiences
to be examined and enough participants were involved to identify themes that these mothers
face. And while the sampling strategy is not able to address, or fully address, the realities of
families living in rural areas, on reserves, or northern communities due as a result of the
recruitment strategy used and participant self-selection, it does provide a basis on which
further research can build when exploring these equally important realities.

Data Collection

Data was collected through in-person, in-depth, semi-structured interviews
consisting of open-ended questions (see Appendix A). This type of data collection strategy
ensured that participants were able to tell their stories as they wanted them to be told while
also ensuring that the research questions were addressed. The interviews were carried out in
the participants’ towns in which they were living. Participants were given the option of
having the interview take place at their home or at another location in the community. Four mothers chose to be interviewed in their homes and two mothers were interviewed at a location of their choice in their community. The interview questions were developed through an examination of the existing literature on caring for a child with life-limiting illnesses and pediatric palliative care to identify areas requiring more research. The questions were created with the goals of supporting or disproving existing findings in the literature, building on current knowledge, and filling in gaps found in the literature. Confidentiality of participants was ensured by replacing the participants’ names with codes on transcripts of participants’ responses. The master list of codes and participants’ names are kept in a database with password-restricted access. Data collection took place in July and August 2008 after ethics approval was received.

Procedure

The study applied to the Wilfrid Laurier University Ethics Review Board in June 2008. Once ethics approval was received for the research July 2008, participants were contacted by phone about participating in the study (see Appendix B). They were informed that this portion of their involvement would be part of a separate Master’s of Social Work thesis project looking at care and pediatric palliative care and were informed of what participating in the study was to involve. Informed consent was received from all participants in the study before they took part in the interviews – both verbally over the phone when initially contacted with regard to the interview and in writing at the start of the interview session. Participants were interviewed individually, except in one case, in which the partner of one participant sat in during the interview. This partner had expressed curiosity in the interview and asked if she could observe during the interview. The
participant (given the pseudonym ‘Ann’) indicated that that was fine with her and I agreed as well. Ann was very frank during the interview and I did not sense that her answers were affected by her partner’s presence.

During the interview, I asked participants open-ended questions related to the research questions allowing for the participants to reveal information that they felt was significant and relevant to their experiences (see Appendix A). Interviews ranged between approximately one and two hours in length. As indicated above, data recording involved the audio-taping of all interviews to ensure the accuracy of the data. I checked in with participants immediately following the interview in order to discuss any questions, concerns, or feelings they may have had about the interview experience. A summary of the analysis was later sent to participants for feedback and their responses were incorporated into the findings. Once final analysis and write-up has been completed, participants will be sent a summary of the final results.

Process of Analysis

Transcription

I transcribed the data collected through the audio-taped interviews. I outlined the guidelines for transcribing the interviews before I transcribed the interviews in order to ensure consistency in the process as recommended by Schilling (2006) (see Appendix C). General observations about the interviewees’ reactions were noted at the start of the transcriptions. After all of the interviews were transcribed, all identifying information was removed from the transcripts in order to ensure confidentiality. After transcription and analysis was completed, quotes were selected to include in the final write-up. Words such as
'uh', 'um', and 'you know' were removed from these quotes, as well as words that were repeated unnecessarily in order to ensure clarity and conciseness.

Elo & Kyngas (2007) indicate the necessity of "striv[ing] to make sense of the data" by "becom[ing] immersed in the data" and reading the interviews through "several times" at this point in the process of analysis (p.109). In order to gain an overall understanding of the data, I transcribed the interviews myself and read the transcriptions in their entirety twice before starting content analysis.

Analysis

Once the transcription process was complete, analysis was conducted using content analysis, as Sandelowski (2000) identifies (qualitative) content analysis as "the analysis strategy of choice in qualitative descriptive studies" (p. 338). Content analysis requires staying close to the data collected and involves simultaneously generating codes from, and applying codes to, the data (Sandelowski, 2000). More specifically, in this case, inductive, as opposed to deductive, content analysis was used, which involves "deriv[ing]" categories "from the data" and "mov[ing] from the specific to the general" (Elo & Kyngas, 2007, p. 109). NVIVO was used in the coding process to assist in organizing and categorizing the data. The decision-making processes that took place during the coding were documented through memoing in order to ensure consistency and clarity in the coding process and to provide an "audit trail" allowing a means for others to understand, verify and repeat the process (Tutty, Rothery, & Grinnell, 1996).

Stages of Analysis

The analysis process for this study followed the three main stages: "preparation, organizing and reporting" (Elo & Kyngas, 2007, p.109). The preparation phase involves
making a choice regarding the unit of analysis to be used, selecting the type of content to be analyzed, and gaining "...a sense of the whole..." in terms of making sense of the data (Elo & Kyngas, 2007, p.109). The goal in this phase, as pointed out by Elo & Kyngas (2007), "is to become immersed in the data" (p.109). For this research study, "whole interviews" were selected as the unit of analysis, which Graneheim and Lundman (2004) indicate are "the most suitable unit of analysis" when they are "large enough to be considered as a whole and small enough to be possible to keep in mind as a context for meaning unit, during the analysis process" (p.106). Graneheim & Lundman also discuss the concept of "meaning units" and define them as "the constellation of words or statements that relate to the same central meaning" (p.106). Schilling (2006) discusses the importance of defining meaning units before beginning content analysis and indicates that there are three elements of this defining process: determining "the smallest text component to be categorized," determining the "biggest text component to be categorized," and determining the order in which "the text components be analyzed" (p. 31). For the purposes of this study, the smallest meaning unit defined as a sentence and the largest meaning unit was defined as multiple sequential paragraphs conveying a common meaning. Because the unit of analysis was chosen to be whole interviews and the answers to the interview questions often related to more than one of the questions asked, the texts were analyzed using a "cross-question strategy" (i.e. one whole interview was coded, followed by the next interview, etc., until all the interviews had gone through the coding process, at which time analysis continued by starting again at the first interview)(Schilling, 2006, p.31). Schilling indicates that this strategy is ideal when "the
guiding questions are overlapping" such that the answers provided to the questions asked by the interviewer may relate to more than one of the questions asked (p.31).

The next stage in the analysis process identified by Elo & Kyngas (2007) involves organizing the data and includes "open coding" of the data, "creating categories," and "abstraction" (p.109). In order to open code, interviews were read through while "notes and headings" were recorded to describe the content at the level of the meaning units (p.109). After this process was complete, "lists of categories" were generated to group data that I interpreted as "belonging" together and these categories were then grouped under "higher order headings" and then under higher order "main categories" (p.111). This process of generating categories and then continuing to group the categories into "higher order" descriptive categories or headings is referred to as ‘abstraction’ (Elo & Kyngas, 2007; Graneheim & Lundman, 2003). This process was continued until I felt that the data had been abstracted "as far as is reasonable and possible" within the scope of the qualitative descriptive research design, which requires that the researcher stay close to the text in terms of meaning (Sandelowski, 2000). An example of the process is outlined in Table 1.
Table 1: An example of the analysis and abstraction process

<table>
<thead>
<tr>
<th>Meaning Unit</th>
<th>Sub-category (Subtheme)</th>
<th>Category (Theme)</th>
<th>Main Category (Main Theme)</th>
<th>Overarching Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I wouldn’t want anybody else taking care of her now. I feel confident. I trust these people. Their well-being is – I feel – as important to them as it is to me. So, like I said, you know, they’ve known this child for fourteen years now. She was a baby, you know. And they’ve been there all this time. When I say that the team doesn’t move, it doesn’t.</td>
<td>Continuity and Turnover</td>
<td>Strengths and Barriers in Caregiving Long Term</td>
<td>Long-Term Caregiving and Coping</td>
<td>Overwhelming nature of the experience</td>
</tr>
</tbody>
</table>

Once the abstraction process was complete, and the main categories, or themes, were identified, concept maps were created to represent these themes. In order to ensure accuracy of findings and continue to build trust between myself as researcher and the participants, the overarching themes, concept maps, and a brief explanation of the themes and concept maps were sent to all participants through mail or email - whatever was identified by participants as most convenient. Participants were asked to complete and return a feedback form indicating whether the themes, concept maps, and explanations reflected their experiences and additional comments (see Appendix D). Once the feedback was received from participants, the comments were incorporated into the findings. Feedback was received by three participants and all felt that the concept maps and themes reflected their experiences. Some participants included questions or comments that were addressed by incorporating their feedback into the findings. After
reviewing the original data and the feedback, additional changes were made to the first concept map in terms of combining and renaming some of the themes in order to represent the data more effectively.

CHAPTER 4: FINDINGS

The purpose of this chapter is to present the findings. As indicated in the methodology chapter, content analysis was carried out on the interview data to explore mothers' experiences of the care provided to their child with a life-limiting illness and their understanding of pediatric palliative care. Through the process of content analysis, a number of themes emerged that reflected mothers' experiences. These themes are explored in the sections that follow.

I. Description of Participants

Six mothers living in either Ontario or Quebec participated in the study. All of the participants have been given pseudonyms.

Ann lives in a city approximately 30 minutes from a major urban city. She and her child's father have been separated for many years. She is self-employed and works full time. Ann has a daughter who is fourteen years old and who was diagnosed with Cystic Fibrosis (CF) at ten months of age. Ann is the primary care provider for her daughter. Ann and her daughter travel a few times a year to the nearby major city to access specialized services at a hospital. Her ex-partner had been providing some practical support in caring for her daughter until his death a number of years ago. This mother is living with a new female partner who has been part of the family for a number of years. Ann's partner is not involved in providing care to the daughter.
Betty lives in a major urban city and is employed part time. She is married and has three children. Her partner is also involved with providing care to their daughter. The oldest child is a thirteen-year-old girl who was originally misdiagnosed as having a rare, non-life-limiting, hereditary disorder that involved retinal degeneration and visual impairment and later at age five correctly diagnosed with a chromosomal disorder and life-limiting heart condition. She and her family access services in the city in which they live.

Celia lives in a medium-sized city. She is married and stays home full time to care for her daughter. Celia is the primary caregiver for her daughter. Celia’s daughter is eleven and was diagnosed with a genetic disorder and suspected neurodegeneration. Her daughter also has developmental delays, seizures, and motor control problems. While symptoms began much earlier, her daughter recently received the diagnosis of the genetic disorder at the age of eleven. She accesses some services in her home town, but often has to travel approximately an hour to a major urban city to access specialized services, as well as to other nearby cities within an hour’s drive.

Debbie lives in a major urban city and accesses services in that city. She is married and has two children. She stays home full time to care for her son who is ill. Her partner is also involved with providing some care to their son. Debbie’s five-year-old son began exhibiting loss of muscle tone as an infant and was later determined to have an undiagnosed degenerative neuromuscular disease.

Elizabeth lives in a large city approximately twenty minutes away from a major urban city. She is employed full time and is an active volunteer in the community. Debbie has a daughter who is seventeen years old who was diagnosed with cancer at age fourteen.
Her daughter is currently in remission. This mother is divorced and has one other child who lives in the home.

Frances lives in a small community that is minutes away from a large urban city. She is employed full time. She is the sole caregiver for her child. Frances has a son who is thirteen who was diagnosed prenatally with hydrocephaly and was later diagnosed with epilepsy, weakness on one side of the body, and a severe intellectual delay. Frances is divorced and has two older children. Her son with hydrocephaly lives with her, while the oldest child has moved out and lives on his own and the middle child alternates between each parent. She accesses services both in her community and in a large urban city.

II. The Overwhelming Nature of the Experience

It was evident from the mothers' stories that the experience of caring for a child with a life-limiting illness is overwhelming in terms of finding and accessing health care services and in terms of providing care to the ill child. Mothers expressed the overwhelming nature of the experience around three themes: (1) Realizing the Strengths and Barriers of the Health Care System, (2) Long-Term Caregiving and Coping, and (3) Advocacy (see Figure 1).

Figure 1 outlines the themes in relation to each other. The center circle, which signifies the theme of ‘Realizing the Strengths and Barriers of the Health Care System,’ represents the first layer of mothers’ experiences as mothers began to experience strengths and barriers within the health care system.
Figure 1. Mothers’ Experiences Caring for a Child with a Life-Limiting Illness

The Overwhelming Nature of the Experience

This centre circle, or thematic layer, is encompassed by another thematic layer (Long-Term Caregiving and Coping), which is encompassed by a third (Advocacy) thematic layer. Each layer represents different aspects of mothers’ experiences in caring for a child with a life-limiting illness. Experiences within each thematic layer have the potential to either cumulatively add to, or minimize, the overwhelming nature of mothers’ experience depending on the gaps, barriers, or strengths mothers encounter at each layer. The impact of experiences at each thematic layer can vary for individual mothers depending on the amount of positive or negative events experienced within an individual layer and/or the emotional or physical impact of incidents within that layer. As a result, the size of each circle may be larger or smaller depending on the significance each individual mother places on the experiences within each circle. It also appears that the overwhelming nature of the experience leads to mothers wanting to make change for other families and/or
to give back so that they do not have to face the same gaps and barriers. This idea is represented in Figure 1 as an arrow leading to the final theme, which is 'Wanting to Make Change or Give Back.'

Realizing the Strengths and Barriers of the Health Care System

The first thematic layer is 'realizing the strengths and barriers of the health care system'. The experience of providing and accessing care started even before mothers received a diagnosis for their child. The mothers lived a range of experiences in terms of getting a diagnosis for their child; however, the experience of getting a diagnosis was not easy for any of them. While searching for and eventually finding a diagnosis, mothers began to encounter barriers that would impact the care received by their children. Mothers encountered strengths and barriers throughout their experiences at three main levels or themes: (1) health care providers, (2) health care and community systems, and (3) government policy. The level of health care providers includes three subthemes: (a) communication; (b) approach to care; (c) social workers. The following discussion will describe these three themes and subthemes.

Health Care Providers

Throughout the child’s illness, as mothers were finding, accessing, and providing care, mothers began to realize both the strengths and barriers within the health care system. One area in which this was evident was with regard to health care providers, particularly with regard to three areas: (a) communication; (b) approach to care; and (c) social workers. All mothers described instances in which they experienced factors related to health care providers as both strengths and as barriers, except for Elizabeth, who identified professionals only as strengths.
A) Communication.

Communication is the first subtheme regarding health care providers. Positive communication from health care providers was a strength identified by some mothers. Mothers shared positive experiences they had had in terms of health care providers communicating with them in positive and constructive ways. Providing the right amount of information, communicating patiently, checking in with the mother about the well-being of the child, communicating with the mother as part of the treatment team, and being open to feedback, questions, and concerns were important to mothers. For Ann, it was also important for health care providers to ask her about other issues related to her child beyond just her child’s medical needs, particularly with respect to how she was coping with her child’s behaviour. She also talked about the importance of interprofessional communication in ensuring high quality care for her child.

Communicating respect and acceptance was a strength identified by Elizabeth - Elizabeth identified herself as an immigrant and raised the fact that she felt that she had not experienced discrimination or second-class treatment by hospital staff: “...they always say that immigrants are always second class... But I never felt that. I never felt that.”

Mothers, however, also encountered poor communication from professionals, which emerged as a major barrier. Debbie described the impact that poor communication can have on a parent, particularly in terms of communicating difficult news:

Granted different people have different people skills, but I think there should be a general base level of knowledge of how to tell parents very difficult things... To them, they might see ten kids walking in, but for that parent, they don’t realize how [they have] completely destroyed their world with just a few words.
Some professionals asked questions mothers did not like, dismissed mothers’ concerns, and communicated to parents that they, not the mother, were the expert. Ann describes one such instance in which professionals dismissed her concerns that something was wrong with her child and in fact labelled her as mentally ill for persisting in trying to find a correct diagnosis:

Two [pediatricians] told me to go see a shrink for Munchausen. So I was pretty upset. I was pretty upset. But my gut feeling just told me to just keep looking and I finally found the pediatrician in the [area], [name of doctor], and she’s African. And she was the one that pointed out CF. ...Like she was my 9th pediatrician that I saw.

Other aspects of poor communication raised by some of the mothers included not being consulted or kept fully informed by professionals about their child’s condition or changes in their treatment. For example, Celia shared ongoing issues about having to ask health care providers about medication changes that had been carried out rather than physicians’ consulting her regarding changes in medication that had been made. Betty described the lack of communication about the meaning of her child’s diagnosis and the reason for certain medical procedures. Ann raised the issue that professionals had not talked to her enough at the beginning of her child’s illness to validate negative thoughts and feelings that she might experience in caring for her child, such as sometimes feeling like she does not want to be a mother and then feeling like a “bad mother” for having those feelings. Some mothers highlighted that professionals sometimes do not provide information unless mothers request specific information, and many times these mothers do not know what questions to ask, as Betty pointed out: “You know the sad part I think
is that sometimes you don’t ask the right question and you don’t get the right answer. And not everybody’s so forthcoming with information.” Betty described a specific situation in which she did not know what services her family was eligible for because a community care access center coordinator did not provide her with that information when her child became sick and palliative:

I was never told, sort of, you know, this is what you’re eligible for. I would imagine that there was probably a lot of things that would fall under the umbrella of eligibility, but, you know, she could have identified the immediate needs – and she didn’t do that. And she didn’t say, you know, ‘What do you need? Or how do you live? Or how can we help you?’ Yeah. So, we didn’t know.

While at times mothers were not provided enough information, they were sometimes overwhelmed with too much information. Betty described that it was difficult to receive information while also dealing with receiving the news of a life-limiting diagnosis: “They gave us information, like handouts and books, and they were throwing all this information at us. And you know, we’re like stunned…” This mother, who felt as though the hospital “booted us out,” described her mixed feelings about the information she received at that time:

They’re telling you that your daughter’s gonna go. You know, this is it for your kid. There’s nothing we can do. And so even though the information today – 2 years and a half later – I can tell you today, yeah it probably was helpful… at the time, I don’t know that you feel that way.

Poor communication also involved not thinking about the impact of what was being said and how it was being said, as was shared by Debbie:
And even though no one had at that point discussed things like do not resuscitate and I remember being in the room and a resident who was completely heartless, just standing there saying, ‘Well does he have a DNR? Does he have a DNR? Do you have a contract?’ And he kept on saying this to me and it didn’t even register what he was saying. I just stared out because [child] is being, you know, it was like a code pink - there’s millions of doctors around and everything and they’re pricking him to get IV in, and he’s asking me about contracts and stuff. And I only realized after, he was asking about a Do Not Resuscitate, which no one had discussed with me [at] that point.

Similarly, some of the mothers also talked about health care providers (non-physicians) expressing a reaction to a test result that they could not discuss with the mother, which caused the mother to be concerned while having to wait to find out the results from a physician. Lastly, Celia, who had to commute to larger cities to access some care, identified communication barriers in terms of trying to arrange appointments, assessments, and consultations. One such instance involved the hospital forgetting about, and not communicating to the mother about, an upcoming teleconference for an anaesthesia consultation that the hospital was supposed to arrange.

B) Approach to care.

A second subtheme in the category of health care providers is approach to care. Positive interactions with professionals were appreciated and memorable, particularly when mothers felt that the professionals were going above and beyond their job description. They often described aspects of the professionals’ approach to providing care beyond just applying medical knowledge. While a couple of mothers did identify that
some of their professionals were very knowledgeable or kept up-to-date on new information, mothers mainly focused on aspects that extended beyond technical knowledge.

