EXPLORING AND DEVELOPING RESOURCES FOR FAMILIES OF CHILDREN
WITH A LIFE-LIMITING ILLNESS

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Abstract

Nothing can prepare a person to care for a child with a life-limiting illness. Children are not supposed to die before their caregivers. Caregivers sometimes are left alone to figure out how to navigate through their children’s illnesses. The health care professionals around them may lack the knowledge and experience to support them. The resources available to families of children with a life-limiting illness are scarce and scattered. Often health care professionals do not have access to information to provide support to these families. The purpose of this research study was to explore what resources are available for families and develop a resource booklet for health care professionals to use to support the families of children under the age of 18 years with life-limiting illnesses. A qualitative research study with open-ended interviews was conducted with eight health care professionals. The interviews were both face-to-face and by telephone. The intention was to gather information that would be utilized to develop a resource booklet. The findings suggest that there is a lack of resources available for health care professionals who provide support for families of children with a life-limiting illness. The research also showed that health care professionals would utilize a resource booklet if available. Health care professionals, families and children with a life-limiting illness are impacted by the lack of resources and would potentially benefit from a resource booklet.
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CHAPTER ONE: INTRODUCTION

This qualitative research study used a case study approach to interview eight health care professionals who worked with families of children with a life-limiting illness. The research had undergone a harmonized review by the University of Regina, University of Saskatoon and Regina Qu’Appelle Health Region and received approval by the University of Regina Research Ethics Boards (REBs). A request for ethics approval was also sent to Five Hills Health Region and was approved.

1.1 Why Life-Limiting Illness and Not Palliative

The title of my research report is Exploring and developing resources for families of children with a life-limiting illness. Before I discuss why I have chosen this as my research topic, I would like to address the reason why I have chosen the wording of life-limiting illness (LLI) instead of the term palliative. Children with a LLI have incurable diagnoses and are likely to die before adulthood or limited expectation of life into adulthood (ACT, 2003). Palliative is defined in the Oxford Dictionary as relieving pain without dealing with the cause of the condition (Oxford Dictionary). People fear the word palliative. The meaning is not well understood or accepted by many health care professionals and the general public. The word palliative is seen as “giving up,” or end of life care instead of a person having an incurable disease, which is the same as life-limiting illness.

Health care professionals are hesitant to use the word palliative with their patients and families. If the word palliative is used instead of LLI many families and their children would not get the benefits of this resource as they may not see it being applicable to them, or the word palliative would prevent them from even reading it.
Using the term LLI will be more beneficial for reaching families and other health care professionals than the word palliative. Health care teams continue to struggle with the definition of palliative care and end of life care (Wallace, Halpern, Joshi & Zwerdling, 2015). Throughout this report I will use the terms life-limiting illness and palliative interchangeably as it is done in the literature. In the resource booklet the term life-limiting will be used consistently. I have also chosen to use the term caregivers instead of parents throughout this report. I have done this so no one is excluded. If children are being raised by their parents, grandparents, other extended family members or foster parents the term caregiver is all inclusive.

1.2 Personal Reflection

I have chosen *Exploring and developing a resource booklet for families of children with a LLI* as my research topic, because as a social worker who has worked in various settings in health care I have encountered situations where I needed to provide support to families but felt I had very few tools. I have spoken with colleagues who have been in the same situation that I had been. The frustration of not having the knowledge or the resources to support the families and their children is a common theme among health care professionals. This research practicum developed from those frustrations along with seeing a gap in services for families. I wanted to research what were the practices of health care professionals, and what sources of information they had. Being a social worker in palliative care, I realized that there are some resources available on the internet, but what is available is spread out, very long and not concise.
1.3 Purpose of the Study

I felt that a resource booklet would be beneficial for both health care professionals and families to navigate through a rare, but very specialized area. Since this booklet would be utilized by health care professionals working with families of children with a LLI, the development of a resource booklet would be based on the health care professionals’ experiences working with this population. This study explored what a resource booklet for families of children with a LLI need, and what sources of information would be useful to families and the health care professional providing the support. The goal of this research practicum is to develop a resource booklet that has information that can support families, and provide a tool for health care professionals, given that there is not sufficient information available in our province of Saskatchewan. For the information in the resource booklet to be beneficial for families and health care professionals, it needs to be informative, supported, clear, precise and at an understanding level for all who may need to access it.

This research report will include a literature review on a family-centered approach and a strength-based approach; and an examination of why a resource booklet would be a useful tool for families and health care professionals. The literature review will also look at pediatric palliative care, the lack of resources for families, the lack of training and resources for health care professionals and the unique needs of the children with a LLI and their families. This report will then have an explanation of methodology, findings, discussion, and a conclusion.
CHAPTER TWO: LITERATURE REVIEW

2.1 Pediatric Palliative Care

Pediatric palliative care (PPC) is defined by the Canadian Hospice Palliative Care Association (2006) as;

A holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and the families who face a progressive, life-threatening condition, and helping them fulfill their physical, psychological, social and spiritual goals (p.7).

Pediatric palliative care (PPC) can be provided at home or in a hospital/hospice. PPC programs have an interdisciplinary team that provides care to children and their families (Knapp, 2009). The team can be made up of physicians, registered nurses, social workers, music therapist, occupational therapist, dietitians, chaplains, and care aids. Programs can vary across regions and populations (Brandon, Docherty, & Thorpe, 2007; Friedrichsdor, Remke, Symalla, Gibbon & Chrastek, 2007). Research shows that PPC is associated with fewer symptoms and less suffering at the end of life (Heath et al., 2009; Wolfe et al., 2008).

When Widger et al. (2007) looked at who received care from PPC programs in Canada, there were only eight programs that were dedicated to pediatric palliative care. Since 2007, two more children hospices have opened up: one in British Columbia and one in Ontario. A small percentage of children in Canada receive care from PPC programs. “There remain large areas of the country in which children do not have access to a formal PPC program” (Widger et al., p.600). In Canada this lack of access is due to geographic availability of such services. Currently, in Saskatchewan there are no PPC programs. Studies show that the current quality of PPC is not what is should be for
children and their families, and that children are left suffering from pain and other symptoms left untreated (Jalmell, Kreicbergs, Onelov, Sterineck & Henter, 2006, Theunissen, et al., 2007).

The Canadian Hospice Palliative Care Association (2006) reported that in Canada where there is a geographic area of 250,000 people with a child population of 50,000, 50 children are likely to have a LLI and will need palliative care, and of those 50 children 5 will die. In Saskatchewan 22 children a year that will die and more than 200 families could benefit from the expertise in the area of pediatric palliative care.

The lack of PPC is not specific to Canada. A study done in the USA reported that 89% of children with cancer experience significant suffering in the last months of life (Wolfe et al., 2000). In the USA only 20% to 25% of hospitals have PPC programs (Meier, 2006). Another study completed in Florida and California found that less than 11% of children received hospice care in the last 12 months of their lives (Knapp & Thompson, 2011). The American Academy of Pediatrics (2000) supports an integrated model of PPC; it is offered at diagnosis and continued throughout the course of illness whether the outcomes end in a cure or death for all children with a LLI.

Davies et al. (2008) looked at the barriers for children receiving PPC and they found that the number one barrier was the uncertainty of prognosis. Children with a LLI suffer from a wide range of conditions including congenital abnormalities, chromosomal disorders, neurodegenerative disorders, and malignancies (Goldman, 1998). These illnesses and disorders are difficult to predict their disease trajectory and prognosis, so will affect when to refer children to palliative care (Hynson, Gillis, Collins, Irving & Trethewie, 2003). Uncertainty in prognosis can lead to parents pursuing curative
treatments until there is a certain prognosis (Davies et al., 2008). The second barrier to referring a child to PPC was that families were not ready to acknowledge the incurable conditions of their children. The discomfort in using the word palliative with families and insufficient communication skills are also barriers for referrals to PPC (Durall, Zurakowski, & Wolfe, 2012).

2.2 Lack of Resources for Families

Parents want to be equipped with the tools and knowledge they need to be the primary caregivers (Weidener et al., 2011). When families have a child with a life-limiting illness they are in brand new territory. It is out of the ordinary for a child to be diagnosed with a life-limiting illness and die before their parents or caregivers. Unless families are connected in a support group with other families of children with a life-limiting illness they may never gain the knowledge of how to navigate through their children’s illness. A resource booklet may be beneficial to these families as the information that is needed to assist these families is not readily available.

Cadell, Kennedy and Hemsworth (2012) looked at posttraumatic growth in parents who cared for a child with a life-limiting illness. They reported on how parents spent substantial time researching on their own to find relevant services, supports, and resources. It was also reported that parents learned where to find resources and funding information from other parents and caregivers, and the search went on for years. In this study, the parents were in centers for sick children, but for families who are more isolated or not connected to other families finding the information may not come so easy. For example, there may not be other families available to them to offer the support or information they are in need of or requesting. This is the situation for many of our
families in Saskatchewan as they are often isolated from other families. There is a greater need to be aware of how isolated the families of children with a LLI may feel.

Stevenson, Archille and Lugasi’s (2013) meta-summary stated that five of the studies reported families have a simple need for basic information. Findings in this study also showed that families want information about what to expect at the end of life. When families do not receive the support and information needed during their child’s illness and after their children die, they are left feeling abandoned by health care professionals (Kreibergs et al., 2005; Woodgate, 2006).