Mothers identified a number of professionals’ personal characteristics that were viewed as supportive. Kindness, friendliness, wanting to help others, humour and youthfulness were some of the supportive characteristics identified. Elizabeth, whose child was in remission, identified positivity, which was not identified by other mothers. When asked to explain what she meant by “amazing staff” at the hospital, among other characteristics, she indicated that “you don’t find negativity there.”

Some mothers, like Betty, appreciated the fact that there were professionals in their lives who were loyal, committed, trustworthy, and reliable. A significant strength for mothers in terms of approach to care was that the professionals cared about the child and family. Mothers felt that it was important for professionals to care about the well-being of both the child and the family and for professionals to see their child as an individual and not as an illness or a number. In discussing some of the positives in her experience, Ann described her trust in her child’s medical team because she knows that they care about her child:

But, no, I wouldn’t want anybody else to take care of my child and I wouldn’t want someone that doesn’t seem as concerned as they are, because they are concerned. They are. It’s part of their success as well. You know. Like the child’s success is also their success.

Elizabeth also shared her experience in terms of professionals caring about her and her daughter: “Because they make you so comfortable. ...It just seems like they understand
all your problems. And they are in pain with you. And they feel the same pain as we are feeling it.” Similarly, Elizabeth vividly remembered instances in which professionals had gone above and beyond their job description in order to make her feel cared about and supported, such as receiving a personalized letter from a physician who was leaving the hospital. Ann also described a physician who she feels cared because he is “thorough” and does not like it when his patients get sick. However, she did indicate that when he gets upset, it sometimes makes her and her child feel fearful and upset.

Another aspect of health care providers’ approach to care that mothers identified as a strength was flexibility. Flexibility in the role taken with the family, hours of availability, and services provided to the family were appreciated. For example, Celia described her personal support worker’s flexibility in the support she provides by providing both respite and social support: “The one [personal support worker] comes for 2 hours so I used to go to the bank, grocery store, whatever. But we now sort of do it half social time for me and half care for her.” This was similar for Betty whose worker helps her by primarily providing practical support in caring for a sibling of the child who is ill rather than the ill child.

Some mothers also talked about the importance of accessibility. Mothers appreciated being able to reach a professional when they needed to and receiving a prompt response when they had a question or concern. Ann, who has to commute to the hospital, found it a “great strength” for the CF team that “...when you go to the clinic they’re all there. The whole team is there.” She indicated that “you don’t have to go out of your way if you have a CF clinic” because appointments can be arranged with any or all the members of the team all on one day.
Moreover, some mothers highlighted professionals’ involvement in the children’s care and their willingness or ability to take action. While many of the mothers expressed challenges involving the health care system in searching for and finding a diagnosis, Elizabeth described the positive involvement that her family physician played at the beginning of her child’s illness:

The thing is my family doctor was very, very involved. ... [She tried one hospital] and they didn’t have any pediatric surgeons. So she got into [another hospital] and, after that - after 6 days only - I got the appointment with [a third local hospital]. That was quite lucky with that. Because the family doctor played a very important part in my intake.

Ann also discussed other ways in terms of involvement in which professionals supported her and her child, such as being proactive in providing practical support like working with the insurance company to get medications covered and supplying medications until the insurance company would cover them, and preparing her and her child to transition to an adult hospital.

Negative interactions with professionals in terms of their approach to care often stood out clearly in mothers’ memories. A couple of mothers identified that a person’s experience “depends on who you get.” Mothers brought up instances in which professionals were unfriendly, had a “big ego,” or “bugged” the mother. One mother described that sometimes it was just a personality conflict that affected her relationship with professionals.

In terms of accessibility, Celia talked about a number of instances in which professionals were not accessible to her when she needed them. She talked about
difficulty getting in contact with certain medical professionals because they are busy or are out of the office and because of their limited work days and work hours. She also described unreturned messages as a barrier to care:

But I also have a palliative care nurse contact now that I try to phone, but I find half the time she doesn’t phone me back so I never know if she got my message. And like in June, we were supposed to go down for dental surgery. I phoned her 3 times: ‘Do you have the ambulance booked for us to come home?’ Never heard nothing.

Negative interactions in terms of approach to care also included mistakes. A number of mothers experienced instances in which professionals made mistakes. Mistakes included misdiagnosing a child, making medical errors, which sometimes caused additional suffering or harm to the child, providing misinformation, losing test results, and misconduct. These actions had an impact on mothers’ trust in health care providers or in the health care system. Celia described a number of mistakes made in her child’s care, including the following instance:

Well she has a … burn – thanks to the hospital, too, ’cause her IV went and they hadn’t changed it 4 hours later. So they gave her Dilatin and didn’t realize at the time, but it ate away all her skin right down to the bone. It wasn’t ’til we saw the blood blisters that there was a problem. The same doctor didn’t know how to treat it and they were puttin’ – he had us puttin’ Vaseline on it. It didn’t heal after 6 weeks.

She described the rift this caused between her family and the hospital after she found out how easily the problem could have been resolved:
We saw a surgeon who looked at it, you know, a couple minutes, gave us a prescription for this $85 tube of stuff that the insurance company won’t pay for and it healed right up. So we kinda went, well thanks doctor, you know. This could have been healed a long time ago if you had known what you were doin’.

Ann described a serious mistake that involved forgetting to freeze and “knock [her child] out” when having incisions made during a pic line operation: “And, well, they forgot that part. And they missed her. So it took an hour and a half. And she was awake. Wide awake and alert and feeling everything.” She described the future impact that this will have on her and her child in terms of accessing care:

Next time she needs to go in, I think it’s going to be in our minds. And she’s going to anticipate pain and stuff like that. And then I don’t think it’s good for your morale, or when you’re afraid of something, like it’s gonna hurt even more.

*C) Social Workers.*

The third subtheme is social workers. Many mothers accessed social workers, and discussions arose during the interviews specifically around social workers. Social workers were experienced as strengths in the health care system by providing information to help mothers find and access services and funding and by assisting mothers with practical support, such as filling out paperwork. They also provided crisis and longer-term counselling through hospitals and community care access centres or through private agencies, as well as assisted mothers in terms of providing parenting support and organizing informational roundtables. However, mothers pointed out some barriers they faced in terms of their ability to access social workers: mistakes in terms of not being connected to a social work coordinator, difficulty finding publicly-funded social workers,
difficulty finding social workers knowledgeable about pediatric palliative care, and social work support not provided early enough to the family. One mother made recommendations as to how social workers could be more supportive. This mother, Ann, indicated that social workers should “get involved earlier” before there is a problem as opposed to waiting “for any drama to happen” or for the family to ask for help. She indicated that the family is “already in vulnerable position. And it’s not everyone that’s able to go ask for help.” Ann also talked about being provided a lot of “tools” and “literature” at diagnosis, but described needing emotional support. Here she talks about the need for the social worker to become involved with the family in providing emotional support immediately upon diagnosis:

I mean, nobody can receive news like you got fatal cancer or you got a fatal disease, or lifetime illness, or – no one can receive information like that and not react to it and I think [a] social worker can come and deal with the, like, trying to understand more of the psychological effect of news like this.

Health Care and Community Systems

The second level at which mothers realized strengths and barriers in the health care system was at the level of health care and community systems. Mothers reported varying levels of availability of and accessibility to services and resources provided at the level of health care and community systems. Mothers were able to find and access services through hospitals, doctor’s offices, respite and rehabilitation centres, illness-related organizations, specialized schools, and community care access centres (CCACs/CLSCs). Mothers discussed a number of strengths in terms of the services and resources that they had been able to access. Mothers described helpful informational
material such as CD-Roms, games, educational resources that they were able to access through various sources, such as the hospital, illness-related organizations, and early years centres. Some mothers were also able to access at least some home care support, such as personal support workers or nurses. One mother, Debbie, whose child often has respiratory distress when transported, identified that home care support was a significant strength. She indicated that “the single most helpful thing” was “being put in touch with home care,” a program offered through a hospital allowing her to have access to a number of specialists, 24-hour emergency care, and medical supply delivery. She described the importance of having access to this type of care: “I wouldn’t be sane if – I probably wouldn’t be here if it wasn’t for that home care component. Literally.” Being able to access some care at home was identified as a strength by Frances because of her son’s challenging behaviours:

One example, my son needs to get regular blood checks. And taking him downtown to the [hospital] to get a blood test was like... Am I allowed to swear a little bit? ...Hell on Earth. And so, we were able to work out with the readaptation centre that the nurse comes to the home. So that was really helpful.

A respiratory distress team that included a chaplain was also identified as a strength by Debbie, and Elizabeth described strengths in terms of having access to a number of services offered by the hospital, such as specialized summer camp, free activities such as movies and spa days, parking reimbursement, and a wish from the Children’s Wish Foundation.

Having services and resources in one’s community was seen as a strength in terms of accessing services and resources. Three of the six mothers lived in large metropolitan
cities and were able to access all care for their child within the cities in which they lived. Debbie, who lives very close to a number of medical facilities in her community, commented on her access to medical facilities and physicians in her community when asked about the overall care that her child has received:

But once again, I think we’re lucky that we’re physically close to the two centres that provide his – the most care. That they do have home programs for like the [hospital]. And that the [other hospital] has enough doctors and things that we are able to have arranged a team for him that I’m satisfied with.

A few mothers noticed that more supports at the health care and community levels were starting to be offered than were available previously. One mother, Celia, heard that the community care access centre was changing their policies so that families caring for a ‘palliative’ child would get unlimited hours toward nursing and personal support workers as opposed to “maxing” out. Frances indicated that more support groups are offered now than in the past. Debbie indicated that in recent years, some agencies and services have been created to provide respite and hospice care support to families, albeit with limited spaces. She also noted, in discussing positives about a hospital, that “they’re constantly trying to make improvements that way – not just for the strict medical care, but also for other types of care,” referring to other aspects of pediatric palliative care, such as psychological and spiritual support.

While all mothers accessed numerous services and resources at the health care and community level that had at least some strengths and provided some support, most mothers also experienced barriers in finding and accessing care at this level. Some mothers identified a lack of specialized doctors available. A number of mothers identified
finding qualified, knowledgeable, appropriate or even willing caregivers as a major challenge. Some mothers described that it took a long time to find 'good' caregivers. In discussing the challenge of taking her child out on errands, Celia identified the challenge of finding a babysitter who can deal with her child's medical needs.

But, it's not easier to get her a babysitter. I mean, you gotta get either family or one of her workers to watch her because technically I can't leave the feeder on and now with her medical stuff. I mean, I can't just have anybody. But even they don't really know. I'll say what to look for, what to do, or what's - It's like, I'm really the only one qualified. But I mean, I gotta go out. So, I've gotta have somebody here.

Other mothers described that often it is hard to find babysitters or other caregivers because these caregivers are afraid of taking care of the child. Betty described this fact:

...I think if she were high-functioning and palliative it's one thing, but because she's visually impaired, non-verbal, a chronic vomiter, you know, she becomes very cyanotic. If you don't know her and you're not familiar with, you know - I think people get afraid.

She also indicated that her child's needs and how she feels that the caregivers might experience her child affects her willingness to access overnight respite:

And to put her in an overnight respite, with just a stranger, not knowing her... [child]'s going to suffer, because she's... going to be frustrated and angry because you're not going to understand what she wants. And that, you know, the caregiver will be confused and frustrated and going to fear she's not going to treat her well because, you know... yeah. So we've never done one.
Betty also raised additional challenges of finding caregivers, such as individuals applying for the wrong reasons, caregivers finding the job boring or not being “sensitive and aware of everybody in the family.” Betty described how the shortage of nurses is an issue in terms of finding caregivers, particularly at the beginning, and in terms of finding replacements when one caregiver takes time off. However, while the situation has been “better” for this mother since she changed agencies and her family has been considered a “priority family,” she feels that the problem is that “I kind of feel like it’s not about us. Like, you know, when people need to take time off, they take time off.” And when they need a caregiver to replace the one who has taken time off, they pull a caregiver from another family and “that other family [doesn’t] get service.” Moreover, this mother indicated that “now that she’s palliative, my insurance at work covers for further nursing,” but that she is not able to find enough nurses to provide additional care: “So we have the resourcing for it – the funding for it – we just don’t have the bodies for it. Yeah. Yeah. But can you imagine? Most people, they don’t have the money – the resourcing. We have it. We can’t use it.”

Distance to resources also played a part in mothers’ experiences of finding and accessing care for some mothers. The three mothers who did not live directly in major city centres were able to access some of their children’s care in their home city, but also had to travel to nearby metropolitan cities to access additional care. Most, if not all, travel to these cities was not optional for these families as their children required testing, access to specialists, and other care that was not available in their home communities. One of these mothers, Celia, indicated that distance was a significant barrier for her in terms of accessing care. For Celia, who lived the furthest from the large urban city in which she
often accessed care, driving to other cities for care required extra time and energy in terms of commuting, arranging transportation (since she does not have a wheelchair accessible vehicle) and arranging accommodations for overnight stays, as well as extra costs in terms of expenses such as accommodations, food, and phone calls to family at home. When after two years of receiving ambulance transportation to travel to a hospital in a major city her palliative care nurse indicated that that would no longer be an option, Celia was placed in a difficult position as she did not have access to a wheelchair accessible vehicle. She identified that affordable transportation is a gap in the system:

Well we’re obviously at the point where we need a wheelchair vehicle, but I don’t have the funds to buy a van and try to get a third party to fund converting it. I just thought, ok. To me there’s a gap in the system. But then I thought, I guess that’s what the patient transfer people are for. But then you still gotta spend a couple hundred bucks or something to get there and back. But, like I got a couple a hundred bucks kickin’ around just for a doctor’s appointment. ’Cause I phoned the wheelchair taxi and it’s huge, too. I just thought, I can’t afford that and I don’t think anybody else is going to want to pay for it.

Another barrier in terms of accessing and providing health care at the level of community resources encountered by mothers involved arranging and scheduling care. The complexity of filling out paperwork for care, tracking down physicians, arranging test results to be sent to a particular doctor, and scheduling appointments were challenges for mothers in this respect.

Existing requirements for services were also at times a barrier to at least one mother in accessing services. This mother, Ann, described not being able to access respite
care either at home or outside of the home because her child was not ill enough: “It’d be nice to have someone saying, yes ma’am, go do your shopping and bring the kid here, or you know, I’ll go to your place, or... That doesn’t exist. Unless you’re dying or something.” She described the sense that the situation for a parent needs to be desperate before support is provided: “The caregivers don’t get supports. Unless you go beserk, you end up in the hospital with a nervous breakdown or something.”

Some mothers also encountered funding and insurance coverage as a barrier. Celia talked about the inadequacy of the funding that she receives to assist her in covering the costs of items related to care, such as catheters and gloves, and the challenges with her insurance company in covering expenses. Ann described her insurance company as “messing with our brains” in their attempts to avoid covering expenses that are supposed to be covered by law:

They won’t tell you the real reason why they’re not covering it. They’re just telling you that, oh, well, your employer didn’t choose that in their agreement with the insurance company. It’s like bull... You know. They just give you the run around. We’re still trying to get covered for some medication and they just – Last time they told me I think three or four different stories. So, we’re still trying to figure it out.

Meanwhile, she needs to pay these costs while the insurance company gives her the “run around.” Furthermore, this mother described her frustration in being asked every year by the insurance company, and every five years by the government, whether the child still has CF: “Is she still sick? Oh – oh. Once I got pretty sarcastic and I said, ‘Oh why? Did you guys find a cure?’”
In some cases, barriers involved a lack of services or resources available. Mothers identified a number of areas in which there were gaps in terms of the care available for their children at the level of health care and community systems. Lack of home care, before- and after-school programming for children with specialized needs, and hands-on occupational therapists and physiotherapists were identified by some mothers. Ann talked about a lack of access to home care: “I find the barrier is just not getting any help.” She described not caring what type of professional came in to the home, as long as they could provide support in helping her adolescent child with her treatments, as her child often resists her daily treatments: “If they could just walk in here and say ‘I’m here for [child]’s treatment.’ ‘Oh God, thank you!’ You know. Just once in a while to have a break…”

**Government Policy**

The third level at which some mothers came to realize strengths and barriers in the health care system was at the level of government policy. However, mothers did not focus much on ways in which the government was a strength. Mothers primarily discussed government policy as supportive in terms of providing some financial support through grants, such as the Trillium Foundation or tax credits. One mother, Celia, who indicated that costs of care were a challenge for her family, identified some ways in which the government provided some support to her family, such as a baby bonus, an income-based financial assistance program for costs related to severe disability, and a disability allowance.

Government policy emerged as a barrier in mothers’ experiences in terms of not providing sufficient funding or support to families or adequate numbers of health care providers, not only for specialists, but for generalists and home care professionals, and
not addressing the issue of wheelchair accessibility quickly enough. Some mothers
described feeling “on their own” in terms of support and having to be “self-sufficient.”

Ann described the inadequacy of government support:

I think that there’s no support from the government at all when it comes to care.
Like they were saying, when you do your income tax, I think they’re asking you if
you’re a caregiver now, eh? Natural caregiver for someone. It’s like a real joke.
...They offer money but then they offer money like $90 a year or something.

Celia described another aspect of inadequate government funding in terms of having
to wait to get new, improved, equipment for her child. She identified that a new pump
was out that would make feeding her child a lot easier for her and for other parents, but
that “...you gotta wait. The government only buys it every 5 years, so... I mean, they
allot you so much money every 3 years [and] you gotta wait every 5 to get a new pump.”

In describing the fact that she is providing most of the care for her child, Ann
called for more governmental support to families, either financial support directly to
parents or to agencies “towards getting the proper help” in terms of caregiving/respite
support. This was a similar issue for Frances, who described the need for more financial
support for services to support families with respite and emotional support.

A few mothers also discussed the need for better coordination between
government, hospitals, and other agencies or suppliers, particularly with relation to
funding and some noted the structural problems in terms of the lack of medical
professionals. Celia summed this up by stating: “I mean, there’s so many headaches in
the medical field. Well I mean, I guess, everyone’s gettin’ a headache with the lack of
doctors and whatnot.”
Long-Term Caregiving and Coping

While the first thematic layer, or circle, involves the overwhelming nature of the experience for mothers in terms of realizing the strengths and barriers of the health care system, the second thematic layer involves the overwhelming nature of the experience in terms of long-term caregiving and coping (see Figure 1). Finding, accessing, and providing care for their children was an ongoing process for these mothers. All of the mothers have been providing and accessing care for their child for many years after receiving a diagnosis of a life-limiting illness. Some of these children have survived years beyond what was expected, some children’s conditions have stabilized over time, while others have lived with their condition for a number of years before their health began to deteriorate. Long-term caregiving and coping involves four themes: (1) coping with the psychological toll of the illness; (2) ongoing guilt or regrets; (3) giving up part of self; and (4) strengths and barriers in providing and accessing care long term. Strengths and barriers specifically related to providing and accessing care long term involved three subthemes: (a) continuity; (b) costs of care; and (c) time and energy. Coping and caregiving for mothers did not appear to be a linear or stable process. Ann highlighted this concept in her written feedback on the preliminary themes:

I would add that as far as coping is concerned, it almost as if it needed constant adjustments. You deal with the disease but this disease progresses and you need to get used to the disease itself, but also it’s progression, which is a constant reminder that your child is living with a life-threatening disease. Do we get used to this? No of course [not].
Coping with the Psychological Toll of the Illness

Coping with the psychological toll of the illness is one theme with regard to long-term caregiving and coping. These mothers have had to cope with the overwhelming physical, emotional, social and psychological, and, in some cases, financial and familial impacts of providing long-term care to their children while trying to continue on with their lives and, in some cases, trying to raise other children. In many of the cases, the physical living spaces of the families were filled with care-related equipment.