Families, who are faced with the situation where they have a child with a LLI, may find that they are in a system that may not have the resources to support them. Research shows that if people do not receive the support that is needed during the illness of their children, it could result in them experiencing complicated grief after the death of their children. Complicated grief has been defined as an intense grief reaction characterized by emotional burdens, including symptoms of yearning, anger, guilt, recurrent sadness, difficulty accepting the reality of the loss, and a sense of loss in the meaning of life (Fernandez-Alcantara et al., 2016). The needed support includes the information needed to care for their children, and for the families and their children to receive care in a supportive environment (Contro, Larson, Schofield, Sourkes & Cohen, 2002; McCarthy et al., 2010). Families may not even realize they have the option to take their children home to care for them, or even understand what that would entail. Families need to be informed about the supports and services available to them.
2.3 Lack of Training and Resources for Health Care Professionals

Davies et al. (2008) states that caring for a seriously ill child places heavy responsibility on the parents as well as on the primary health care team who rarely encounter dying children and thus often feel ill-equipped to deal with either the medical or emotional needs of the child and family. PPC is an evolving field of practice as well, and few health care professionals are educated in PPC. Social workers receive on the job training, and a resource booklet would benefit social workers and other health care professionals. Many social workers and other health care professionals are not necessarily trained or educated on how to support dying people and their families. They are even less prepared to do so when the dying person is a child and the family needing support are the parents. Jones (2005) found that social workers reported not feeling prepared for bereavement support, discussions from curative care to palliative care, and education about disease progression. Studies looking at the barriers to PPC found that education in palliative care and communication skills is needed for health care professionals (Junger et al., 2010).

Families and their children with a LLI from rural areas have been historically cared for in larger urban centers. In recent years, there has also been a shift in families wanting to take their loved ones home to care for them instead of being cared for in a facility. This shift has not only been for adult patients but also for children. A study looking at PPC in Canada (2007) showed most children (43.9%) died at home (Widger et al., 2007). Many children and their families prefer to be at home at the end of life (Balk, Zaengle & Corr, 2011; Rapport, Obwanga, Sirianni, Librach, & Husain, 2013; Shipkey, 2008). Knapp (2009) also found that an increasing number of children with chronic
conditions are dying at home. Being away from their home and other family members can be an added stress for families of children with a LLI. Families prefer their children to be cared for at home with professional support from those who are known to them (Neilson, Kai, MacArthur & Greenfield, 2011; O’Leary, Flynn, MacCallion, Walsh & McQuillan, 2006). Health care professionals in rural areas are even more likely to have little to no training or experience with families and their children with a LLI.

Many families and their children with a LLI are cared for by a variety of pediatric and adult programs none of which specialize in PPC (Feudtner et al., 2011). If children receive PPC they are receiving services from an adult program. These programs are not specialized to care for children with a LLI and their families. Children and their families have complex medical and psychosocial needs that adult programs may not be equipped to address. Children have unique disease processes with diagnoses and prognoses that are very different than those of adults; and pediatric patients are more likely to receive concurrent palliation and life-prolonging treatments than adults (Levine et al., 2013). Quinn and Bailey (2011) also found that the transition from curative to palliative care for children and their families is even more complicated than for an adult patient. The experience of a LLI is added to the normal growth and development of mind, body and spirit of children. Working with children requires knowledge of normal growth and development and the dynamics that may follow them (Himelstein, 2006). Pediatric palliative care is vital work that requires a distinct set of clinical skills. Approaches that are based on adult models do not work for this population (Levine et al., 2013).

Bergstraesser et al. (2013) examined the attitudes of PPC, the support needed by health care professionals, and the role of specialized PPC teams. The need for PPC, as an
overarching specialized service in acute settings was widely acknowledged in this study. It was also thought by the health care professionals/participants in the study that PPC should offer support not only for families and their children but also for attending teams. This would be beneficial for health care professionals who do not specialize in PPC as they could consult with the PPC team members.

Even though social workers may not necessarily be educated or trained to work with families and their children with a LLI, they bring a set of skills with them. Social workers bring their skills of advocacy, empowerment, assessment, support, cultural competence, developmental understand of children and ethical commitment to the children and families (Himelstein, Hilden, Boldt, & Weissman, 2004; Jones, 2006). Jones (2006) looked at a social work perspective on the needs of children with cancer and their families at the end of life. This social work perspective presents children and their families in their contextual environment and includes an understanding of family dynamics, cultural history, and concurrent stressors. Her research offers an understanding of the social workers’ perceptions of the psychosocial needs of children and their families. With these understandings, social workers are in a position to better support these families and their children.

2.4 The Needs’ of Families and Their Children

2.4.1 Children with a Life-Limiting Illness

Children with a LLI and their families tend to have more unique and complex medical, psychosocial needs than adults who have a LLI (Jones & Weisenfluh, 2010). With children there are development needs to consider and the needs of the family. In this
section of my literature review I will discuss the needs of the families and their children with a LLI.

When caring for children one must be aware of their developmental stages of a child. Caring for young children and teenagers presents different challenges. How one supports a young child with their illness and eventual death compared to an adolescent will not be the same. The spiritual, emotional and physical needs along with the decision making and ethical issues that may arise will differ with the age of the child (Jones, 2006). Adolescents are more capable cognitively, emotionally, and spiritually to be able to understand their LLI and be involved in the decisions of their care. Social workers in pediatric oncology reported that adolescents need to have medical information, autonomy, and empowerment for personal control over life and end-of-life decision making (Jones, 2006; Weir & Peters, 1997). Children and adolescents need to be given developmentally age appropriate information. Families need to be provided some information on how to talk to their children with developmentally appropriate language so they have the tools to support their ill child and his/her siblings. Health care professionals who work with these children need to be educated in the developmental needs of children (Jones & Weisenfluh, 2010).

Children and adolescents with LLI need to be children as much as possible. Children need to be able to play and have fun and to have as normal a life as possible. They also need to attend school as much as possible. Maintaining school attendance can be crucial to their overall well-being, especially when survival to adulthood is unlikely (Craig, Boden & Samuel, 2012). Maintaining school attendance affirms a child with a LLI that they are of value, with the capacity for growth and a purposeful future, however
short it may be. For a child with a LLI, attending school can be an escape from the reality of their illness. Health care professionals may play a role in aiding children with a LLI to attend school. Families of children with a LLI, along with the health care professional, can work with the schools to provide what they need to know to help the children and their siblings be supported. Families need to know they have options or have access to the support and the material needed to have a healthy relationship between family, school and health care professionals. Upton and Eiser (2006) found that a closer school hospital liaison is essential to maximize integration and achievement in children with a LLI.

Gaab, Owens and MacLeod (2013) looked at discussions around a child’s impending death. Caregivers were asked whether or not they had discussions about the impending death of their children with the ill child and their siblings. Caregivers who avoided having the discussions did it for reasons they felt were protecting the children. These caregivers felt they were protecting the children by avoiding negative changes in relationships, perceptions and emotions. The caregivers who had the discussions did this to prepare the children; they prepared the children by acknowledging, enabling and teaching. Many of these caregivers reported that they were aware that the children/siblings knew the truth of the situation. “Armed with knowledge about their prognosis, children were enabled to make decisions around how to react to the situation around their families, including the patients themselves” (Gaab et al., 2013, p.324). It was suggested in this study that if families of children with a LLI were to receive information about how to talk to their children early on in their illness, and how others have coped in similar situations they (children or parents?) may be better prepared to make decisions when the time comes.
2.4.2 The Caregivers and Siblings

Caring for children with a LLI must also take into account the psychological well-being of the family. Research to date suggests the American and Canadian health care systems do not adequately meet the needs of children with a LLI and the needs of their families (Stevenson, Achille & Lugasi, 2013). Stevenson et al. (2013) found that the majority of parents talked about the importance of having health care providers respect their preferences regarding their role as parents caring for their child, and want to be equipped with the tools and knowledge they need to be the primary caregivers. Widger, Steele, Oberle and Davis (2009) found that parents did not always have the knowledge, energy and/or the desire to provide care to their sick children. Groh et al. (2013) looked at specialized pediatric palliative home care and found that this specialized care is able to alleviate caregivers’ psychological distress and burden. Their study findings indicated that families need the support of the health care professionals to provide them with what is needed to care for their children.

Families of children with a LLI can also face financial burdens with medical costs and employment constraints (Ireys, Anderson, Shaffer & Neff, 1997). One or both parents may have to reduce their hours of work or even give up employment. The children may come from a single family home. Families need to have access to the information and resources that may assist them in caring for their children. Siden and Steel (2015) found that parents of children with LLI found it difficult to meet their financial needs and most parents could not meet the medical costs. Some families require assistance with paper work when seeking financial help (Weidener et al, 2011).
Stevenson et al. (2013) found that health care providers reported that care needs to be more family oriented and includes the siblings. Families felt that the siblings of their children with a LLI did not receive the support they needed; that it was not recognized that the support was needed; and parents also reported that they lacked the information about how to support the siblings. Some families reported that the siblings were forgotten by health care professionals (deCinque et al., 2006). Families may not know how to balance between parenting a child with a LLI and their siblings, or even be aware that support for the sibling may be needed as they are engulfed by what is happening around the child with a LLI. Heath et al. (2009) also found that the families felt there was a failure to meet siblings’ needs, and found that there was little interaction between health care professionals and siblings. The siblings of children with a LLI need the support and care from health care professionals and their families. Living in a family where a child has a LLI or disability can detrimentally affect the social and psychological functioning of healthy siblings (Sharpe & Rossiter, 2002).