For mothers, a major aspect of providing long-term care for many of the mothers was coping with the ups and downs of their child’s illness. One of the aspects of coping with the illness over the long-term was that mothers had to deal with and be prepared for unknowns in terms of when a child might deteriorate quickly or become life-threateningly sick. Debbie talked about the unpredictability of her child’s illness: “…you know, we didn’t realize that every day is life and death. And that he could seem wonderful one second and then collapse the next.”

Mothers also had cope with witnessing the impact or gradual progression of the illness over time. Ann shared that her daughter had been doing okay up until about a year and a half ago and talked about the challenge in accepting the progression of her daughter’s illness:

And, I felt at one point that everything I was trying with her was just not working. And her health was not getting any better. It took me a while to realize that this was just… progression. Of CF. So, that was like, I don’t know, I just had a hard time with that – accepting the unacceptable, I call it.
Coping with the illness was different for Elizabeth and Frances. Elizabeth, who was caring for a child in remission, indicated that she is currently coping with her child having to go for ongoing check-ins to ensure that the cancer has not returned. Frances identified that “Luckily we’re sort of backed more away now from the medical stuff. Other than for the epilepsy. I guess that’s still a constant, ongoing, you know, struggle to get it under control.”

Because of the serious nature of the diagnoses and, for many of the mothers, the reality of ‘close calls,’ mothers have to cope with their fears on an ongoing basis. Some of the mothers dealt with this reality by going day by day and trying not to think about or dwell on the possibility of their child dying.

In contrast to those mothers who tried not to think about the possibility of the child’s death, Betty had thought about and begun planning her child’s funeral. Because doctors originally conveyed a sense of imminence, she and her partner began planning for the child’s funeral around the time of her diagnosis of the life-limiting component of her condition. She indicated that she and her partner spend a lot of time even now thinking about their child’s funeral: “But we’ve have a year to think about it, or two years to think about it, and now going on three years. And it’s funny – there’s not a day I don’t think about it.”

Ann, who is caring for an adolescent, described having to cope with ensuring that her child carries out her treatments as her child often exhibits challenging behaviours with respect to her daily treatments: “Although it’s like only like 20 minutes, but she’ll fight me for an hour and a half. ...That’s what I find exhausting. It’s fighting all the time. I don’t like confrontation.” She talked about the effect of ensuring that her child
undergoes her daily treatments on the mother-child relationship:

It’s always like, ‘Why are you always on my back and da da da?!’ ‘Well because I
love you.’ ‘If you love me, leave me alone!’ ‘Well, it doesn’t work like that!’ You
know. It’s very conflictual. A situation with chronic disease. Because you have to
impose.

Ongoing Guilt or Regrets

With respect to long-term caregiving and coping, ongoing guilt or regret was also
a theme for some mothers. Some mothers continued to feel guilt or regret over the cause
of illness, not finding the diagnosis earlier, and not taking enough action in preventing
their child’s deterioration. Ann described the impact of guilt over the genetic nature of
her child’s illness on her relationship with her partner: “‘Cause there’s a bunch of like,
guilt. Guilt is mainly the one that’s killing the couple.” She went on to explain:

It’s a genetic disease. Both parents are carriers. And it’s hard to accept that even
though you didn’t order this, you didn’t, you know, tick the ‘Oh, yeah, I’d like my
child to have CF, let’s put a checkmark here, you know’. It doesn’t work like that.
But, when you get the diagnostic, you know that you are partially responsible for
transferring that gene anyways, you know.

Celia described her regret that doctors were not able to diagnose one aspect of her
child’s illness earlier, despite the fact that she had raised concerns about her child’s
symptoms, and wonders about the damage that may have been prevented if they had been
able to begin treating the condition earlier.

And I kind of wish we had found this before and then she may not be as
regressed. ‘Cause you know, if we’d stopped it before any other damage maybe
she wouldn’t be the way she is now. But there’s no way of telling. ...Well, we kind of blew that by a long shot... But I mean, I know for years I said symptoms, but, you know, obviously they never could [diagnose the problem] because nobody had heard of it, I don’t know. It’s just unfortunate.

Celia also questioned her decision regarding switching her child to a special needs school and the impact that might have had on her child’s development. She also expressed guilt in terms of feeling that she should have done more to slow the progression of the illness:

And I mean you kind of blame yourself and go, well maybe if I had exercised her more it wouldn’t be so bad. But I did everything else, I just don’t exercise her. Everybody else exercises her. But I keep thinking I’ve got to do it more. I mean, you always look back and think, I should have done speech, this, that or whatever, but I just never got around to it. Or I was all gung-ho and somebody said something to discourage me so I didn’t do and I should have done it anyway.

She indicated that this is a constant thought despite the fact that she is doing the best she can to provide care to her child:

So I’m always thinking of the things I didn’t do right, or enough. I mean, I don’t know if it would have made a difference, but I mean, I can only do what I can do, you know, you can only do so much. ...It’s still not 100 percent.

Giving up Part of Self

Giving up part of self is another theme with respect to long-term caregiving and coping. Mothers talked about the impact on their life and their family’s life and having to give up, or lose, a part of their ‘selves’ in order to provide care to their child long term.

One mother, Celia, described this aspect of providing care: “Well I mean, on a personal
level you give up half of your life to take care of her. So you lose part of yourself.”

Mothers shared the loss of being able to go out, whether it be down the street for a walk or out of town to visit relatives, and the loss of the social or recreational, and in some cases, the work aspect of their lives. Celia, who does not have a wheelchair accessible vehicle, described not being able to “just get up and go” and the impact that this had on not being able to leave the house with her daughter as “los[ing] part of your life” and “part of your freedom.”

Betty described the long-term toll on herself and her partner in terms of spending time together in non-caregiving activities:

I think that you’re in - like we’re in crisis all the time. All the time. And it’s funny because when have an opportunity to relax – on those rare occasions – we don’t know how. Yeah. And that’s really sad. You know? On a Saturday when we get nursing – ‘what do you want to do?’ ‘I don’t know, what do you want to do?’ ‘I don’t know’ Because it’s not something that... is offered to us all the time.

She also shared the challenge of participating in self-care and of spending time away from her daughter:

It’s a challenge, right? ’Cause, I mean, when you’re sad and broken it’s hard to go and see a movie. I know that’s what normal people do, but, when your kid is stuck in hospital you don’t feel like eating, you don’t feel like going for a walk. You don’t feel like doing anything. You just feel like sitting there and holding your child. The problem is, it takes toll. And we recognize, that after doing this for 8 years, it starts to take a toll on you.
**Strengths and Barriers in Providing and Accessing Care Long Term**

Another theme pertaining to long-term caregiving and coping is that of strengths and barriers in providing and accessing care long term. Mothers identified a number of strengths and barriers related to finding, accessing, and providing care long term. These strengths and barriers, which are outlined below, revolved around three subthemes: (a) continuity; (b) costs of care; and (c) time and energy.

**A) Continuity and turnover.**

The first subtheme is continuity and turnover. As seen in Realizing the Strengths and Barriers of the Health Care System, professionals played an important role in mothers' experiences of finding, accessing, and providing care. Many of these professionals had been involved with the child and family throughout much, or all, of the child's illness. Often professionals came into mothers' homes to provide care and support. A number of mothers saw this stability in professional caregivers as an important and meaningful strength of the health care system. When asked about how she felt overall about her child's care, Ann highlighted the trust she felt for the health care team involved with her child as a result of their long-term stability:

> I wouldn't want anybody else taking care of her now. I feel confident. I trust these people. ...So, like I said, you know, they've known this child for fourteen years now. She was a baby. And they've been there all this time. When I say that the team doesn't move, it doesn't.

Being able to develop a relationship with professionals over time was a strength for mothers. Many mothers reported forming a strong relationship and some felt that they had become like family or friends.
While some of the professionals involved stayed very stable over time, this was not always the case. Turnover was an issue for both Betty and Frances. Because of the chronic nature of their children’s life-limiting illness, life events in the professional caregivers’ lives (such as pregnancy, illness, retirement, school schedules, the temporary nature of a job, or wanting a job change) eventually impacted on the professional caregivers’ ability to work with the family. Frances pointed out that it seemed to her that social workers had a high turnover rate due to pregnancy as many social workers are women. Turnover was an area that was particularly salient for Betty. Accessing caregivers was a challenge for Betty as once she found loyal and committed caregivers, they became social supports to her, and losing them was particularly difficult for her:

So, I think because in our case it’s a very chronic situation, we sort of lost service and we haven’t really requested it back because we lost a therapist, and when we lost a volunteer, it was hard. It was really hard. Because we don’t have much of a social life other than – like we sort of work in the home and take care of our family. So this was sort of external social experiences that were coming into our home and when they left, it was a huge loss. Do you know what I mean? I was devastated.

Turnover was a barrier to accessing similar services in the future for Betty because she did not want to become close to other caregivers only to have to go through the grieving process again when they have to leave:

And then I just didn’t bother calling. Those services are available to me if I want them – it was just too hard. It was a loss. Yeah. And you know, I thought, if I re-introduce them again, then what? We’re gonna go another 2 years and we’re
gonna – and you know they have their own lives and they’re gonna move on and... Yeah. It’s hard. So, I never reintroduced that.

Professionals coming in and out of the home, while in some respects a strength can also be experienced as a challenge. Celia, who has a number of health care providers in and out of her home, talked about being overwhelmed at times by health care providers coming in her home and telling her what more she needs to be doing.

**B) Costs of care.**

The second subtheme is costs of care. All of the mothers have had to cope with the long-terms costs of providing care to their child who is ill and the impact of care on their financial situation. The cost of care was manageable for some and a challenge or obstacle for others in terms in finding, accessing, and providing care in terms of finding a way to cover costs in order to access services, equipment, transportation, and renovations.

Elizabeth indicated that grants and other funding allowed her to access services, whereas as a single, working mother she would not have been able to afford the same services. Frances, when asked about financial impact, indicated that she had been able to stay out of debt, but that she and her family had had to cut back on activities. She had had to stop working for three years and then when she returned to work, she returned part time, which meant that she was not receiving a full salary. Celia talked about wanting and needing to either renovate or move in order to provide a house that was accessible since she and her partner can no longer carry their daughter up stairs. However, she indicated that it is not feasible unless they get the funding for renovations that they have been trying to get “for over two years.” This mother stayed home to care for her child and described the impact of providing care on the family’s financial situation:
Okay, we live on one income because I can’t work obviously. So we’ve lived on credit cards and loans, so we keep going in circles: borrowing money and then having to borrow money to pay that off. So we keep going in circles. So we were at the point where we didn’t think anybody would re-fund us and I mean the bill collectors were constantly phoning. I mean, we were far enough at the end of, like, we can’t do this anymore...

Celia indicated that “after 10 years” the “bank finally agreed to remortgage – consolidate” and “So we kind of have a life again, but not really, ’cause I mean we’re still broke. But at least the bill collectors don’t phone anymore.”

In contrast, Debbie indicated that she “was lucky enough not to have to go back to work” and described her and her family’s financial situation as a strength because she is able to access a lot of caregiving-related services, equipment, and renovations more easily than might other families.

**C) Lack of time and energy.**

The third subtheme is lack of time and energy. Providing care was a time consuming process which required a lot of effort for many of the mothers over a number of years and that some mothers described as a barrier to both their child’s care and their own self-care. One mother, Celia, described a lack of time or energy to accomplish everything that she needed to accomplish in terms of non-essential care-related activities, such as charting her child’s feeding. Debbie described the overwhelming nature of her child’s care in terms of time and energy required to coordinate care as well as provide care to her child, particularly before she received home care services. She describes the amount of daily care required by her son at home:
...the actual care of [child], which is 24/7, you know, really. He needs chest physio at least four times a day, he has to go in his stander, he has to, you know, suction - and in his case, suctioning is like an hour four times a day. It’s not like, just, a five minute thing. His ...machine, which we do two times a day, he has medication which he’s on and the feeding tube and all that, and his cleaning – all the tubes, and machines, and... It’s just mind-boggling, actually. I don’t know. Because you are running a hospital at home. And in the hospital you have all kinds of employees to do that and supplies people and all that, but at home you’re doing it yourself. So it’s quite overwhelming.

Advocacy

The third thematic layer that contributed to the overwhelming nature of the experience for mothers, involves advocacy (see Figure 1) in terms of advocating for one’s child and family. Mothers needed to advocate for themselves and their children throughout their experiences of finding, accessing, and providing care. As outlined in the previous sections, mothers faced a number of challenges, barriers, and gaps that affected their ability to find, access, and provide care for their children with life-limiting illnesses. Mothers did, however, strive to find ways to overcome or avoid many of these obstacles in order to improve their child’s care in addition to all of the other caregiving and non-caregiving responsibilities in their lives.

Mothers advocated for their child and their families in a number of ways. Mothers had to take a proactive role in continuing to bring the child to the physician and in raising their ongoing concerns about the child’s health. Some of the mothers used connections
they had in the health care system, either prior to the child's illness or developed over the course of the child's illness, to help them find, access, or improve care for their child.

Some mothers tried to arrange for health care providers who were more responsive to their needs to avoid having to deal with a health care provider whose actions or demeanour were experienced as a barrier to care. Both Frances and Elizabeth indicated that their relationship with professionals made it easier for them to find and access services. Elizabeth stated that, "It goes hand in hand how you approach them and how they take care of you." Ann recounted talking to a number of health care providers on the ward an attempt to get test results faster.

When asked about challenges or positive experiences of finding different services for her child, one mother, Frances, indicated that her employment at a disability-related organization helped her both find out about services and advocate for services.

The good thing where I work here [name of agency] - it's one of what we do. We provide services and things. So in a way, when there's been a service missing - like this summer there was no camp for his age, for his needs and, I fought - a lot of advocating and I fought that a camp be made and it ended up serving 20 kids. So that's the bonus of where I work. I'm able to, you know, kind of fend for his needs and my needs.

A few of the mothers had experience in a medical setting or had relatives who worked in the medical field and therefore were able to use their or their family members' existing knowledge to find and access services more easily. Knowing what services or funding should be available helped mothers in knowing what questions to ask and where to look for services. Elizabeth described her experience in these regards:
I do a lot of volunteering... So I knew all the services that were available through something out there. And plus if you have a medical doctor in the family, then you know the services. Because my brother is [a doctor], not here, you come to know a lot of things, like how to approach the doctors, what to ask, what not to ask.

Advocacy also took the shape of knowledge-building and applying knowledge learned. Some of the mothers talked about doing a lot of research, such as researching on the Internet and reading informational material beyond that provided by the hospital. Debbie talked about researching in order to understand her child’s illness, but also to keep up-to-date on the research and successfully advocating for doctors to use new techniques and equipment in their practice:

...So, I do a lot of reading about neuromuscular disease, respiratory stuff, and with the Internet of course it’s so easy. And because of that I’ve been able to suggest actually to doctors things that I’ve read. Especially from the States, techniques they use and things like that, which they’ve actually adopted at the [hospital].

For other mothers, this involved learning about legislation and contacting lawyers, ombudsmen, or human rights lawyers to help them fight for their rights. Betty described having to educate herself about human rights legislation and hire a human rights lawyer to help her in terms of her right to accommodation at work:

You become very aware of human rights legislation. You’re very aware of all the other acts that can support you as a parent. Because even though you’re not disabled – I mean, yeah I know it’s palliative – but in my situation with [child],
it's a child with a disability who's become palliative, as opposed to a child who's become palliative, and then becomes disabled, right? So you learn all about your rights. Your child’s rights. Your rights as a family. You learn how to push back. You learn how to be assertive. Yeah, you learn – you know what – I think this experience either it breaks you or makes you stronger.

Wanting to Make Change or Give Back

It appears that the overwhelming nature of the experience leads mothers to want to make change for other families and/or to give back so that they do not have to face the same gaps and barriers. Wanting to make change or give back is the final main theme illustrated in Figure 1. In caring for child with a life-limiting illness, mothers experienced barriers and gaps that made finding, accessing, and providing care much more challenging than necessary. Mothers expressed not wanting other families to have to experience the same challenges that they went through and wanting to make change to this end, as well as appreciation to the system and wanting to give back as a result (refer to Figure 1). The way in which mothers’ accomplished this can be seen through five themes: (1) participating in research; (2) making donations/endowments; (3) volunteering, fundraising, and helping other families; (4) providing feedback; and (5) hoping to make future changes.

1) Participating in Research

One theme that emerged with respect to wanting to make change or give back is that of participating in research. Mothers discussed the importance of participating in research to further others’ understanding about their situations and to improve care and support provided to families with children like theirs. In sharing her experience about
coping with long-term caregiving and not wanting to do anything except spend time with her child, Betty indicated the special nature of participating in this research study:

And this is sort of like a special thing, 'cause we’re squeezing it into our day, like this interview. But, for me, it’s like I kind of feel like it’s going to bring a better good to what I’m already doing. Like I’m doing it on a small scale, but maybe it’s going to help on a big scale. But that’s the only reason I’m doing it.

At the end of the interviews, when asked if there was anything else she wanted to add, Debbie indicated the following:

Well I think research like yours is important because I don’t know if that’s an area that has been studied very much. And that’s why I wanted to participate because I think that it’s important to get that information out there and I hope that studies like yours will lead professionals to realize that a lot of support has to be given in many ways – the medical, the financial, but also the personal perspective. So, I’m really pleased that you’re doing that.

One mother, Ann, indicated that she had participated in other research studies. She shared how participating in research allows her to feel that she has a role in her child’s treatment beyond “...just driving the kid to the hospital and giving the cards or paying for medication…”

2) Making Donations/Endowments

Another theme that arose with respect to wanting to make change or give back is making donations/endowments. One mother identified that she has been able to make change and offer support through donations:
Actually, last year I was very lucky because some shares I had forgotten about ended up being very lucrative, so, it was last year – around almost exactly a year ago we gave a donation to the hospital [for specific type of care]. And it will be an endowment fund where they get money every year to things we specify.

3) Volunteering, Fundraising, and Helping Other Families

Volunteering, fundraising, and helping other families is a third theme that emerged with respect to wanting to make change or give back. A couple mothers identified concrete ways in which they give back to other families, the hospital, and other illness-related organizations, such as through volunteering, fundraising and being a resource for other families. Betty indicated “I mean, I’m a good resource today for other people because I’ve been through it and you know, on some level 13 years that we’ve been through this.” Elizabeth spent a great deal of time describing the importance of volunteering her and her child’s time both during and after the interview: “And, plus, I mean now, it is for me and [child], it is like giving back to them. So we do. We are very much involved with the volunteering.”

4) Providing Feedback

Providing feedback is another theme that arose in terms of wanting to make change or give back. Providing feedback to professionals or others in the community about things they need to improve on or change with regard to care was another way in which some mothers tried to make change. This was stated explicitly by Debbie:

A few times, even when he’s in the hospital, I don’t like his resident or something like that, you know, they’ve done – And I feel it’s my obligation, not to complain, but to give them feedback because, for example, the respiration therapist at the
hospital – a lot of them don’t know what to do with someone like [child] and I give them feedback because, yes, he’s a rare case, but there’s certainly aspects of his disease that must appear elsewhere and they’re not doing it properly, so I give them back a lot of feedback on that.

5) Hoping to Make Future Changes

Lastly, hoping to make future changes was another theme that mothers raised with respect to wanting to make change or give back. Some mothers also identified ways in which they would like to make change, but have not been able to to date. One mother, Debbie, indicated that in the future she might try to educate professionals about communication skills. Betty indicated the following:

But, you know what? If I could change anything, and I’ve thought about it a few times, that you know, under the Human Rights Code, there’s no provision for the word ‘caregiver’ of the person with the disability to receive accommodation. And I don’t think people ever think that way. I mean, I think people quit their jobs. Right? And do things because I think they think it’s the only way and don’t feel like socially there’s a bigger responsibility. Do you know what I mean? For your employer, communities. Yeah. It’s your problem – and you’ve got to deal with it.

Celia described wanting to make change in the community: “’Cause, I mean, one day I said – I thought, part of my – part of this purpose was for me to go around town and find all the wheelchair-friendly places and non-wheelchair-friendly… You know, make a note. Get things changed.”
III. Understanding of Pediatric Palliative Care

The second focus of this research involved exploring mothers’ understanding of pediatric palliative care. Mothers had indeed developed an understanding of pediatric palliative care and it had developed through their experiences. Each mother placed a different emphasis or significance on different elements of pediatric palliative care. The experiences that contributed to mothers’ understandings of pediatric palliative care are explored below in the overarching themes of ‘development of an understanding of pediatric palliative care’ and ‘mothers’ understandings of pediatric palliative care’.

Development of an Understanding of Pediatric Palliative Care

All of the mothers had some idea of what pediatric palliative care comprised. It was evident that their understanding of pediatric palliative care was shaped, and continues to be shaped, by their own experiences. Mothers thus constructed a knowledge of pediatric palliative care from their experiences with regard to four themes: (1) their understanding of their own child’s illness and lifespan; (2) adult palliative care; (3) professionals communication about pediatric palliative care; and (4) other experiences with pediatric palliative care. These types of experiences overlapped and intersected (refer to Figure 2). Figure 2 represents these themes as overlapping circles, with mothers’ understanding of pediatric palliative care in the centre, as all four types of experiences help mothers understand pediatric palliative care. In this figure, the size of each circle can vary depending on the number, type, and significance of experiences in each circle.
Figure 2. Factors Affecting Mothers’ Understanding of Pediatric Palliative Care

Understanding Child’s Illness and Lifespan

The first theme with respect to the development of an understanding of pediatric palliative care is understanding the child’s illness and lifespan. Mothers’ understanding of their child’s illness and their lifespan played a role in their development of an understanding of pediatric palliative care. Some of the children had already survived past their initial prognosis. While there was a level of uncertainty for all mothers in terms of their child’s lifespan, because of the rarity of the illnesses and the fact that the children had surpassed physicians’ expectations, these mothers did not know what the potential lifespan of their children would be. Betty describes this uncertainty below:

And with us, they keep telling us it’s gonna happen and it never does, so on some level we don’t believe that it’s actually going to happen because we’ve been there so many times and it’s never actually happened.

In this case, because her child had not been expected to survive very long after diagnosis, Betty understood that she needed to focus on aspects related to end-of-life care and
indicated that she had spent time thinking, talking with her partner, and planning regarding pediatric palliative care issues, such as decision-making and funeral planning.

Celia expressed uncertainties about the reasons in which the pediatric palliative care team became involved with her child in terms of her understanding of her child’s lifespan:

...I don’t know how they really got involved because, I mean, we’re not at that point. But maybe the ’07 was pretty rough so maybe they thought it’s time to introduce... where it’s going... I mean, they say her lifespan is shorter, but I mean, it still should be quite a bit.

She indicated that later she realized that the palliative care professionals were not dealing with end-of-life issues, but rather helping her with issues that she was having with the hospital.

Ann who understood that her child’s lifespan should be fairly long described the challenge for her in dealing with the idea of pediatric palliative care and death because of her child’s current level of health: “But at this time – Today would be a tragedy right now. It would be, like, you know. It’s way too early.”

Other mothers expressed not thinking about pediatric palliative care because of their understanding of the nature of their child’s illness. For example, Frances, whose child has hydrocephaly and epilepsy, who did not require extensive medical treatment at this point, and who expected that her child would have a long life-expectancy, indicated that she had not thought about pediatric palliative care.
Experiences with Adult Palliative Care

The second theme is experiences with adult palliative care. In addition to understanding the child’s illness and lifespan, experiences with adult palliative care could also impact mothers’ understandings of pediatric palliative care. Debbie described having a great deal of exposure to palliative care: “And at some points I was seeing three palliative care doctors, if you can believe it: for [child,] for my mum, and [an adult relative].” In discussing her experiences with adult palliative care, Debbie described significant events around “pain control” and “psychological support.” In talking about witnessing her mother’s experience with palliative care, she indicated: “I saw with her, you know, what would be involved” in terms of palliative care and what to expect with her son.

However, Ann, when providing written feedback on the themes, expressed that understanding adult pediatric palliative care does not help her in accepting the reality of pediatric palliative care for child, and identified some differences for her between the two types of care:

I have had experience with palliative care but mostly on elderly people. There is nothing abnormal about being sick or dying when you’re old but I don’t feel I can use this experience and accept it as well for my child. For an older person, you want it to be painless and quick as for a child, my first thoughts are aimed at stretching it as long as possible. For some reason I feel selfish because I don’t feel ready to let go as I would for my grandparents for example. Maybe it’s because my child is not there yet and that eventually it might be more of a relief to see her go than to see her suffer.
Professionals’ Communication about Pediatric Palliative Care

The third theme with respect to development of an understanding of pediatric palliative care is professionals’ communication about pediatric palliative care. Mothers had different experiences in terms of how physicians communicated with them regarding pediatric palliative care. The way professionals communicated, or did not communicate, with mothers also affected how mothers understood pediatric palliative care.

Betty described two different styles of communication that she experienced from professionals about pediatric palliative care. First she described not having had specific conversations around pediatric palliative care at the time of diagnosis:

Back then, that’s when she, technically, became palliative, but it was never said to us that way. It was like, she’s got this illness, and we’re going to manage it the best way we can, and I think back then, they thought that she’d probably go a year or two, you know, that’s why we had the G-tube and the rest of it… 8 years later… [Laughs]

However, she did describe being connected with and speaking to a resource person and palliative coordinator who talked to her about end-of-life issues, such as funeral planning. She also later recounted a doctor having a specific conversation with her around the meaning of pediatric palliative care after her child had been palliative for a number of years. This later discussion helped her to change her understanding of pediatric palliative care from one of end-of-life care to one that encompassed her child’s reality of having “been palliative for 8 years” and thus extended beyond the “community” definition of palliative as meaning “3 months or 6 months”: 
And I went to talk to him and he says, you know, there is such a term, have you ever heard of a term called ‘long-term palliative care’? And it’s like, no, I always thought that when you were diagnosed as being palliative it’s – you’re at the end. Yeah. So, that was a new term for me. You know, there’s probably been a lot of people I’ve met in 13 years and it’s - I’ve thought a lot about him.

Other mothers did not describe having such specific conversations around the meaning of pediatric palliative, but reported varying levels of communication related to components of pediatric palliative care. Debbie described having a number of conversations with palliative care doctors about decisions regarding pediatric palliative care at end-of-life: “We’ve always said that we don’t want to talk about a ventilator, for example. I don’t know if push came to shove and they said he won’t survive without it what we would do, but you know, we’ve had discussions with palliative care doctors about that.”

Celia indicated that she did not really know why the palliative care team was involved in her child’s care and that the palliative care providers took on more of an advocacy role as opposed to care. She indicated that the hospital communicated in a vague way about palliative care:

I guess you get it far enough along like [hospital] started hinting at the neurodegenerative to try to prepare us, I guess. I guess with palliative care coming on they’re trying to throw that in. [Laughs] Or, you know, try to give you a hint or make aware of, you can’t predict how things are gonna go, or really what to expect.
On the other end of the spectrum, some mothers did not have conversations about pediatric palliative care. One mother, Ann, did not identify that health care providers had talked to her about pediatric palliative care. She did, however, indicate that at one point in time, she had had conversations around her child’s behaviours around treatments and that “...the hospital was saying, well maybe it’s time to let go. [Pause] You know...” Her reaction to that suggestion is reflective of her perception of pediatric palliative care as giving up:

And I said, well, letting go of the treatment is like accepting the fact that the CF is gonna to kill my child. And I’m just gonna look at it? And do nothing? You don’t have the right girl here for that because I can’t. I’m a fighter. I’ve always been a fighter and I’m not – you know. I tell [child] yes you have CF, but it doesn’t mean it has to take over all of your life.

Frances, who identified her child as non-palliative, also did not identify that doctors spoke to her about pediatric palliative care. Elizabeth, whose child had cancer, when asked, indicated that a doctor had in fact discussed not thinking about that possibility: “Never. Because the doctor was - he said that [type of cancer] is very, very treatable. I shouldn’t have any kind of negative things.” She indicated that he had communicated to her that “…he was so sure that [child] will grow up to be a beautiful girl and all those things and he said, oh no, don’t even worry there, don’t even go there, you know.” This mother described pediatric palliative care as end-of-life care and indicated that “…I never thought about that.”
Other Experiences with Pediatric Palliative Care

The fourth theme is other experiences with pediatric palliative care. Some mothers had also identified connections with other families with children with life-limiting illnesses and described significant events that these other families have gone through. These events or experiences impacted mothers and were learning experiences for them in terms of pediatric palliative care in relation to their own child. For example, Betty shared examples of two children in her extended family having recently passed away from life-limiting illnesses and that, emotional as it was, “...it gave us an opportunity to see what a young person’s funeral looked like, first hand, as opposed to people telling you this is what we do, this is what we’ve done.”

Debbie described having conversations with some bereaved parents. She shared that in one case, in which she believed the child had not received palliative care, a parent was “…very unhappy that [child] was in a lot of respiratory distress before she died” and that that parent had witnessed the child’s distress. This mother indicated that that is a concern for her, but that she has a palliative care team to support her: “…we know they’re here and that they will do everything they can that way.”

Frances described that she felt that not knowing anyone receiving pediatric palliative care affected her understanding: “I really don’t know too much about this, thank goodness. Because that means I don’t know anybody who’s been there.”

Mothers’ Understandings of Pediatric Palliative Care

As indicated above, mothers expressed various understandings of pediatric palliative care. Mothers expressed their understanding of the concept of pediatric palliative care around three themes: (1) end of life; (2) more than end-of-life; and (3)
questions and uncertainties. Four subthemes emerged in terms of mothers’
understandings of pediatric palliative care as end-of-life care: (a) pain control; (b) family
support; (c) place of death; and (d) decision-making.

End of Life

End of life is the first theme with respect to mothers’ understanding of pediatric
palliative care. All of the mothers described pediatric palliative care as including care
provided at the end of a child’s life. Some mothers described pediatric palliative care as
comprising only end-of-life care, such as Ann: “That would be towards the end of life,
for me.” Frances, described the concept as the following: “Just in general… Well, I mean,
to my understanding palliative means like, there is a foreseeable end to their life, I
guess.”

A) Pain control.

The first subtheme in terms of the theme of end of life is pain control. A number
of mothers identified pain control at end-of-life as an aspect of pediatric palliative care.
One mother, Debbie, had discussed issues surrounding pain at end-of-life with her child’s
palliative care doctors: “Our number one concern, from day 1, was pain and discomfort. I
think they’ve been telling us that they could make him as comfortable as medically
possible.” Ann described the idea of dignity with respect to pain control: “But I also see
leaving with dignity. Having someone making sure that you’re comfortable in your last
moments.”
B) Family support.

The second subtheme is family support. Family support at end of life was another aspect of pediatric palliative care that was identified by many mothers. Frances described family support as non-judgmental and facilitating the family’s wants or needs:

I guess different families react in different ways to it. Maybe some want to be there all the time and some can’t handle being around. Maybe just to facilitate whatever’s better or what the family wants. You know, don’t judge if they can’t be there and support them if they can or want to be.

Debbie weaved her understanding of pediatric palliative care throughout her responses to a number of interview questions. This mother, whose child has almost died several times, described psychological support to the parents as part of pediatric palliative care in talking about quality of care issues. For some mothers, support to the family in terms of practical support was a part of pediatric palliative care. Betty described practical support provided to her family in terms of funeral planning: “So, you know, they told us that we needed to prepare, you know, and there was somebody – like a resource person – to help us, you know, cemeteries, and funeral homes, and the rest of it.”

For Ann, spiritual support to her child at end-of-life was identified as an important aspect of pediatric palliative care:

So that’s my understanding – Someone that’s there not – mostly for, not necessarily for the physical aspect other than maintaining a comfortable zone, but mostly for the morals of it. You know. Could be spiritual, could be, that someone’s walking that way with them.
Further to this spiritual support to her child, Ann also described pediatric palliative care as support to the child that the parent might not be able to provide at that time, such as giving the child permission to let go:

I guess it’s a good thing that somebody is doing it because not everyone can – like as a natural caregiver, it’s not, obvious. You can be there to fight the battle with them, but not necessarily to let go of the gloves when it’s time to let go. Give your permission – give permission to your child to let go. Not sure I could do that. So it’s a good thing that there are nurses and other, you know, medical specialists that are working on this and trying to help the patient come at peace with their last moments.

C) Place of death.

The third subtheme is place of death. Some mothers talked about part of pediatric palliative care as considering where they would like, or where they envisioned, the child’s death in terms of physical location. Some of these mothers described wanting their child to be at home, such as Debbie: “We said that, we would like him to be at home if it ever came to that.” Betty shared her understanding in this respect:

And I guess the beginning thing now is that, you know you have children dying at home now as opposed to in hospital. And so, I guess, you know, the [name of palliative care centre], and you know, having this team at [name of hospital], so that families can go home and sort of die the way you want to die, as opposed to being hooked up to a hospital bed and dying in a hospital.

Ann indicated that she thinks of palliative care as taking place in a hospital:
... so the palliative care for me is something that's done in the hospital. It's not done home. And it'd be nice to be able to do it at home, but I know that it could put a lot of pressure in the house. Like, a lot of – some people are more comfortable with it than others, I guess, and so to me it's always like hospital and grey corridors, and, you know, dimmered lights, and nothing to distract or to disturb...

D) Decision-making.

The fourth subtheme is decision-making. Over the course of these children’s illnesses, a number of decisions need to be made regarding issues pertaining to end of life. Betty, in sharing her experience about being connected with the palliative care team, indicated that she and her partner had had a conversation with the “transplant care doctor” about “if that’s something that we wanted.” Debbie described pediatric palliative care as involving choices about her son’s care when she was asked about her understanding of pediatric palliative care: “That we have certain choices about his care, for example, that we can decide not to resuscitate or – We’ve always said that we don’t want to talk about a ventilator, for example.”

More Than End of Life

Beyond end of life is the second theme with respect to mothers’ understanding of pediatric palliative care. While all mothers identified pediatric palliative care as end-of-life support, some mothers also described pediatric palliative care as comprising other aspects of care that continued beyond solely end-of-life issues. Some of the mothers talked about pediatric palliative care as quality of life and pain control throughout the child’s illness. Frances described the importance of the child’s quality of life: “I guess what’s important is just the quality of life – keep it as upbeat and happy until the end?”
After talking about her mother’s experience with pain control in adult palliative care,
Debbie indicated pain control issues with respect to her son:

Thankfully, with [name of child], it’s more uncomfortable things rather than
painful things. Other than, things like injections and IV and stuff, where I’ve also
learned a lot also about in terms of putting Lanacaine and other things they don’t
always think of and – that I’ve learned to do for him. Other than that, it’s more
discomfort and things, where we know he has to suffer a bit from a discomfort
point of view, in order to do something, and he’s okay with it.

One mother brought up the concept of stages of palliative care. This mother,
Celia, described seeing pediatric palliative care as end-of-life care, but indicated that her
child was not at the end of her life: “But I mean obviously palliative care is supposed to
be end-of-life but she’s not admitted for that…” As a result, this mother later explained
what pediatric palliative care meant for her: “So I guess maybe there’s different stages of
palliative care. I mean, I know… Like I say, the experience I’ve had isn’t really
palliative, it’s more social. Or… or… assisting me. Advocating… not really medical
stuff, or health wise”

Questions and uncertainties

The third theme in terms of mothers’ understanding of pediatric palliative care is
questions and uncertainties. Some of the mothers were uncertain about how pediatric
palliative care at end-of-life would come into play for their child, what comprised
pediatric palliative, or whether their understandings were ‘correct.’ Celia indicated
having wondered why the palliative care team was involved with her child because to her
palliative care meant “old people.” When she thinks of palliative care she “…think[s] of
the seniors in the building on morphine drip, sort of waitin’ to go…” and indicated “I – I
don’t know what – how that would play out?” in terms of her child. Frances asked
whether or not pediatric palliative care continued after the child’s death: “Um… I guess
in terms of your study or whatever, is there a post… palliative – is there a post-palliative?
Is there such a thing? Like once the child does pass?” Ann expressed some of her
uncertainties about pediatric palliative care: “I think that’s what I understand from that –
palliative care. Um… I think that they’re working pretty closely with intensive care unit,
but I’m not sure about that.”

Conclusion

In sharing their experiences, mothers’ revealed a great deal of insight and
information with regard to finding, accessing, and providing care to children with life-
limiting illnesses. Overall, it was clear from mothers’ experiences that caring for a child
with a life-limiting illness was an overwhelming experience. Mothers encountered a
number of strengths in the health care system; however, they also faced a great deal of
barriers and gaps that affected the care received. Long-term caregiving also raised
particular challenges for mothers in caring for their children. In order to ensure that their
children received appropriate and optimal care, mothers needed to advocate for their
children throughout their children’s illnesses. Mothers’ experiences in all of these
respects appeared to lead mothers to want to make change for other families and/or to
give back so that other families would not have to face the same challenges that they had
had to experience.

Mothers also had their own understandings of pediatric palliative care. They
developed an understanding of pediatric palliative care through their experiences in terms
of their understanding of their own child's illness and lifespan, their experiences with adult palliative care, how professionals have communicated to them about this type of care; and other experiences with pediatric palliative care. Overall, mothers' primarily understood pediatric palliative care as comprising end-of-life care.
CHAPTER 5: DISCUSSION

Introduction

As previously stated, the purpose of the study was to examine mothers’ experiences of the care provided to their child with a life-limiting illness. The study asked (1): ‘What are mothers’ experiences in finding, accessing, and providing care for their children?’ and (2): What do mothers perceive as gaps, barriers, and strengths in care for their children? A secondary focus of the study was to explore mothers’ understandings of pediatric palliative care and within this scope asked (3): ‘How do mothers understand pediatric palliative care?’ As outlined in the previous chapter, a number of findings emerged with respect to these research questions. The focus of the current chapter is to discuss these findings and explore them in relation to the existing literature.

The Overwhelming Nature of the Experience

It is clear from mothers’ interview data that the experience of caring for a child with a life-limiting illness, including finding, accessing, and providing care, is overwhelming in nature. This finding is consistent with the literature (Monterosso, Kristjanson, Aoun, & Phillips, 2007; Steele, 2002, 2005). Regardless of whether mothers’ had primarily positive or negative experiences with the health care system, the experience of caring for a child with a life-limiting illness was nonetheless overwhelming for all mothers in terms of finding, accessing, and providing care. The overwhelming nature of the experience for mothers was evident with respect to the themes of Realizing the Strengths and Challenges of the Health Care System, Long-term Caregiving and Coping, and Advocacy. While strengths in the system ensure a good quality of care for children and their families and help mothers in coping with their child’s illness, barriers and gaps add to the overwhelming
nature of the experience for mothers in terms of increasing their distress, stress, and burden in finding, accessing, and providing care for their child.