A meta-analysis of psychological functioning in children whose siblings have a chronic health condition found a small but statistically significant negative effect suggesting siblings of children with chronic illnesses exhibit more internalizing and externalizing problems than of siblings of healthy children (Vermaes, van Susante & van Bakel, 2012). For example, siblings of oncology patients showed an increased concern about the impending death. During adolescent years they are more vulnerable to a reconstruction of death related concepts, and the loss of a sibling threatens their developmental needs and ability to cope (DeVita-Raeburn, 2004; Havemans & Eiser, 1994; Noppe & Noppe, 1997). Some agencies that work with children with a LLI, have
programs to support the siblings and an example of this is SuperSibs (see http://www.supersibs.org). This agency supports the siblings by sending out newsletters and other gifts, given that the child with a LLI may receive a lot of attention.

Brennan, Hugh-Jones and Aldridge (2012) looked at coping and adjustment in siblings and found that siblings play a major role in negating their own needs, and the role they often take is a caregiver rather than a care receiver. It was concluded by the same authors that the siblings may not seek out support and will continue to try to cope on their own even when their coping strategies are no longer effective. Siblings not only take the role of the caregiver in their families, they also take on other extra roles providing practical tasks of running errands, picking up school work and mediations, transporting equipment and extra chores around the house (Gaab et al., 2014). Siblings also reported that it meant a lot to them when other people spent time with their families and their brother or sister with a LLI.

Self-care for the caregivers of children with a LLI is an important area for health care professionals to be aware of. In addressing self-care for caregivers women and men cope and grieve differently from one another. Hill et al. (2013) looked at the problems and hopes perceived by mothers, fathers, and physicians of children receiving palliative care they found that fathers were more likely than mothers to report hopes related to miracles, cures and longer life. Caregivers may need assistance with self-care when caring for their children with a LLI. Caring for a child with a LLI puts greater demands than average on a caregiver (Bresley, Staruch & Morimer, 1982). Studies show caregivers experience higher levels of stress, distress, emotional problems and depression (Brehaut, Kohen & Raina, 2004). Brehaut et al. (2009) looked at caregivers of children
and found that they have greater incidents of reporting chronic health issues, activity limitations, poorer health, and higher levels of depression than caregivers of healthy children. Parents can spend on average of 85 hours a week caring to the needs of their ill children (Siden and Steele, 2015).

Respite care is an integral and essential component of providing palliative care to children with life-limiting illnesses and their families (Ling, 2012). ACT (2003) suggest that regular respite care should be offered to all families caring for children with a LLI. Caring for a child with a LLI is a huge undertaking, and affects the whole family. Respite care can provide opportunities for the family members to have vacations, rest, spend time with other children in the family, or for the parents to have time together.

Health care professionals can support families in accessing respite care, and should be encouraging the families to take the breaks. This is if there are respite services available or services that employ trained staff (Collinson & Bleakley, 2009). Some families are in a better position to financially afford to pay for respite services, but this is not the reality for all families. Merriman and Canavan (2007) stated that respite care can come in many forms including informal help from families and friends and formal services in and out of the home. Then there can be the challenge that families may not recognize that they need a break (Eaton, 2008). Support and encouragement from health professionals can enable families to reach out for respite care.

2.4.3 Advanced Care Planning for Children

Advanced Care Planning is something that needs to be addressed with families, but it is not done until well into the children’s illnesses. It is not a discussion that people want to have with parents. Research shows that during a crisis situation it is more
difficult to make decisions regarding the health and treatment options for children. Families are able to hear and understand health care options/treatments when their children are not in a health care crisis. Discussion around Advanced Care Planning with families of children with a LLI early in a child’s diagnosis may be beneficial (Dussel et al., 2009)). Often the discussions around Cardiopulmonary resuscitation (CPR) happen with parents only hours before a child’s death (McCallum, Byrne & Bruera, 2000; DeGraves & Aranda, 2002). CPR is a medical interventions used in an attempt to restore heart and lungs stop working unexpectedly (www.rqhealth.ca). Resuscitative measures may be successful in the technical sense of the word allowing the medical team to sustain vital functions, but rendering the child unconscious without the ability to communicate is something that should be explained (Postovsky & Ben Arush, 2004). Originally CPR was used in specific circumstances, which was sudden cessation of cardiorespiratory function (Willard, 2000). If a child has an irreversible disease like cancer, the results of CPR could be devastating, and CPR does not change that the child has the irreversible disease. The general public does not understand what CPR entails and the effects if it is successful on a patient with a life limiting illness (Agard, Hermeren & Herlitz 2000). Sittisombut, Maxwell, Love and Sitthi-Amorn (2008) found the use of CPR could be reduced if terminally ill patients are informed well in advanced and their preferences using CPR are taken into consideration. Social workers and other health care professionals are in the position to have these tough discussions that include Advanced Care Planning. Families of children with a LLI need to have these discussions as it is a necessary part of the care for these children and families. Health care professionals should go as far as discussing different scenarios from relative health to deteriorating
health with families in order for them to articulate their wishes (Edwards, Kun, Graham & Keens, 2012).
CHAPTER THREE: RESEARCH DESIGN