Realizing the Strengths and Barriers of the Health Care System

Realizing the Strengths and Barriers of the Health Care System was a significant theme that emerged from mothers' stories. This theme included mothers' experiences encountering strengths and barriers in terms of issues related to health care providers, health care and community systems, and government policy. Positive experiences and strengths in the health care system helped mothers feel that their child was receiving a good quality of care and that they were supported in caring for their child with a life-limiting illness; gaps and barriers in the health care system, however, affected the child's quality of care and isolated mothers from others, from resources, and from their communities.

Health Care Providers

It was clear from mothers’ stories that factors related to health care providers, including social workers, could be experienced as both a definite strength and a barrier in the health care system. How health care providers were experienced depended on factors related to communication and approach to care. However, it is important to keep in mind that additional factors besides solely individual factors may play a role in health care providers' actions and interactions with children and families. Hospital policies, time constraints, and lack of training in areas such as communication may play a role in the quality of care these professionals are able to provide. For example, some studies that have looked at health care providers' perspectives of pediatric palliative care have found that challenges identified by health care providers in terms of providing this type of care to children and families are inadequate education or a lack of education on how to provide
pediatric palliative care (Clarke & Quin, 2007; Docherty, Miles, & Brandon, 2007) and high case loads (Pontin & Lewis, 2008).

While positive experiences with professionals did not necessarily diminish the overwhelming nature of the experience of caring for a child with a life-limiting illness for mothers overall, they did allow mothers to feel supported emotionally and practically. Having positive experiences with professionals was extremely significant to mothers and impacted the quality of care received. However, negative experiences with professionals were major barriers to the quality of care received by both the child and family. Dealing with professionals who acted in ways that resulted in barriers to care created an isolating disconnect for mothers between themselves and these professionals. This disconnect often resulted in a lack of trust, as well as feelings of anger, stress, devastation and fear. These isolating actions impacted the quality of care received by mothers and their families and added to the overwhelming experiences of these mothers, who were already trying to deal with understanding and coming to terms with their child’s diagnosis and prognosis.

A) Communication.

Health care providers were seen as a strength in the health care system when they demonstrated positive communication skills. Positive communication involved providing mothers with an appropriate amount of information, interacting patiently with mothers, communicating in a non-discriminatory and inclusive manner, and checking in with mothers not just about the health of the child, but about the child and family in general. Moreover, treating the mother as an important part of the treatment team, which involves respecting, validating, and addressing mothers’ concerns regarding their child, checking in with mothers about the well-being of their child after the child has left the hospital, and
welcoming mothers' questions, concerns, input, and feedback were significant aspects of positive communication for mothers. The importance mothers placed on being considered as part of the treatment team and being involved in decision-making is supported by existing literature (Contro et al., 2002; Hsiao, Evan & Zeltzer, 2007). Positive communication also involved taking part in interprofessional communication. Hsiao et al. (2007) found that communication between health care team members can decrease barriers by decreasing parental confusion and anxiety and “prevent[ing] fragmented care” (p.363).

Conversely, poor, or insensitive, communication was a barrier to finding, accessing, and providing care. Poor communication included not preparing mothers for negative thoughts and feelings that they might experience in caring for their children, dismissing mothers’ concerns and seeing oneself as the expert, not informing mothers about hospital routines, and failing to keep mothers informed about changes in their child’s condition and treatment. Similarly, Hsiao et al. (2007) found that “changing a treatment course without preparing the patient and family” was harmful (p.355). Communication was also a barrier when professionals did not communicate with mothers regarding arrangements related to the child’s care. This added additional stress and burden to mothers’ experiences in that they then had to take multiple steps to ensure that arrangements were in place.

Withholding information, such as information regarding services or funding the family is eligible for, was also a concern. When health care providers did not provide information except when specifically asked, mothers were unable to access services that would directly impact quality of care and could decrease mothers’ isolation, stress and
burden. Withholding information has also been found to be "harmful to satisfying communication" and resulting in a lack of trust (Hsiao et al., 2007, p.355).

Poor communication at the time of diagnosis and in delivering bad news had a particularly negative emotional impact on mothers. Poor communication at this time involved overwhelming mothers with too much information, insensitive communication of serious information and a lack of awareness of the significance and impact of what is being communicated to mothers. Moreover, a lack of communication regarding the meaning of the child's diagnosis and the reason for certain medical procedures impacted mothers in dealing with their child's diagnosis. Contro et al. (2002) provides parental suggestions for improving the way "difficult news" is conveyed by health care providers, including having a "familiar person" convey the information and communicating in a way that is compassionate, caring, straightforward, honest and directly, while still leaving space for parents to hope (p.16).

The findings support the literature that good communication skills have a positive impact on parent caregivers leading up to and including time of diagnosis (Davies, Davis & Sibert, 2003) and throughout the illness trajectory (Contro et al., 2002; Hsiao et al., 2007) and that poor communication can result in serious consequences (Davies et al., 2003) and increased distress for children and families, even over the long term (Contro, 2002; Hsiao et al, 2007). The literature clearly identifies the need for positive communication with parents with a child with a life-limiting illness; however, there are clearly still gaps in how some health care providers' communicate with mothers in their actual practice.
B) Approach to care.

Health care providers’ approach to care was another factor in whether professionals were experienced as a strength or a barrier in the health care system. Professionals who were seen as strengths in the system were caring, flexible, accessible and approachable. They were viewed as kind, friendly, loyal, committed, trustworthy, reliable and wanted to help others. Sometimes they were seen as appealing to children in terms of youthfulness and humour. They were also very involved in the child’s care and willing to take action when necessary. Trustworthiness, caring, and accessibility, match desirable health care provider characteristics identified by Contro et al. (2002). Contro et al. (2002) also identified “clinical accuracy” as a characteristic identified by parents. Mothers in this study rarely explicitly identified “clinical accuracy” as important to them, however, they identified many instances in which clinical accuracy was not present, which suggests that this characteristic was indeed important to them, however, it is likely that mothers assumed that clinical accuracy should have been a base level of knowledge for professionals.

Of primary importance to mothers was that the health care provider cared about the child and family. Caring about the child is a part of, but extends beyond, relationship building with a family as it involves truly caring about the child and family and sharing their experience. Knowing that the professionals involved in the child’s care cared about the child and the family and made a personal connection with them was a significant strength. Heller & Solomon (2005) found that “being known” by health care providers “increases confidence about the quality of care” received and “may reduce hypervigilence” (p.339). One caveat, however, is that while showing strong emotions or reactions can and
does demonstrate caring, it can sometimes result in the mother and child feeling fearful and upset.

Having access to health care providers involved with their child’s care was also key for mothers. In order for mothers to be able to access information, services or resources, they needed to be able to contact professionals and to feel comfortable in dealing with them. Accessibility of health care providers allowed mothers to access care in a way that was supportive and less stressful and burdensome than otherwise would be the case. Being able to contact a professional quickly and easily, and to receive a timely response from professionals, whether it be by phone, email, or in person, was a strength, which supports findings by Hsiao, Evan & Zeltzer (2007). For mothers who had access to a team of caregivers, being able to access members of the team easily and all on one day, particularly when mothers had to travel from out of town to access care, was greatly appreciated. Being able to access health care providers allows mothers to feel as though these professionals care about them and their children and builds trust between mothers and professionals. Mothers need to know that professionals can be relied on to address their concerns when they arise. Mothers also need for health care providers, particularly those supporting families in their own homes, to be flexible in their hours of availability, the nature of the support provided, and to whom they are the providing support.

Health care providers’ approaches to care were also experienced as barriers in the health care system. Some professionals were not accessible to mothers because they had limited days and hours of availability, busy schedules, were frequently out of the office, and did not return mothers’ messages either in a timely manner or at all. This affected mothers’ ability to access information and care regarding their child. Some professionals
had big egos, were unfriendly, “bugged” the mother, or their personality “clashed” with the mother. These findings are supported by findings from Hsiao et al. (2007) which identify “having a disrespectful or arrogant attitude” and “not establishing a relationship with the family” as problematic (p.355). In some cases, the professionals who isolated mothers through their demeanour or actions were professionals who needed to be involved in the child’s care and who needed to be involved in an ongoing way with the child and family. As a result, mothers had to deal with them until they found ways for other professionals to provide the same care for their child.

A significant way in which professionals were experienced as barriers to care was as a result of mistakes and misconduct. These incidents were significant events in mothers’ experiences that resulted in additional suffering or harm for and to the child, delays in the child’s care, and frustration and stress. These actions affected the trust between mothers and professionals, which supports existing literature (Contro, Larson, Scofield, Sourkes & Cohen, 2002; Hsiao, Evan, & Zeltzer, 2007; Steele, 2002). Some studies (Contro et al., 2002; Hsiao et al., 2007) have found that “a single event could cause parents profound and lasting emotional distress,” in terms of mistakes and insensitive communication (Contro et al., 2002, p.15). The current study supports this finding, but also found that mothers and children had many times experienced multiple ‘isolated’ incidents throughout their experiences. Steele (2002) also found that sometimes “a series of experiences gradually challenged their [parents’] trusting and uninformed stance” (p.422); however, the impact of multiple mistakes, misconduct, and insensitive care and communication is an issue that extends beyond broken trust. While the incidents may have been isolated in terms of particular professionals involved or in terms of being not typical of the care normally
received, the fact that a number of mothers experienced multiple unnecessarily distressing events suggests that these events may not be as isolated as they appear. There may be structural issues at play with respect to these incidents, such as understaffing, underfunding, or inadequate oversights in place, which is an area that future research should explore.

The findings highlight the fact that health care providers are key players in mothers' experiences of care and can have a major impact on the type of experience mothers have while finding, accessing, and providing services. This finding supports previous literature in this respect. Communication skills and aspects related to approach to care are all aspects of care that professionals can learn, implement, and improve on their practice. Because of the primacy of their role with families, it is critical for health care providers to receive ongoing education, training, supervision and feedback on these aspects of care. Similarly, Liben (2007) points out the need for more training and education for health care providers in pediatric palliative care and bereavement care. As well, health care providers and policy makers need to be particularly cognizant of the impact of mistakes and strive to address policies and practices that may promote less than adequate care.

C) Social workers.

Social workers had diverse roles to play in helping mothers find, access, and provide care, which ranged from practical support to crisis and long-term counselling, and advocacy. However, it was clear that there is still space for social workers to take on a greater, and more effective, role with families caring for a child with a life-limiting illness. Mothers valued the support they received from social workers in terms of emotional, educational and practical support, but, earlier and proactive involvement with families and
involvement at diagnosis and when bad news is provided were identified as important areas of need. As well, finding and accessing social workers, and more specifically social workers knowledgeable in pediatric palliative care, was not always easy for mothers. As pointed out by Jones (2006), pediatric palliative care is not normally a part of social worker’s education.

Health Care and Community Systems

The services and resources available through the health care system and community-level agencies affected the amount of support in providing care mothers received, the ability of mothers to access care, and the quality of care children received. Mothers’ access to specialists and other professionals, programs, and services were affected by the size of their community and the accessibility of transportation to and from services for mothers and their children. Differences in terms of access to services across provinces, however, did not appear to be evident from these mothers’ experiences. They reported access to similar services and resources in Ontario and Quebec.

Gaps in services involved a lack of home care support, before- and after-school programming for children with specialized needs, and a lack of hands-on involvement by occupational therapists and physiotherapists. Respite and home care were considered vital services for mothers; however, not all mothers were able to access such support or as much support as needed or would have liked. With respect to pediatric palliative care, the American Academy of Pediatrics (2000) identifies that both respite and home care are components of pediatric palliative care that are “essential to maintain the integrity of families and the safety and well-being of the child” (p.355). When services and resources were not available, a number of barriers existed that made accessing these services more
challenging than necessary for mothers. Insurance companies tried to avoid covering costs and in one case added to a mother's frustration and isolation by continually requiring that mother to confirm that her child was ill. Distance to resources was a barrier to care in some respects. Mothers do not always have a vehicle with which to transport their child within their communities, let alone to other communities for care. As a result, arranging transportation could be an additional challenge that often involved additional time, cost, and accommodation.

Finding qualified, knowledgeable, appropriate and willing caregivers, such as home care nurses, personal support workers, and even babysitters, was a particularly challenging barrier for mothers. Barriers also existed in terms of finding specialists, arranging care, a lack of fit between services offered and family needs, and existing requirements for services. For one mother, interpretation and translation services were also identified as a gap. The gaps and barriers at the level of health care and community services and resources were primarily chronic structural issues, which had significant impacts on quality of care and level of burden on mothers and families throughout their experiences. However, in some respects, some positive changes were gradually being evidenced over recent years by some mothers in terms of programs and services available. This change was likely due to the growing awareness and understanding of pediatric palliative care within the health care community.

**Government Policy**

Many of the mothers were very aware of the impact of government policies on their families. Government policies set the tone for how isolated or supported mothers were in the health care system and in their communities. A number of the mothers felt that the
government expected them to be autonomous, despite the incredible needs of their children. Funding, numbers in terms of health care providers and specialists, and financial assistance were generally experienced as inadequate for the needs of these families. More funding and programs for in-home support was identified as a key need. Coordination of services between government, hospitals, and other agencies was also identified as an area for improvement. Government policies with regard to pediatric palliative care were seen as inadequate for families caring for a child with a life-limiting illness over a long period of time. By not taking into account families that care for children with life-limiting illnesses for periods of years, the government further isolates these families by rendering their reality of long-term caregiving invisible. Moreover, by failing to both provide adequate funding or support to caregivers and acknowledge mothers' realities as long-term caregivers, the government continues to make invisible the unpaid work of women, as women continue to be primarily the ones who take on the role of caregiver (Quittner, Opipari, Espelage, Carter, Eid, & Eigan, 1998). The gaps and barriers facing mothers at the level of government are ongoing structural problems that require an ongoing commitment to making change.

**Long-Term Caregiving and Coping**

It became clear through the research that mothers’ experiences in finding, accessing, and providing care for their child is inexorably linked to mothers’ day-to-day lives over the long term and that this does have an impact on mothers. While the focus of this study did not start out to examine the impact of providing care on mothers, it became impossible to ignore this aspect of mothers’ experiences as it was so prominent and intertwined with their experiences of finding, accessing, and providing care. Caregiving
became a primary factor in mothers’ day-to-day lives over the long term and had, in fact, become a central focus of their lives.

As one mother pointed out, mothers never get used to the fact that their child is living with a life-limiting illness and coping, for them, is an ongoing process and one that is constantly changing in order to adapt to the progression of the illness. Steele (2005) explored strategies that parents caring for children with neurodegenerative life-limiting illnesses use in coping with their experience of caring for a child with this type of life-limiting illness: seeking and sharing information, “going into slow motion”, “focusing on the child”, “putting life on hold,” “getting rid of excess baggage,” “taking one day at a time,” “reframing the experience,” “reaffirming faith,” “participating in research,” “living by the clock,” “coordinating services,” “providing physical care,” “promoting the child’s health,” and “forming new relationships.” A number of these strategies were evident in the current study in the mothers caring for a child with a neurodegenerative life-limiting illness, as well as mothers caring for a child with other types of life-limiting illnesses. Future research should explore and compare the coping strategies of mothers caring for children with other life-limiting illnesses to further delineate their experiences.

Coping with the Psychological Toll of the Illness

An important component of providing long-term care for mothers was coping with the ups and downs of their child’s illness and the gradual progression of the illness and the deterioration of the child’s health over time. Fear of their child’s death and dealing with the unknowns in this respect were a part of life for mothers. This is supported by Katz (2002) who indicates that “the inability to foresee and plan for the future . . . and the intensive care needed to care for the child influences almost every aspect of parents’ lives.
(Sloper, 2000)" in terms of parents caring for children with cancer (p.460). Mothers often coped with these fears and unknowns regarding their child's illness by approaching things day to day. Steele (2005) describes the experience of parents caring for children with neurodegenerative life-limiting illnesses as "paradoxical" in that parents approach life one day at a time and focus on the "present and near future," but also "planned ahead" in terms of resources and to avoid problems (p.106). This was very much the case for many mothers in the current study, but not for all. One mother described spending a lot of time thinking about and planning her child's funeral - "there's not a day I don't think about it" – and wanting "do right by her" in this respect. Her experience may have been different because this mother identified having had communication with health care providers and resource workers specifically regarding funeral planning. However, there may be another component involved. Funerals, and other end-of-life rituals, can be a way for families to celebrate the life of a loved one and express their love for the individual who has died. They can be a way for families to share their child's life with themselves, other family members, friends, and community members. Funerals are a way for families to find and make meaning in their child's life and their own lives. For some mothers, thinking about and planning their child's funeral may help find meaning in their child's life and in their own life, and in relation to their role as 'mother' and 'caregiver.' Additionally, it may also be a way of coping with the isolation that the family and child experience in the community during the illness. Funerals can be a way for mothers to share and express the meaningfulness of their child's life with others.

Depending on the age and stage of the child, the child's personality, and the child's level of independence, children are not always compliant in participating in
treatments or other care-related activities, particularly when treatments are frequent and
time-consuming. Whereas this issue is not necessarily faced with children who are
naturally more compliant or who are more physically dependent, these treatments and care-
related activities add another dimension to raising a child for mothers. Normal behavioural
challenges can be compounded by having to ensure compliance with treatments and care.
For example, literature shows that children's adherence to treatment for Cystic Fibrosis is
often a problem for parents and one that increases as the child gets older (Williams,
Mukhopadhyay, Dowell, & Coyle, 2007). These challenges can result in conflicts between
the mother and child over treatments and can affect how the mother and child relate to each
other. Conflicts between mother and child can also result in added stress in other family
members, such as partners, who are present during conflicts. Interventions with families
need to be aware that children are not always compliant with treatments and that parents
may need support in addressing and coping with their child's behaviours.

*Ongoing Guilt or Regrets*

Guilt and regret was expressed as a part of some mothers' experiences as a result
of the genetic nature of the child's illness, as found by Steele (2002). However, mothers'
also experienced guilt and regret in terms the diagnosis not having been found earlier,
decisions made and actions taken (or not taken) by mothers that they wonder may have
affected the child's condition and quality of life, and health care providers' mistakes that
impacted the child. As well, it did not appear that guilt was exclusively experienced by
mothers as found by Steele (2002) – one mother reported that both her and her partner felt
responsible for the genetic cause of the illness. Interventions with mothers should not
ignore these feelings of guilt and regret and the impact that it can have on mothers and their partners.