3.1 Theoretical Framework

3.1.1 Family-Centered Approach

The goal of this research was to develop a resource booklet that is grounded in evidence-based research and clinical practice with a family-centered approach to assist health care professionals in supporting families of children with a LLI. Developing a resource booklet with a family-centered approach reflects a strength-based perspective as the resource booklet will build supports around the families’ strengths that will enable them to care for their children. Given the tools and the resources families can learn, adapt and create their own solutions (Early & GlenMaye, 2000).

Family-centered approach has become well known in health care, and is an approach that incorporates many social work values and principles (Miller, 2012). Family centered approach in pediatric PPC involves preserving the integrity of each person and the family as a whole (Gaab, Owens & MacLeod, 2014). Family-centered care is a partnership approach to health care decision-making between the family and health care provider. It is commonly used to describe optimal health care as experienced by families (Kuo et al., 2012). It includes planning, delivering, and evaluating health care to children and adolescents grounded in a mutually beneficial partnership and collaborations between health care professionals and families (Dunst & Trivette, 2009).

The terms like *partnership* and *collaboration* are often used to describe family-centered care as the health care team and the families work together. The parents/caregivers are seen as the experts in their children, so they need to be included in making health care decision and plans. No one knows children’s needs more than the
parents/caregivers. Making a care plan without including the child’s families or their environments may not be successful. A discharge plan for home needs to look at all the factors in the families’ lives.

Family-centered care can lead to parents/caregivers empowerment, and self-management (Wagner et al., 2005). When families are informed and included in their children’s illness, care needs, and care plans, they are in a better position to make informed decisions and manage their lives. Children’s health and behavior are also impacted by a family-centered care approach (Dunst & Trivette, 2009).

Family-centered care is also how health care professionals treat, interact and include family members in the care and treatment of the children. When family members have interactions with health care professionals that are in a family-centered environment parents report they feel that they are with trusted and committed professionals who are very familiar with their children’s treatment regimen and the family (Mastro, Johnson, McElvery & Preuster, 2015). Families also report that they have fewer unmet health care needs and lower financial burdens (Kuo, Birds & Tilford, 2011).

3.1.2 Strength-Based Approach

It is the position of the researcher that you cannot work with children within a family-centered approach without looking at the families’ strengths. The child’s primary source of strength is his/her family. Valuing families through recognizing and building on their strengths can assist families in improving their lives (Early & GlenMaye, 2000). The research process had already began when this realization that a strength-based approach needs to be taken into account in developing a resource booklet. Working with families from a strengths-based perspective focuses on the families’ competencies and
the resources available in their environment. Families are seen as the experts in their situations, and a health care professional’s role is to assist these families with their knowledge and resources (Saint-Jacques, Turcotte & Pouliot, 2009). Families need to be empowered and not labeled. A strengths-based approach believes that families have the resources, knowledge, skills, and competence to help them during distress. Seeing families’ “pathologies” is not beneficial, but valuing families through recognizing and building their strengths can assist families in improving their lives (Early & GlenMaye, 2000; Saint-Jacques et al., 2009). The strengths-based approach is based on six principles;

- the focus is on the individual strengths rather than pathology;
- the community is viewed as a source of resources;
- interventions are based on client self-determination;
- the practitioner-client relationship is seen to be primary;
- essential, aggressive outreach is employed as the preferred mode of intervention;
- people are seen as being able to learn, grow, and change (Arnold, Walsh, Oldham & Rapp, 2007; Smith, 2006).

From a strength-based perspective families/parents are important actors in the resolution of family difficulties and they usually act in the child’s best interest. It is important to acknowledge though that not everything depends on strengths, and that services need to be identified in families’ environment that can actualize their strengths (Saint-Jacques et al., 2009).

From a strengths-based approach the social workers/health care professionals and families build a partnership in defining problems, goals, strategies and success. Families
must take a role; it is not all on the health care professionals (Lietz, 2011). Together social workers and families can take action and access resources, learn skills, and practice behaviors that can help improve their lives. From a strengths perspective a resource booklet may give families the support, information and the tools to empower them to care for their families whether that is funding information, practical resources, or self-care suggestions. With the information provided by the resource booklet families can use their own competencies and will have more resources in their environment.

3.2 Research Methods

3.2.1 Case Study

This research study used a qualitative approach; in qualitative research the researcher’s purpose is to understand people’s experiences as they are lived (Schultze & Avital, 2011). This study used a case study approach and involved the study of a case within a real-life, context or setting (Yin, 2009). Case study methodology has a history of use in the health and social sciences (Stake, 1995). In case study research the researcher explores a bounded system or multiple systems over time, through detailed in-depth data collection (Creswell, 2013). This study is considered a collective case study as it examined one issue but the researcher selected multiple case studies to collect the data. A collective case study allows the researcher to analyze within each setting and across settings (Baxter & Jack, 2008). In multiple case study design, it is suggested that the researcher replicates the procedure for each case (Yin, 2009). To ensure replication of the procedure, the researcher in this study had a set of structured questions that were asked in each of the eight interviews.
3.3 Sampling and Recruitment Strategies

The criteria for the inclusion of participants was to be a health care professional who had provided psychosocial support to families of children with a LLI in a health care setting in Saskatchewan. Purposeful sampling was utilized as the researcher wanted the potential participants to be from diverse settings in the health care field as this would ensure different perspectives were being collected from the participants according to their work settings. The researcher sent out twenty letters of invitation to health care professionals including social workers and registered nurses. Usually these are the two professions in Saskatchewan that provide psychosocial support and arrange services to families. The researcher had anticipated conducting a minimum of six interviews due to the size of the available population (20 potential participants); eight health care professionals agreed to participate in the research study.

The recruitment of potential participants was facilitated via a review of the Saskatchewan Regional Palliative Care Contact list, and then compiling a list of pediatric programs and units in Saskatchewan with the assistance of the field supervisor. Once a final list was completed the researcher contacted the potential participants by telephone and explained the purpose of the study. The potential participants were asked if a letter of invitation, consent form, and research questions could be sent to them by email or mail, and then decide if they wanted to participate.

After the documents were sent out to the potential participants the researcher contacted them by telephone or email approximately one to two weeks later to inquire if they wanted to participate in the study. Once the participants agreed to participate, the interviews were scheduled over a two month period from February 2015 until April 2015.
3.4 Data Collection

3.4.1 Interviews

The data collection occurred through face to face interviews and over the telephone interviews. Consent forms were signed before the interviews began. In the face-to-face interviews, copies of the consent forms were given to the participants, and for over the telephone interviews, copies were emailed to the participants. Interviews are common procedures in studies for data collection. In interviews the researcher and participants talk and talking is natural (Griffé, 2005). A researcher can generate deeply contextual accounts of the participants’ experiences and their interpretations of those experiences (Schultz & Avital, 2011). The telephone interviews were done due to geographical distances. Glogowska, Young and Lockyer (2011) pointed out that a telephone interview differs from a face-to-face interview because of the lack of non-verbal communication. The researcher or the participants are unable to use gestures to convey understanding during the interview. During the telephone interviews, the researcher would convey understanding and listening through making small comments during the conversation. By the second interview the researcher learned the need to define palliative and life-limiting illness. The interviews were audio recorded then transcribed verbatim. The interview had standard open ended questions. The interviews took approximately 50 minutes each. Some were longer than others if the participants had more experience working with families of children with LLI than other participants.
3.5 Ethical Considerations

3.5.1 Participants

There was some concern that the researcher may have had a pre-existing, current or expected working relationship with the potential participants and the participants as the researcher is a social worker in Saskatchewan. The researcher was not in a position where there was any power differential. When the researcher contacted potential participants that she did have a pre-existing relationship, careful considerations were in place so that they were not made to feel they needed to participate. All participants were contacted the same number of times even if the potential participants were known to the researcher, and this was done as the researcher did not want to influence the potential participants by their pre-existing relationship.

There was minimal risk involved in this research study. The researcher provided a list of counselors at the beginning of each interview explaining that if they experience any distress during or after the interview they could contact a counselor. If the participants were to experience any distress or discomfort during the interviews the researcher would have stopped the interview until the participant was able to continue. If the participant was unable to continue the interview would have been rescheduled for another time or the participant would have had the right to withdraw.

3.5.2 Confidentiality

The participants in this study signed written consent forms that indicated to them that the research was voluntary and at any time they could withdraw from the study. The participants also consented to have their interviews recorded and transcribed. The
participants received a signed copy of the consent form. This study was approved by the Research Ethics Board of the University of Regina.