*Giving Up Part of Self*

In providing care to a child with a life-limiting illness over a long period of time, mothers had to give up a part of themselves in order to care for their child. Finding, accessing, and providing care required a huge time commitment in terms of taking care of the child, taking the child to appointments or to the emergency room, and advocating for the child, among other activities, and required a great deal of physical, emotional, and mental energy. In many cases, mothers’ mobility outside of the home was limited as a result of their child’s needs. Many of the social identities and roles mothers took on prior to caregiving were no longer possible as a result of their commitment to providing care to their child. Mothers described a sense of loss of part of their self and part of their freedom as a result. Identity and caregiving is an area in which the literature is surprisingly scarce. The few studies that have addressed caregiving and identity have mainly focused on caregivers’ caring for adult children or for parents with mental health diagnoses or disabilities and have explored caregivers’ caregiving identities (e.g. Milliken & Northcott, 2003), as opposed to parents’ identities outside of their caregiving role or changes to their previous social identities and roles. Sawatzky & Fowler-Kerry (2003), however, did look at the impact of caregiving on the well-being of a small sample of women caregiving for adult and children with disabilities and life-limiting illnesses and their findings support those of this study with respect to the loss of personal and social identities and the impact of these losses. Sawatzky & Fowler-Kerry found that women caregivers experienced loss and grieving as a result of having to give up or modify their social roles and in relation to
the social isolation they experienced as a result. As well, women had to significantly readjust, or “put on hold,” their “personal goals, roles, and life expectations” (Sawatzky & Fowler-Kerry, 2003, p.285). Steele (2005) also found that families had to “put life on hold” and “many parents shelved their previous identities outside of the home to remain at home with the child” as they gave up work and recreational activities to provide caregiving to their child (p.105). Part of the need to give up these roles and identities over the long term by mothers’ in the current study involved personal factors, such as being afraid to leave the child, and factors related to the child’s needs, such as 24/7 care; however, barriers and gaps in supports available to caregivers, such as lack of, or minimal, respite and in-home support, contributed to mothers’ challenges in participating in social, recreational, and self-care activities in or outside of the home. The concepts of identity and caregiving, and their relation to loss and grief, as well as the impact of barriers and gaps in caregiving support in caregiving identity, are important for research to explore in the future as it is an area that can affect both mothers’ emotional well-being and their self-care behaviours. Further research can help provide guidance for professionals in helping mothers cope with this aspect of caregiving.

Strengths and Barriers in Providing and Accessing Care Long Term

Mothers identified a number of strengths and barriers related to providing and accessing care long term that were often chronic and systemic. Three main issues arose in terms of strengths and barriers in health care that were particular to long-term caregiving and coping: continuity and turnover, costs of care, and lack of time and energy.
A) Continuity and turnover.

Continuity in the health care providers involved in a child’s care has been identified as an important aspect of quality of care (Clarke & Quin, 2007; Heller & Solomon, 2005; Reid et al., 2002; Spencer & Battye, 2001). Reid et al. (2002) identifies three types of continuity as being important: relational, informational, and management. The importance of relational continuity primarily emerged through the current study. Continuity in health care providers, or relational continuity, helped maintain stability in an ongoing situation in which many aspects of the child’s illness and care are unstable or unknown. Continuity has been found to facilitate and promote information sharing among health care providers and health care providers and parents (Heller & Solomon, 2005; Widger & Picot, 2008). Clarke & Quin (2007) found that health care providers felt that maintaining continuity in terms of the unit the children are in and the personnel they deal with when the child is nearing the end of her or his life was an important role for professionals. However, Clarke & Quin, as well as Docherty et al. (2007) and Spencer & Battye (2001), also found that health care providers identified that maintaining continuity in terms of the professionals involved with the child and family is a challenge in providing pediatric palliative care. With bereaved parents, when continuity extends through the child’s death and through parent’s bereavement, parents feel supported and comforted (Heller & Solomon, 2005). In the current study, continuity allowed mothers to build relationships with the health care providers, see that they cared for their child and family, and develop trust in their ability to care for their child and family, which supports findings by Heller & Solomon (2005) and Sawatzky & Fowler-Kerry (2003). Often mothers had developed strong relationships with professionals who had worked with the family for a
long period of time and considered them to be like family or friends. This supports findings by Steele (2002). Mothers also saw these professionals as sources of social support because of the large role that they played in their lives and the fact that their informal social support networks had diminished. While mothers’ informal social support networks often shrunk, their formal, or professional, support networks increased.

Continuity, however, was not always possible because of the chronic nature of the child’s illness. Finding caregivers in the first place was a challenge, but once mothers found formal caregivers, keeping them and finding replacements was a challenge. Health care providers faced their own life events that affected their ability to continue to provide care to a child indefinitely. The end of relationships with health care providers who had been with a family for a long time had the potential to be particularly challenging for mothers and have an effect on mothers' willingness to access similar services in the future. How caregivers end long-term relationships with families and whether or not, and how, they try to connect families with other care providers may affect families’ willingness to ‘replace’ the health care provider. Clarke & Quin (2007) found that bereavement follow-up is important to parents and how relationships are ended “between care facility and family” when a child dies is significant. However, some mothers also appear to experience grief and loss when significant health care providers leave the family when the child has not died and the literature does not address the issue of ending close relationships between health care providers and family when the child has not died but the professional is moving on for other reasons.
B) Cost of care.

The impact of providing care to a child with a life-limiting illness on a family's financial situation has been shown in the literature (Clarke-Steffen, 1997; Monterosso, Kristjanson, Aoun, & Phillips, 2007). For those mothers who struggled to cover costs, the cost of care was an ongoing obstacle to accessing services, equipment, transportation, and renovations to adapt the home and a source of stress in trying to find ways to overcome this barrier. As opposed to mothers who provide care to a child for a year or less, for these mothers, care-related expenses were a reality for periods of years.

C) Lack of time and energy.

As discussed above, providing and accessing care for a child with a life-limiting illness is a time consuming process requiring a great deal of time and energy from mothers. Lack of time and energy was a barrier to both the child’s care and mothers’ self-care in that the amount of time required for caregiving sometimes affected the ability of mothers to access services for their child and for themselves that they otherwise might have accessed. Also, the sheer amount of demands related to caregiving placed on mothers had the potential to affect whether or not mothers were able to accomplish all the aspects related to care that they needed or wanted to accomplish in a day. One mother, who had a lot of support and indicated that she was “luckier than a lot of people,” still indicated that in caring for a child “you are running a hospital at home” and goes on to describe that, as opposed to a hospital, “at home you are doing it yourself.”

Overall Discussion of Gaps, Barriers and Strengths

The gaps and barriers identified reflect some of the barriers identified by Liben, Papadatou & Wolfe (2008) in their review of the literature on pediatric palliative care with
respect to general barriers (emotional considerations, prognostic uncertainty and diversity of illness), community barriers (geographic diversity), and hospital barriers (caregiver team). However, this study provides a more comprehensive examination of barriers and gaps experienced at varying levels. The existence of these gaps and barriers had significant consequences for mothers in terms of finding, accessing, and providing care, including some identified by Liben et al. (2008), such as “avoidance,” “poor quality of care,” “delayed focus on palliative care,” and “conflict.” A complete list of these areas for improvement and consequences to finding and accessing care can be found in Appendix G. These areas need to be addressed in order to ensure good quality of care for children with life-limiting illnesses and their families, as well as to reduce unnecessary stress and burden for mothers who are caring for these children and coping with an already overwhelming situation.

The fact that numerous strengths were identified by mothers indicates that there are successes in the health care system with respect to care for children with life-limiting illnesses and that professionals can build on these strengths to improve quality of care for children and their families. These strengths, and the impact of these strengths on quality of care, are summarized in Appendix H.

Advocacy

Because of the gaps and barriers in place in finding, accessing, and providing care, mothers have had to step in and advocate for their children and families in order to overcome those limitations in the system and improve the quality of care received. Mothers needed to begin advocating for their children very early in the process of seeking care for their child: for some, advocacy began in trying to seek a diagnosis for their child,
which reflects findings by Davies, Davies & Sibert (2003) that mothers had to persist to receive a correct diagnosis.

Mothers used multiple strategies to advocate for their child, such as consulting multiple health care providers, using existing connections in the health care system, creating new connections, using their existing knowledge of the health care system, and seeking new information and applying new knowledge. Steele (2002) also noted that parents “work with health-care providers in ways that increased their chances of receiving sufficient and appropriate care” (p.424). Steele (2002) views “developing adequate knowledge and obtaining information related to the child’s illness” as strategies used by families to cope with their child’s illness and help them understand what is happening to their child, reduce their fears and uncertainties, and to provide the best care for their child (p.424). While this study supports this finding, it also finds that the actions of mothers in terms of seeking new information and knowledge is not only a strategy for coping, but is a strategy to make change, to ensure that their child and family receives the services and the quality of care that they should be receiving, and to overcome the power imbalances inherent in the medical system and in the community as it relates to caregivers and their seriously ill children. This study found that beyond finding information related to the child’s illness, mothers needed to learn about their rights and the rights of their children and take action to ensure that their rights were recognized. Mothers were not always able to advocate for their rights successfully on their own because of the power imbalances that existed at various levels in the health care system and the community, and thus sometimes had to advocate for themselves by contacting lawyers, ombudsmen, and human rights lawyers to help them.
Wanting to Make Change or Give Back

Mothers did not want other families to face the same barriers that they had experienced, which was also found by Steele (2005), and they found ways within their means and abilities to make changes in the health care system and community, as well as to empower other families so that they were able to overcome existing barriers and find and access existing strengths in terms of services and resources. By making change and empowering other families, it appeared that mothers were trying to minimize the very real power imbalances that existed between the medical system and parents. In addition to this, there was also a sense of appreciation for what the medical system had done for them and wanting to support, and improve the strengths of, the system.

Mothers participated in research and provided information to other families and to health care providers, which was also found by Steele (2005). They made donations, volunteered, fundraised, and also provided feedback to health care providers. Mothers had varying financial situations, energy levels, caregiving demands, and other life demands, which affected the extent to which they were able to make the changes they wanted. Mothers were not always able to work toward all of the changes that they would have liked, but had very clear ideas of what changes they hoped that they might be able to make in the future when they had the ability, means, energy or time to do so.

The decision to participate in research in particular was a conscious, purposeful, and meaningful decision made by mothers that was not made lightly. Steele (2005) describes participating in research as one strategy used by parents to create meaning in their experience of caring for a child who was dying in terms of helping other families and children and working towards a cure for the illness. While the current study did not
focus on meaning-making, the findings would suggest that donating money, volunteering, fundraising, being a resource to other families, and providing feedback to professionals are also part of the meaning making process for mothers. Moreover, this study would add that making change in and of itself is an important finding to highlight: creating meaning is something that occurs within the individual parent or family, while making change and giving back extends beyond that – it creates new meanings and new outcomes for other parents, families, and professionals. As a result, it is important to validate and highlight mothers’ power as agents of change not only in their own experiences, but in the experiences of other families.

Differences Between Cancer and Other Life-limiting Illnesses

The mother who was caring for a child in remission from cancer was very positive about her and her child’s experience with the health care system and identified the health care providers involved with her and her child as supportive. This mother may have viewed the period of diagnosis more positively than the other mothers because of the positive outcome of her child’s illness, the increased knowledge of the illness trajectory for cancer by professionals, or, because of her focus on positives, positive events may have overshadowed the negative events. She identified a number of free activities and services offered through the hospital that were not identified by the other mothers and indicated that she was able to get funding for most costs. As well, negative outcomes were not a focus of discussions with the physicians involved with her child’s care and in fact she reported that physicians told her to focus on the positive and not on a negative outcome.
While it is unclear from this study whether the differences in experiences between the mothers caring for children with non-cancer diagnoses and the mother caring for a child with a diagnosis of cancer were the result of the types of illness (cancer vs non-cancer diagnoses), the child's current health status (e.g. in remission), or factors related to the mother (e.g. personality or positivity), these differences were evident. These findings do support the research that mothers caring for children with cancer have different caregiving and coping experiences than mothers caring for children with other life-limiting illnesses (Clarke & Quin, 2002; Monterosso, Kristjanson, Aoun, & Philips, 2007; Steele, 2005). For example, Steele (2005) found that parents caring for a child with a neurodegenerative life-limiting illness did not use the coping strategies of accommodations and normalization that parents caring for a child with a non-neurological illness used, rather "the opposite was true" for these families (p.110).

Further research should continue to explore the differences and similarities between these types of caregiving situations.

Understanding of Pediatric Palliative Care

The second focus of this research study involved exploring how mothers understood the concept of pediatric palliative care. The following sections discuss the findings related to mothers' understandings of this concept with respect to the literature.

Development of an Understanding of Pediatric Palliative Care

Mothers had all developed an understanding of pediatric palliative care. Each mother had a unique understanding that placed a different emphasis or significance on different elements of pediatric palliative care. While the few existing studies on parental understandings of pediatric palliative care (Clarke & Quin, 2007; Monterosso,
Kristjanson, Aoun, & Phillips, 2007) found that parents did not have a good understanding of this type of care, this study found that mothers do have knowledge about pediatric palliative care and their understanding of the concept is multi-faceted; however, their conceptualizations may not incorporate all facets of the World Health Organization definition. Rather, their understanding of pediatric palliative care fit their own experiences with this type of care with respect to their particular reality in caring for a child with a life-limiting illness. As each mother’s reality was different, so too were their conceptualizations of pediatric palliative care. Mothers’ understandings changed and expanded as they were confronted with new experiences or information about pediatric palliative care: mothers’ understanding of their child’s illness and lifespan, their experiences with adult palliative care, professionals’ communication to them regarding pediatric palliative care, and their other experiences with pediatric palliative care all impacted their view of pediatric palliative care. One mother pointed out in her written feedback that she guessed that “concept 1 [Figure 1] is the road to concept 2 [Figure 2].” A complete understanding for mothers may only come through time and experience. This same mother highlighted in her feedback, “We never fully understand or get all req’d information for concept 2 [understanding of pediatric palliative care (Figure 2)]. ‘Final destination’ concept 2 will always be out of reach.”

Understanding Child’s Illness and Lifespan

How mothers understood the trajectory of their child’s illness played a role in their understanding of pediatric palliative care. Mothers who understood their child’s illness to be an illness in which there was a likelihood of a positive prognosis, or an illness which has a long trajectory had not spent time thinking about pediatric palliative
These mothers identified that their children were not receiving pediatric palliative care and it was challenging for these parents to think about this type of care because of their child’s current level of health. While all mothers viewed pediatric palliative care as comprising end-of-life care, these mothers were more likely to view pediatric palliative care as solely comprising end-of-life issues.

In another case, when the child’s health had stabilized and the mother expected the child’s lifespan to be relatively long, the mother’s understanding of pediatric palliative care as end-of-life care was challenged. For her, an understanding emerged that pediatric palliative care meant advocacy for the child and family rather than end-of-life care.

Other mothers had spent time thinking about issues related to pediatric palliative care. These mothers had identified that their children were receiving pediatric palliative care and recognized that pediatric palliative care was being provided to their child because of the seriousness of the child’s condition. These mothers’ had had moments when their child was close to death in the past and their illness trajectories were uncertain. As a result, these mothers’ had had to spend time thinking about and confronting end-of-life issues. These mothers were also more likely to identify pediatric palliative care as extending beyond just end-of-life care.

Experiences with Adult Palliative Care

Experiences with adult palliative care could also impact mothers’ understanding of pediatric palliative care. Some aspects of palliative care for adults are similar to those of pediatric palliative care, such as pain control and psychological support. Witnessing components of adult palliative care allowed one mother to have a better idea of what
pediatric palliative might and should comprise and what to expect for her child. As well, when this mother had experienced instances in which components of adult palliative care had not been implemented effectively, she was able to address the issue and her concerns with health care providers in order to try to ensure that her child did not suffer in the same way as the adult.

For another mother, witnessing adult palliative care allowed her to make distinctions between the adult and pediatric palliative care in terms of the meaning and the impact of palliative care: “There is nothing abnormal about being sick or dying when you’re old but I don’t feel I can use this experience and accept it as well for my child.” For this mother, with experience with palliative care has come a certain acceptance of death and a willingness for death to be “painless and quick” since the person has lived a long life; however, this understanding and acceptance does not translate over for her in terms of pediatric palliative care.

Professionals' Communication about Pediatric Palliative Care

How professionals communicated to mothers about pediatric palliative care also affected mothers understanding of the concept. Mothers who had had conversations with health care providers about pediatric palliative care were clearer as to how pediatric palliative care related to their child. Having conversations with health care providers about components of pediatric palliative care, whether it was labeled as ‘palliative care’ by the health care provider or not, allowed mothers to express their wishes for their child’s care. Talking about pediatric palliative care allowed mothers to start planning and making decisions regarding future aspects of the child’s care and quality of life. While conversations about pediatric palliative care were challenging for mothers to have with
health care providers, it appeared that these conversations could be helpful to mothers when done in a sensitive way. It was also clear from mothers’ experiences that communication around the idea of ‘long-term’ pediatric palliative and pediatric palliative care as comprising more than end-of-life care did not often take place despite the fact that it may have helped mothers better understand their own situation. This was evident in the case of one mother who was impacted by a health care provider who introduced her to the concept of ‘long-term’ pediatric palliative care after her child had been receiving pediatric palliative care for a number of years. This discussion helped her understand the role of pediatric palliative care in her and her child’s life and how it did not necessarily mean that “you’re at the end.”

Some mothers indicated that some vague conversations had taken place about pediatric palliative care and others indicated they had not had any communication with health care providers about this type of care because of the type of illness, the current health status of the child, or the likelihood of a positive outcome. However, particularly in cases in which the child’s current health is relatively stable, having conversations, at least about components of pediatric palliative care, may be helpful for mothers to be aware of the aspects of this type of care that are available and that they would want involved.

It is also likely that when health care providers did communicate to mothers about pediatric palliative care, their understandings of the concept affected what information about pediatric palliative care they communicated to mothers. St-Laurent-Gagnon, Carnevale, & Duval (2008) conducted a study in Canada that found that physicians had a “one-dimensional” view of pediatric palliative care that involved “physical symptom
relief," that they had various feelings about when pediatric palliative care should be implemented, and that they were uncomfortable using the words ‘palliative care’. Studies outside of Canada (Clarke & Quine, 2007; Docherty et al., 2007; Monterosso et al., 2007) have similarly found that health care providers providing pediatric palliative care more often than not understood this type of care to be end-of-life care and a separate stage of the child’s care. It is not surprising that if health care providers do not view pediatric palliative care from an integrated perspective that mothers’ understandings would similarly reflect that view.

Other Experiences with Pediatric Palliative Care

Mothers also had experiences with other children with life-limiting illnesses through family members or friends. The experiences that mothers shared primarily involved children who had died. These events deeply impacted these mothers and were a learning experience for them in terms of pediatric palliative care in relation to their own child. These families were seen as a better resource than professionals as they had gone through the experience themselves. As well, like with their experiences of adult palliative care, when mothers heard about instances in which children had died without pediatric palliative care or had died in a lot of distress, mothers were able to address these concerns in relation to their own child with their pediatric palliative care team so that they could try to ensure that their child would not be in similar distress.

Mothers’ Understandings of Pediatric Palliative Care

As indicated above, mothers’ understandings of pediatric palliative care were varied. Taken together, mothers brought up most of the elements of pediatric palliative care identified by the WHO (1998). Mothers primarily identified pediatric palliative care
as end-of-life care, including pain control, family support, place of death, and decision-making. Some mothers identified aspects of pediatric palliative care that did not just comprise issues related to end of life, such as quality of life and stages of pediatric palliative care. Some mothers also expressed uncertainties and questions about this type of care.

**End of Life**

All of the mothers identified end-of-life care as a component of pediatric palliative care. End-of-life was often synonymous with pediatric palliative care for many of the mothers. This understanding fits with the traditional understanding of both adult and pediatric palliative care (Masri, Farrell, LaCroix, Rocker, & Shemie, 2000), and with many health care providers' views of pediatric palliative care (Docherty et al., 2007).

**A) Pain control.**

Pain control at end-of-life was an important part of many mothers' understanding of pediatric palliative care. It is not surprising that this was the case since pain management has been identified as a primary concern to parents by parents (Contro et al., 2002) and by professionals (Jones, 2006) and it is also a key component of adult palliative care (WHO, 1998). Despite the primacy of these concerns, pain control has been shown to be a problem at end-of-life (Wolfe et al., 2002; Kreicbergs et al., 2005) in terms of ineffective treatment (Contro et al., 2002; Jones, 2006; Wolfe et al., 2002;) or health care providers who were unqualified for managing pain in children at end-of-life (Contro et al., 2002).

**B) Family support.**
Family support was another important component mothers identified as part of pediatric palliative care. Different aspects of family support were described by mothers: non-judgmental support, facilitation of families’ wants and needs, psychological support to the parents, practical support, including funeral planning, and spiritual and psychological support to the child. These findings support the literature, which has identified family support as a key aspect of pediatric palliative care for parents in terms of psychological, emotional support, and spiritual support (Jones, 2006), sibling support (Contro et al., 2002), and practical support (Jones, 2006).

C) Place of death.

Some mothers identified the physical location of the child’s death as an aspect of pediatric palliative care. Wanting their child to die at home was expressed by many of these mothers. However, as pointed out by one mother, families’ need support in having their child die at home, which was also identified by Clarke & Quin (2007).

Not all mothers identified that they wanted their child to die at home. One mother pictured pediatric palliative care as “something that’s done in the hospital” and felt that it could be challenging to have her child die at home. A number of factors may play a role in mothers’ decisions to have a child die at home or elsewhere, such the challenge for mothers, their understanding of the services available to them in terms of end-of-life support at home, in hospital, or in hospice, and their personal or psychological comfort with having the child die at home.

D) Decision-making.

Decision-making at end of life was identified by some, but not many mothers.
Mothers identified that pediatric palliative care involved decisions regarding both the care of the child at end of life and issues regarding organ donation. In looking at bereaved parents, Widger & Picot (2008) found that these parents would have liked health care providers to talk to them about organ donation. Decision-making in terms of pediatric palliative care has been identified as an integral aspect of pediatric palliative care, but one in which there is scant scientific research (Misri, Farrell, LaCroix, Rocker, & Shemie, 2000). Misri et al. (2000), in their review of the literature on end-of-life decision-making regarding critically ill children, call for more research to be carried out to better understand health care providers’ and parents’ decision-making processes at end-of-life. These researchers also highlight the importance of professionals’ communication with parents regarding pediatric palliative care in terms of preventing, mediating, and resolving conflicts that may arise between professionals and families in end-of-life decisions.

*More Than End of Life*

A few mothers described pediatric palliative care as involving aspects of care that comprised more than end-of-life care alone. The child’s quality of life, including pain management and emotional well-being, was identified as important to some mothers not just at the end of the child’s life, but throughout the illness. While Contro et al. (2002) identified pain management at end-of-life as important to families, it was also evident from mothers in the current study that pain management was an issue for children throughout their illness. Misri et al. (2000) point out that the literature shows that quality of life is one factor in decision-making regarding “withdrawing or withholding some
treatment,” although the termination of curative treatments is not necessary for the implementation of pediatric palliative care (p.S48).

One mother identified the concept that there might be stages of pediatric palliative care and that advocacy comprised one component of pediatric palliative care. The idea of stages of palliative care is interesting as it acknowledges that this type of care can involve different components and mean different things depending on the stage of the child and family. In terms of one stage or component of palliative care being advocacy, Jones (2006) recognizes the need for advocacy on behalf of parents in pediatric palliative care and identifies that social workers can fill this need. Advocacy appears to be an under-identified aspect of pediatric palliative care. While advocacy can be an important service provided by professionals, mothers may not be aware that these professionals can advocate for them and their children and that this advocacy is can be a component of pediatric palliative care.

Questions and Uncertainties

While mothers had understandings of pediatric palliative care, uncertainties regarding the concept were fairly common, particularly in mothers who identified that their child was not receiving pediatric palliative care. This would make sense as they had less experience with and communication about pediatric palliative care.

Summary of Mothers’ Understanding of Pediatric Palliative Care

Taken together, mothers brought up most of the elements of pediatric palliative care identified by the WHO (1998) in terms of caring for the child’s “body, mind, and spirit,” providing “support to the family,” and “alleviat[ing] a child’s physical, psychological, and social distress” and in terms of where pediatric palliative care can be
provided (e.g. at home or hospital). Some aspects of pediatric palliative care were more
known to mothers as comprising pediatric palliative care, such as pain control, family
support, and the idea of pediatric palliative care as end-of-life care. Other areas, such as
spirituality (Davies, Brenner, Orloff, Sumner, & Worden, 2002), decision-making
(Larson, Scofield, Sourkes & Cohen, 2002; Nuss, Illinds, & LaFond, 2005), quality of life
beyond end-of-life and including emotional well-being (WHO, 1998), and advocacy
(Sourkes et al., 2005), were identified less often by mothers, and particularly the idea of
pediatric palliative care as extending beyond end-of-life care (WHO, 1998; Misri et al.,
2000). None of the mothers in this study covered all aspects of the World Health
Organization’s conceptualization of pediatric palliative care in their understanding of the
concept. None of the mothers talked about bereavement follow-up, which has been
identified as an important area of pediatric palliative care by bereaved parents (Contro,
Larson, Scofield, Sourkes, & Cohen, 2002; Widger & Picot, 2008), except in the case of
one mother who asked whether ‘post-palliative’ care existed. Interestingly, none of the
mothers explicitly identified that pediatric palliative care could be implemented in
conjunction with curative or maintenance related care, which is an important component
of pediatric palliative (WHO, 1998; Liben, Papadatou, & Wolfe, 2007). These are all
areas in which awareness can be raised and communication between health care providers
and mothers can be improved in order to ensure that mothers are aware of services that
are, or should be, available to them, to prevent misunderstandings and conflicts between
health care providers and families, and to ensure a good quality of care for children and
their families. Communication with mothers about pediatric palliative care long term is
also an area which needs to be improved as it may help mothers better understand the meaning of pediatric palliative care in relation to their own lives.

Recommendations

The results from this study reveal a number of areas for improvement in terms of care for children with life-limiting illnesses. Based on the findings, I would make the following recommendations for action: (1) Increased home support and respite care for mothers and children; (2) Increased education and training for health care providers, including social workers, on communicating with parents; (3) Increased education at the university level and increased workplace training for social workers regarding the experiences of needs of families providing care for a child with a life-limiting illness long term; (4) Earlier and more proactive intervention by social workers; (5) Improved coordination of services and funding sources; (6) Improved policies, programs, and funding related to care, including pediatric palliative care, for children with life-limiting illnesses and their families; (7) Increased accessibility of research and information on care and pediatric palliative care for mothers and their families; (8) Ongoing research in pediatric palliative care.

Extending the Literature

This study adds to the literature by further delineating the experiences of mothers who are finding, accessing, and providing care for their children with a life-limiting illness. This study further identifies strengths, barriers and gaps that exist for these mothers within a Canadian context and identifies how mothers overcome the barriers and gaps that they face. In general, the findings from this study lend support to the literature and in many cases find that there are many areas with respect to care for children with life-limiting
illnesses in which mothers' voices have still not been heard despite literature identifying some of their needs. This study raises these issues, identifies additional issues, and highlights the continued need for change in these respects. This study also highlights the importance of advocacy and wanting to give back and make change and views these aspects of mothers' experiences as important in improving the quality of care for their families and for others. Moreover, this study is one of the few that includes the experiences of mothers who have children with non-cancer illnesses.

This research study is also one of the few that has explored mothers' understandings of pediatric palliative care. This research begins to identify how mothers understand pediatric palliative care, what components are less identified as components of pediatric palliative care, and what gaps in understanding may exist. This research also identifies factors that contribute to mothers' understanding of this type of care, highlights the importance of professionals' communication with mothers in terms of pediatric palliative care, and calls for more research in this area.

Limitations

This study is limited by the fact that it only looked at mothers living in urban areas. As well, participants were mothers who accessed care over a number of years and as a result, the experiences of mothers finding, accessing, and providing 'short-term' care were not reflected in the study. This study may be limited by the heterogeneity of the participant sample, as mothers with a range of experiences were represented. As well, it is always possible that allowing a partner to be present during one of the interviews could have affected the responses provided by that mother.
Future Research

There is a continued need for research in terms of care, including pediatric palliative care, for children with life-limiting illnesses. A number of issues have been raised through this study in which future research needs to be conducted. This study did not explore the experiences of mothers in finding and accessing care in Northern Ontario and Northern Quebec. Research needs to be done in these communities as they may face gaps and barriers that did not emerge through the current study. The mothers in the current study all had access to children’s hospitals and other services within an hour’s drive at most. While some families faced challenges with regard to accessing services because of distance, it is likely that barriers in this respect would be much more pronounced in the above communities. Similarly, this study did not look at the experiences of Aboriginal Peoples living on- or off-reserve. This is an area in which there continues to be a scarcity of research.

Research also needs to be conducted looking at the experiences of immigrants in order to further explore their experiences of discrimination or lack of discrimination in the health care system in order to identify barriers and gaps that might be particular to this population of people. The current study was not able to fully explore the experiences of this population. Further research also needs to continue to delineate the differences and similarities in experiences between cancer and non-cancer experiences.

None of the families in the current study accessed services through hospice. Further research should explore why families are not accessing services through hospice – whether they do not meet their needs, whether they do not meet the requirements for
hospice services, whether they associate it with end-of-life care, and how hospice can work to meet the needs of these families who might benefit from programming.

As this study was exploratory in nature in terms of looking at mothers' understanding of pediatric palliative care, future research should been conducted to further explore the differences in mothers understandings across different types of illnesses and at different stages of the illness trajectory. As well, studies should look at health care providers' understandings of pediatric palliative care and how they communicate to parents about this type of care. Lastly, research needs to be conducted on implementing program and policy changes and education and training programs that can address any or all of the issues identified through this study and evaluate the effectiveness of these changes in order to work toward breaking down existing gaps and barriers and building on strengths.

Conclusion

This study aimed to explore mothers’ experiences of the care provided to their child with a life-limiting illness. A great deal of strengths in the health care system were identified by mothers, and increased services providing aspects of pediatric palliative care was evidenced by mothers over recent years; however, there are still gaps and barriers to services and areas in which improvements need to be made. These gaps and barriers unnecessarily add to the already overwhelming nature of mothers’ experiences in caring for a child with a life-limiting illness. Mothers need for these gaps and barriers to be addressed and often need psychosocial support from professionals in providing care. Social workers can play an important role in this support and need to be more proactive and effective in terms of advocating for the family within hospitals, the medical system in general, the community, and the government.
This study also aimed to explore mothers’ understandings of pediatric palliative care. Mothers’ had various conceptualizations of pediatric palliative care, which were affected by their experiences with their own child, other families, adult palliative care, and health care providers. Understanding how mothers’ conceptualize pediatric palliative care can help professionals in raising awareness about pediatric palliative care, identifying areas in which communication needs to be improved in this regard, ensuring that mothers are aware of services that are, or should be, available to them, and preventing misunderstandings and conflicts. It is hoped that the information gathered through the research will not only increase health care professionals’ and social workers’ understanding of the experiences and needs of mothers in terms of finding, accessing, and providing care for children with a life-limiting illness, but help improve services through professionals’ practices and inform policies at the hospital, community, and government levels in order to better serve the needs of children and their families.
APPENDIX A

Interview Questions

1. Tell me about your child(ren).

   Prompts: current age, age at diagnosis, diagnosis, gender, health status, schooling, Siblings

2. What types of care and services has your child been receiving?

   e.g./prompts: at home, hospital, hospice, respite, palliative care, etc., changed over time?

3. Tell me about your experiences in finding and accessing care for your child?

   Prompts:
   - Finding and choosing services for your children?
   - Why are you not accessing other services (e.g. hospice, home care)?
   - Barriers in accessing care?
   - Positive experiences?
   - Strengths in the system?
   - Challenges?
   - Conflicts?
   - Quality of care strengths/issues/concerns?
   - Significant events/memories/things that stick out

4. How do you feel overall about the care that your child(ren) has received and is receiving?

5. How do you understand pediatric palliative care?

6. Is there anything you think needs to change with regard to pediatric palliative care in Ontario? What suggestions do you have for improving pediatric palliative care services or improving access to these services?

7. Is there anything else you would like to add that we have not covered?
APPENDIX B

Telephone Script: Mother Caregivers' Experiences of Pediatric Palliative Care

Hi _____________ . My name is _______________ . I'm calling about follow-up to a
research study you took part in back in _______ [month] on parent caregivers. You
filled-out a survey and a questionnaire. Do you remember the study?

(If no – the study was looking at the experience of parents who are caring for a child with
a life-limiting illness. You filled out a survey that asked questions about you and your
family and answered a bunch of questionnaires. Sound familiar?)

The reason I'm calling is because you indicated that you would be willing to be contacted
for follow-up. I'm calling to let you know about another study that is being carried out
with a focus on mothers, care for children with life-limiting illnesses, and pediatric
palliative care, and to let you know what would be involved and to see if it is something
you would be interested in. The study is being carried out by myself, Miguelle Ouellet, a
Master's of Social Work student at Laurier University, for a Master's thesis, and it is
being supervised by Dr. Susan Cadell, who is also a lead investigator on the Parent
Caregiver Study. Is now a good time for us to talk?

(If not, ask when would be a better time to call back)

If not interested: Okay. I understand. Well, we really appreciate you taking part in the
first study. Before I go I'm going to give you a 1-800 number to call just in case you
change your mind and decide you would like to hear more about the mothers’ study:
1-800-810-0721. Thanks again.

(If yes, continue)

I will start off by letting you know about the study and what would be involved, and then
I will ask if you have any questions.

The purpose of this study is to explore mothers’ experiences of care of children with life-
limiting illnesses (including families’ needs, barriers to services, challenges, and positive
experiences). The overall goal is to increase social work and health care professionals’
understanding of the experiences and needs of mothers and children, and to inform and
improve health care policies and services.

Participation in this study involves taking part in one in-person interview that will take
approximately 1.5 to 2 hours. You will be given the option of having the interview take
place at your home or at another location in your community, whatever is most
convenient for you. During the interview, you will be asked questions about your
child(ren) and the different types of care and services your child(ren) has been receiving,
as well as about your personal experiences finding and accessing care and pediatric
palliative care for your child. In order to ensure that the information for the study is
accurate, the interview will be audio-taped. You are always welcome to withdraw at any
time.

Your identity and the identity of all family members will be kept strictly confidential.
You can choose not to participate at any time without consequence and all questions are
completely voluntary.

Do you have any questions I can answer at this time?

Would you like more time to think about whether or not you would like to participate in
the study?

(If agree to participate...) Great. I am scheduling interviews in _(name of city)_ for the
week of ________. What day and time would work for you? (Schedule the interview.)
Would you like the interview to take place in your home or at another location? (Arrange
the location and ask for the address of the location.) Thank you very much for your
participation – I am going to give you a 1-800 number to call and leave a message in case
you change your mind about participating in the study or if something comes up with
regard to the interview date. The number is 1-800-810-0721. If I don’t hear from you, I
will see you on _____ (the date of the interview) at _____ (time of the interview).

(If parent declines to participate...) Thank you for considering this project at this time. Is
there any feedback that you wish to share with me about not participating? Is there any
additional information I could provide to you at this time?

(If parent would like more time to think about participation...) Ok, when would be a
good time for me to call back and check-in with you again? (Arrange a day and approx.
time to call back.)
APPENDIX C

Transcribing Rules

1. All questions asked and comments made by the interviewer are to be included in the transcriptions.

2. All of the interviewees’ responses, questions, and comments are to be included in the transcriptions.

3. Sounds (such as ‘uhs’ and ‘ers’ and coughing or crying) are to be transcribed.

4. Pauses are to be transcribed.

5. If speech is inaudible or muffled, it will be indicated in the transcription by the following: [inaudible] or [muffled].

6. Speech will be transcribed as is on the tape recording (i.e., slips of the tongue or misspoken words/comments will be recorded as is).

7. General observations about the interviewees’ reactions will be noted at the start of the transcriptions.

8. After transcription is complete, all identifying information are to be removed (including city and hospital names, individuals’ names, etc.)
APPENDIX D

Preliminary Findings and Feedback From Sent to Participants
(Before final changes)

Summary of Interviews and Request for Feedback

All of the interviews have been transcribed and analyzed. A number of overarching themes emerged in the analysis of the interviews. Two concept maps (diagrams) have been created to reflect and summarize these themes and they are included below. Following each concept map is a brief explanation of each concept map and the themes it contains. In order to ensure that the concept maps and themes accurately reflect your experiences and the information provided through the interviews, your feedback is requested. Please (1) review the concept maps and explanations, (2) complete the brief feedback form included, and (3) return the completed feedback form by mail or email before February 11, 2009. All of your feedback is greatly appreciated.

Summary of Participants

Six mothers participated in the ‘Mother Caregivers Experiences of Pediatric Palliative Care’ research study. All of the participants indicated that they have been caring for a child with a life-limiting illness for a number of years. Mothers were caring for children ranging in age and type of illness.

Please provide your feedback about the concept maps, themes, and/or explanations on the feedback sheet attached. Please comment on whether this reflects your experience. Let me know if you have questions or comments or changes to suggest. If you need more space, please feel free to include another page with additional comments.
Wanting to Make Change or Give Back

In analyzing the interviews, it appears that the experience of pediatric palliative care and caring for a child with a life-limiting illness is overwhelming in nature, regardless of mothers' positive or negative experiences. Mothers expressed the overwhelmingness of the experience around four areas: (1) Getting a Diagnosis, (2) Support/Isolation, (3) Long-Term Caregiving and Coping, and (4) Self-Advocacy.

(1) Diagnosis – This theme includes experiences surrounding obtaining and dealing with the child’s diagnosis. It includes positives and challenges of finding and acknowledging the diagnosis, unknowns with regard to the child’s illness and lifespan, and reactions or feelings about the diagnosis.

(2) Support/Isolation – This theme includes mothers’ experiences of support and/or lack of support at 5 levels: (a) family and friends, (b) professionals, (c) work, (d) health care and community services and resources (e.g. services available and not available), and (e) government (e.g. funding, coordination, resources). Strengths, barriers and gaps identified by mothers will be discussed at each of these levels.

(3) Long-term Caregiving and Coping – This theme includes 2 levels: (1) Mothers’ experiences caregiving and coping with caregiving over the long term and wanting/needing support (e.g. financial, professional) over the long term. Strengths, barriers and gaps identified with respect to long-term caregiving will be discussed. (2) Mothers’ experiences coping with fear and close calls with their child, for example, as well as unknowns with regard to child’s end of life. It also includes mothers’ experiences around both preparing for the future and/or trying not to think about the future.

(4) Self-Advocacy – This theme will include mothers’ experiences needing to be proactive (e.g. ask questions, research information, seek more than one opinion, fight for services/resources) and resourceful (e.g. make and use connections) in order to navigate the health care system and maximize support for their child.
It also appears that the overwhelming nature of the experience as outlined in the concept map, and experiencing the challenges and barriers within each level of the circle, has resulted in mothers to want to make change both for their child and for other families and/or to give back (e.g. volunteering, participating in research). **Wanting to Make Change or Give Back** is the final theme, which will include mothers' experiences of wanting to contribute to change and of taking action.

**Concept Map 2:**

**Factors Affecting Mothers' Understanding of Pediatric Palliative Care**

![Concept Map 2](image)

**Explanation**

Mother's understanding of pediatric palliative care (the centre circle) develops and continues to develop from different experiences with pediatric palliative care (the outer circles): Understanding the child's illness and lifespan, experiences with adult palliative care, professionals' communication (or lack of communication) about pediatric palliative care and what it is, and other experiences of children regarding pediatric palliative care. Each mother has developed a working understanding of pediatric palliative care and what it involves. Some mothers discussed how their understanding has changed over time.
FEEDBACK FORM

Please provide your feedback about the concept maps, themes, and/or explanations. Please comment on whether this reflects your experience. Let me know if you have questions or comments or changes to suggest. If you need more space, please feel free to include another page with additional comments.
APPENDIX E

Wilfrid Laurier University
Information and Informed Consent Statement – Interview

Mother Caregivers’ Experiences of Pediatric Palliative Care

Investigator: Miguelle Ouellet
Master’s of Social Work student
Wilfrid Laurier University

Thesis Supervisor: Dr. Susan Cadell
Associate Professor
Director, Manulife Centre for Healthy Living
Lyle S. Hallman Faculty of Social Work
Wilfrid Laurier University
519-884-0710 ext. 5235

Contact Person: Miguelle Ouellet – 1-800-810-0721

We are inviting mothers to participate in this research study. The purpose of this study is to explore mothers’ experiences of pediatric palliative care. This study is being conducted by Miguelle Ouellet, a Master’s of Social Work student at Wilfrid Laurier University for a Master’s thesis under the supervision of Dr. Susan Cadell, Associate Professor and Director of the Center for Healthy Living at Wilfrid Laurier University, and Co-Investigator on the Canadian Institutes for Health Research’s New Emerging Team (NET): Transitions in Pediatric Palliative and End-of-Life Care.

Information

During the interview, you will be asked questions about your child(ren) and the different types of care and services your child(ren) have been receiving, as well as about your personal experiences finding and accessing care and pediatric care for your child, and about how you understand pediatric palliative care. The interview will take approximately 1.5 to 2 hours. The interview will be conducted by the research investigator and will take place at a location convenient to you.

In order to make sure that we have an accurate record of what you have shared during the interview, your interview will be audio-taped and transcribed. All identifying information will be removed from the transcripts and only the investigator and thesis supervisor will have access to them. The audio-tapes and transcripts will be identified only by code number and stored in a locked filing cabinet or secured information system. They will be stored for 5 years after the publication of the results from this study. After 5 years, the tapes will be
demagnetized and the transcripts will be destroyed. The tapes will not be used for any additional purposes without your additional permission.

Participant's initials: __________

Once a preliminary analysis of the interview has been completed (approximately September 2008), a summary of the themes that came up during your interview will be sent to you by mail or email. You will be asked to read the summary and send back brief written feedback indicating whether you feel the summary of themes is accurate and whether you feel that any changes need to be made. There will be a postage paid stamped envelope included in which you can return this response.

Once final data analysis has taken place, if you have indicated on the information and consent letter that you would like to receive the results of the study, a summary of the final results will be mailed to you (approximately June 2009).

The results of the study will appear in a thesis and may be prepared in a report for publication (e.g. peer-reviewed journal article). The Parent Caregiver research team will also receive a copy of the results.

This study will involve the participation of approximately 6-10 mothers who are caring for a child with a life-limiting illness. Due to the nature of this study, it is possible that quotes from your interview may be used in publication. To maintain confidentiality, all identifying information will be removed from the quotations. Where a specific family or disease characteristic is rare and could potentially be identifying, the information will be changed in the quote. Please indicate your preference below regarding the use of your quotations:

Name: ____________________________

☐ Yes – I can be quoted with no identifying information.

☐ No – Please do not use quotes.

Risks

This research project deals with a sensitive topic. The interviewer will monitor your distress level and will stop the interviewing process if you become upset. The interviewer will then ensure that you are aware of your right not to answer any questions asked and your right to terminate the interview at any time. If necessary, the interviewer will refer you to appropriate services and resources to ensure your support needs are met.
Benefits

You may benefit from the ability to communicate your experiences of pediatric palliative care in a safe, non-judgmental setting. In addition, your participation may benefit other families, researchers, and policy makers in pediatric palliative care by providing a better understanding of the needs of families caring for children with a life-limiting illness.

Participant's initials: __________

Confidentiality

Your identity and the identity of all family members will be kept strictly confidential. All identifying information will be removed from the data. All documents and audio tapes will be identified only by code number and the information will be retained in a secured information system and locked filing cabinet. All identifying information will be kept separate from the data.

All documents that are kept on a computer will be password protected. Identifying information will not be emailed to anyone at any time. You will not be identified by name in any reports or presentations of the completed study. Only the study personnel, which consists of the research investigator, Miguelle Ouellet, and the research supervisor, Dr. Susan Cadell, will have access to the study data.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be destroyed. You have the right to omit any question(s)/procedure(s) you choose.

If you would like to be notified of the results of the study, please indicate below:

Name: ________________________________

☐ Yes – I would like to be notified of results.

Contact

If you have questions at any time about the study or the procedures (or if you experience adverse effects as a result of participating in this study) you may contact the Research Investigator, Miguelle Ouellet, at 1-800-810-0721. This project has been reviewed and approved by the University Research Ethics Board at Wilfrid Laurier University. If you feel you have not been treated
according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

Consent

I have read and understand the above information. I have received a copy of this form.  
I agree to participate in this study.

Participant's signature ___________________________ Date ____________

Investigator's signature ___________________________ Date ____________
APPENDIX F

Feedback from Mothers

Participant 1:

Hello Miguelle,

A belated happy new year. It was so thoughtful of you to send a holiday greeting card!

I think you did a SUPERB job at creating the two concept maps. They certainly reflect my experience, and I find it interesting that other mothers must have identified similar themes.

I greatly look forward to the next step and am happy that I participated.

Warmest regards

Participant 2:

Both maps reflect my experience. I would add that as far as coping is concerned, it almost as if it needed constant adjustments. You deal with the disease but this disease progresses and you need to get used to the disease itself but also its progression which is a constant reminder that your child is living with a life threatening disease. Do we get use to this? No of corse.

Palliative care: I have had experience with palliative care but mostly on elderly people. There is nothing abnormal about being sick or dying when you're old but I don't feel I can use this experience and accept it as well for my child. For an older person, you want it to be painless and quick as for a child, my first thoughts are aimed at stretching it as long as possible. For some reason I feel selfish because I don't feel ready to let go as I would for my grandparents for exemple. Maybe it's because my child is not there yet and that eventually it might be more of a relief to see her go than to see her suffer.
Participant 3:

FEEDBACK FORM

Please provide your feedback about the concept maps, themes, and/or explanations. Please comment on whether this reflects your experience. Let me know if you have questions or comments or changes to suggest. If you need more space, please feel free to include another page with additional comments.

Concept Map 1: The four areas are correct - not sure if the size of circle relates to the more intense feelings, issues, etc. or just drawn that way (or the more important or more problematic)

Themes are correct and explanations are clear on.

Explanations are understandable. Shows where areas that "other groups (medical and other agencies) need to address which is brief".

Concept Map 2:

Understandable but vague:

"Short answer" - questions to ask

Fuzzy understanding of palliative care

Once you comb the facts it makes more sense. Doesn't give examples as clear as 1st step explanation.

The explanation answers the question but doesn't answer the question.

Concept 1 reflects my experiences

Concept 2 - yes, it does show how care varies on understanding of palliative care.

Guess concept 1 is the lead to concept 2.

We never fully understand or get all we'd information for Concept 2, also information fed helps. Concept 2 will always be out of reach.
## APPENDIX G

### Summary of Gaps and Barriers and Their Impact to Care

<table>
<thead>
<tr>
<th>Theme</th>
<th>Level</th>
<th>Barriers &amp; Gaps</th>
<th>Impact to care</th>
</tr>
</thead>
</table>
| Realizing the Strengths and Barriers of the Health Care System | Health care provider-related factors                                 | Misdiagnosis                                                                  | • Diminished trust in health care providers  
• Delayed diagnosis and access to appropriate care |
|                                            |                                                                       | Repeated tests                                                                 | • Delayed diagnosis  
• Emotional distress  
• Possible increased pain for child |
|                                            |                                                                       | Need to consult numerous health care providers                                | • Delayed access to appropriate care  
• Diminished trust in health care providers |
|                                            |                                                                       | Conveying sense that they were ‘giving up’ or ‘kicking’ family out of the hospital | • Lack of hope  
• Ongoing negative feelings, such as anger, towards health care team/system  
• Diminished trust in health care providers |
|                                            |                                                                       | Poor Communication                                                            | • Lack of trust in health care providers  
• Additional distress for mother, including feelings of devastation, anger, frustration, etc.  
• Impact on mothers’ emotional well-being  
• Inability to access services or funding  
• Additional burden and stress  
• Conflict  
• Lack of understanding/Misunderstandings  
• Decreased quality of care |
|                                            |                                                                       | Approach to care                                                             | • Decreased quality of care  
• Additional stress and distress for mother  
• Difficulties in accessing services, information, or care  
• Additional suffering or harm to the child  
• Diminished trust in health care providers/health care system  
• Increased fears in accessing care in the future |
|                                            |                                                                       | Social Workers                                                                | • Decreased quality of care  
• Inability to access, or difficulty accessing, information and practical support |
|                                            |                                                                       | Lack of social workers with knowledge regarding pediatric palliative care     | • Decreased quality of care |
|                                            |                                                                       | Support not provided early enough or proactively                               | • Decreased quality of care  
• Lack of emotional/psychological/family support  
• No prevention of problems within the system |
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Health Care and Community Systems</strong></td>
<td>Finding qualified, knowledgeable, appropriate, or willing caregivers</td>
<td>• Decreased quality of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Increased stress and burden on mother and family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Services not accessed or underaccessed due to quality of care concerns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Services taken away from one family to provide care to another family</td>
</tr>
<tr>
<td><strong>Finding specialists</strong></td>
<td></td>
<td>• Challenges accessing services and care</td>
</tr>
<tr>
<td><strong>Distance from resources</strong></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Challenges access to services and care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Increased time, energy, and financial impacts</td>
</tr>
<tr>
<td><strong>Arranging care</strong></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Decreased quality of care</td>
</tr>
<tr>
<td><strong>Existing requirements for services</strong></td>
<td></td>
<td>• Decreased quality of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Inability to access services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td><strong>Finding funding or getting coverage</strong></td>
<td></td>
<td>• Increased stress and burden on mother and family</td>
</tr>
<tr>
<td><strong>Lack of services, programs, resources</strong></td>
<td>• Home care support</td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td></td>
<td>• Before and after school programs</td>
<td>• Impact on family relationships</td>
</tr>
<tr>
<td></td>
<td>• Hands-on physiotherapists and occupational therapists</td>
<td>• Possible decreased quality of care</td>
</tr>
<tr>
<td></td>
<td>• Interpretation and translation services</td>
<td></td>
</tr>
<tr>
<td><strong>Government Policy</strong></td>
<td>Insufficient funding and support to families and lack of coordination between government, hospitals, and other agencies</td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Impact on ability to access care and equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Decreased quality of care</td>
</tr>
<tr>
<td><strong>Inadequate number of health care providers, including specialists and generalists</strong></td>
<td></td>
<td>• Decreased quality of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td><strong>Not addressing wheelchair accessibility quickly enough</strong></td>
<td></td>
<td>• Impact on ability to access services</td>
</tr>
<tr>
<td><strong>Legislation</strong></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td><strong>Long-Term Caregiving and Coping</strong></td>
<td>Health care providers</td>
<td>• Decreased or fragmented quality of care</td>
</tr>
<tr>
<td></td>
<td>Turnover</td>
<td>• Impact on willingness to access similar care in the future</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Increased stress and burden on mother</td>
</tr>
<tr>
<td><strong>Suppliers and Government</strong></td>
<td>Costs of care</td>
<td>• Impact on ability to access care and equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Impact on ability to provide care-related renovations for child</td>
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<tr>
<td></td>
<td></td>
<td>• Impact on families ability to meet child and family needs</td>
</tr>
<tr>
<td><strong>Mothers</strong></td>
<td>Lack of time and energy</td>
<td>• Impact on quality of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Impact on mothers' psychological and physical well-being</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Decreased access to services</td>
</tr>
<tr>
<td>Theme</td>
<td>Level</td>
<td>Strengths</td>
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<td>-------------------------------------------</td>
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<td>---------------------------------------------------------------------------</td>
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<tr>
<td><strong>Realizing the Strengths and Barriers of the Health Care System</strong></td>
<td>Health care providers</td>
<td>Positive communication • Providing mothers with an appropriate amount of information • Patience • Non-discriminatory and inclusive • Treating mother as an part of treatment team • Involves mother in decision-making • Checking in with mothers about health of child and other aspects of child, including behaviour • Interprofessional communication and collaboration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal demeanor and approach to care • Caring • Flexible • Trustworthy • Reliable • Want to help others • Appealing to children • Involved • Take action • Easily accessible to mothers • Knowledgeable/up-to-date</td>
</tr>
<tr>
<td></td>
<td>Social Workers</td>
<td>Practical support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emotional/psychological support</td>
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<tr>
<td></td>
<td></td>
<td>Informational support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Crisis and long-term counselling</td>
</tr>
<tr>
<td></td>
<td>Health Care and Community Systems</td>
<td>Access to a variety of services &amp; Access to free services</td>
</tr>
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<td></td>
<td></td>
<td>Access to informational materials and children’s activities</td>
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<td></td>
<td></td>
<td>Access to home care support</td>
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<td></td>
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<td>Chaplain support at hospital</td>
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<td></td>
<td></td>
<td>Proximity to resources</td>
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<td></td>
<td>Government Policy</td>
<td>Grants, tax credits, disability allowances, &amp; other financial assistance programs</td>
</tr>
<tr>
<td></td>
<td>Long-Term Caregiving and Coping</td>
<td>Health care providers Continuity</td>
</tr>
</tbody>
</table>
APPENDIX I

Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth

Principal Investigator: Dr. Susan Cadell
Assistant Professor & Director of the Centre for Healthy Living
Wilfrid Laurier University

Are you a parent/guardian caring for a child with a life-limiting illness?

If so, we require parents/guardians who are willing to participate in a study of how the experience of caring for a child with a life-limiting illness changes parents’ lives.

For this study, you will be asked to complete a set of questionnaires. The questionnaires will be sent to you by mail and will take 1 to 1.5 hours to complete.

Questionnaires are available in either English or French.

For more information, or if you are interested in participating in this study, please contact the Research Coordinator at 1-800-810-0721.
APPENDIX J

Sample of Recruitment Letter Sent to Parents for the Caregiving Parents Study

**Caregiving Parents of Children with Life-Limiting Illnesses:**
**Beyond Stress and Coping to Growth**

**OVERVIEW**

When parents are caring for ill children, the stress is often compounded. Indeed, caring for a child with a life-limiting illness represents one of the most traumatic experiences a parent can endure. The negative aspects of caregiving are well documented in the literature. In the face of such adversity, however, there are suggestions that caregivers can also experience personal growth and positive change. Nevertheless, little is known about positive outcomes of caregiving, particularly of parents caring for seriously ill children.

The primary aim of this research addresses the question “What are the factors that allow parent caregivers to survive and even grow in the face of the stressful circumstances of caring for a child with a life-limiting illness?”

The outcome of this research will be a better understanding of whether personal growth occurs in this context and if so, the factors that contribute to it. This understanding will enable policy makers and practitioners alike to better understand the reality of caregivers and to enable intervention and support strategies to be designed. This research will contribute to knowledge in the fields of family caregiving, pediatric palliative care, and personal growth.

This research will occur under the auspices of a CIHR-funded New Emerging Team (NET) grant entitled *Transitions in pediatric palliative and end-of-life care.* This NET was conceived to develop a sustainable research program focused on creating knowledge and evidence to optimize provision of care for children with life-limiting conditions.

**THE STUDY**

This research is comprised of two phases. Phase One will use 8 short scales to study demographics, personal resources, spirituality, stress and growth. Phase Two consists of in-depth interviews, conducted with up to 25 Phase One participants who have requested a follow-up interview. Participants will be asked to dedicate approximately 1 to 1.5 hour(s) to fill out the questionnaires and approximately 1.5 to 2 hour(s) to complete the interview.

**PARTICIPANTS**

Mothers, fathers, and other caregivers (e.g. grandparents, guardians) of children with life-limiting conditions are invited to participate and more than one parent caregiver per family may participate in the study. Parents will be recruited regardless of the
length of time they have been caregiving and at any stage in the child's illness, so long as the child is under the age of 18.

All recruitment materials request interested parents to call a toll-free number and leave a message. At this point, the Research Coordinator at Wilfrid Laurier University will return their call. When parents/guardians agree to participate, questionnaires will be mailed to them. A stamped envelope will be included in the package in order to return the questionnaires. There will also be an information sheet included in the package explaining the study. Additionally, participants will be asked if they would like to be contacted for a follow-up interview.

For more information please contact:

Kathy Wilson-Forrest, Project Coordinator
Centre for Healthy Living
Wilfrid Laurier University
Waterloo, ON
519-884-1970 ext 5261
kwilsonforrest@wlu.ca
APPENDIX K

Sample Recruitment Letter for Caregiving Parents Study Sent by Individual Hospitals
(Calgary)

Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth

Principal Investigator: Lillian Rallison RN, PhD (Candidate)
Co-Investigators: Drs. Susan Cadell, Betty Davies, Hal Siden, Rose Steele, Lynn Straatman,
David Hemsworth & Stephen Liben

Dear Parent/Guardian,

You are receiving this letter as you are a parent/guardian caring for a child with a life-limiting illness and we are inviting you to participate in a research study. The purpose of this study is to discover how the experience of caring for a child with a life-limiting illness changes parents' lives. We hope that through this research we will be able to provide other researchers, practitioners and policy makers with a better understanding of the reality of caregiving.

For this study, the Canadian Institute for Health Research's New Emerging Team (NET): Transitions in Pediatric Palliative and End-of-Life Care has partnered with the Alberta Children's Hospital, the Southern Alberta Child and Youth Health Network and researchers from various pediatric palliative care sites throughout Canada and the United States. The hospital where your child receives care is collaborating with the research team.

If you qualify for this study and decide that you would like to participate, you will be mailed a set of questionnaires and asked to complete them. The questionnaires will ask you about your personal experiences (personal resources, spirituality, stress and growth) of caring for a child with a life-limiting illness. The questionnaires will take 1 to 1.5 hours to complete. You will receive $20 for your participation. Questionnaires are available in both English and French.

If you are interested in participating, or if you would like more information about this study, please contact our Research Coordinator, Kathy Wilson-Forrest, at 1-800-810-0721.

Sincerely,

...cont’d
Lillian Rallison RN BN
Consultant
Palliative Care and Grief Support Service
Calgary Health Region
Alberta Children’s Hospital
2888 Shaganappi Trail NW
Calgary AB T3B 6A8

Sharron Spicer MD FRCPC
Division Chief
Pediatric Palliative and Respite Care
Calgary Health Region
Alberta Children’s Hospital
2888 Shaganappi Trail NW
Calgary AB T3B 6A8

Ann Harding MSW RSW
Manager
Palliative Care and Grief Support Service
Southern Alberta Child and
Youth Health Network
Alberta Children’s Hospital
2888 Shaganappi Trail NW
Calgary AB T3B 6A8
REFERENCES