### 3.6 Data Analysis

Once the eight interviews were completed the researcher transcribed them and, the researcher played back the audio recorded interviews to ensure accuracy. The researcher then became familiar with all the transcripts reading them over, and reading over the reflective notes after each interview. This is the first step in conducting thematic data analysis (Braun and Clarke, 2006). The researcher reads line by line and begins coding what was interpreted in each passage, coding anything that may have been relevant (Gale, Heath, Cameron, Rashid, & Redwood, 2013). After the coding was completed, the researcher was able to identify themes from the transcribed interviews. Thematic analysis “is a method for identifying, analyzing, and reporting themes within data” (Braun & Clarke, p. 6). In case study research, thematic analysis across the cases is called a cross-case analysis (Creswell, 2013). With case study research when multiple cases are chosen, a detailed description of each case and themes is provided and called a within-case analysis; this analysis is followed by the thematic analysis called a cross-case analysis that includes the interpretation of the meaning of the case (Creswell, 2013).
CHAPTER FOUR: RESEARCH FINDINGS

4.1 Introduction

In this section, I will describe the participants, and provide the results of the thematic data analysis; six primary themes will be discussed in detail. The following are the six primary themes: expressions of the lack of resources, expressions of what is needed, and families’ needs, effects on the families, impacts on health care professionals, and suggestions for resource booklet.

4.2 Context of Participants

The study was conducted in three different health regions (Regina Qu’Appelle Health Region, Saskatoon Health Region and Five Hills Health Region) and the Saskatchewan Cancer Agency in Saskatchewan from February 2015 until April 2015. The number of interviews conducted was eight. Of these eight participants seven were social workers and one was a registered nurse and ranged from the ages of 30 to 60 years old with at least eight years of experience in a health care setting. The participants were from acute care, home care, and outpatient center settings. The registered nurse was with home care that provided care for medically fragile children. Two participants were social workers in two different adult palliative care programs that occasionally provide nursing care and psychosocial care for children. Two more social workers in two different regions were with a children’s outpatient program serving medically fragile children. Two social workers worked in inpatient medical units from two different health regions and one social worker was with the Saskatchewan Cancer Agency who at the time carried only a pediatric caseload.
4.3 Detailed Analysis of the Eight Interviews and Themes

The participants in this study have all worked with families of children with a LLI in different health care settings and in different programs. They describe the children with different “labels” for their conditions including: medically fragile, life-threatening, life-limiting and palliative. A description of the eight interviews and the themes will follow in appendix B.

4.4 Expressions of the Lack of Resources

The first theme from the data was *the expressions of the lack of resources*. All eight participants reported not having adequate information. Participant three stated “*no there were no resources… there were never any resource handouts, information to send home with them or packages of anything like that…nothing about the specifics of having a LLI.*” Participant four stated “*I don’t have anything for parents if they were to come to me and say I am super stressed I need “this”. I don’t have anything… and we are lacking resources that will help the family.*” When participant six was asked do you feel you have adequate information to give families?, she stated “*no when I was going through the questions I thought no we definitely don’t…not written material and that would definitely help…nothing for sibling*” The other participants reported they have the same experiences. Participant seven had reported she had only a few children on her caseload as she works in an adult palliative care program. She stated; *No absolutely not. It was, honestly because there are so far and few between you feel like you do not develop the resources and the dynamics involved are so much different than they are in an adult population.*”
The participants in this research study did not have adequate resources to provide to the families that they were expected to support. Both participants are in a pediatric and adult health care setting felt the lack of adequate resources. Providing care for families of children is a specialized area.

4.5 Expressions of What is Needed

The second theme was expressions of what is needed. All eight participants in this study stated a resource booklet would be beneficial and discussed why and/or how it could assist them in providing care. Participant five felt that “if they (families) are not ready to hear, the written material can open the door to having the discussions…it gives it an opening I think as well with health professionals and conversations between family members could be very helpful.” When participant one was asked if it would be useful to have material for other team members to hand out when she was not available she stated “yes it would be useful for other areas of my team.” Participant two thought the resource booklet could assist her in reaching the families she works with as her caseload covers a large geographic area. She reported “mostly our services here are outpatient and we serve all of southern Saskatchewan so trying to reach some of those families is very challenging.”

Participant three stated;

*I have always believed that when people first come in they needed some little booklet, here is the financial resources, here is the medical, and here is the information on advanced care directives, and maybe to be able to go through the information with them and be there. They can look through it on their own if they do not want to talk about it right away. They can look at it on their own and then come to you with questions and say yeah I am ready to discuss this now or whatever they want.*
The participants all thought that written information to give families of children with a LLI would benefit them. There are times when health care professionals cannot meet with families due to geographical distances, the health care professionals are not available, or the families just are not ready or willing to meet. Information on Advanced Care Planning could open the door for further discussions.

4.6 The Needs of Families

The third theme is the needs of families. In this study the work setting influenced what was requested. The one participant who was a nurse stated she did not get requests for information. Information on respite care was needed. According to all eight participants it is a limited resource.

All but one of the participants reported that families seek out information and support. Participant eight stated that “request was how to support her siblings and how to tell her siblings what they were seeing in her.” The same participant reported that when working with the grandmother of the child, she wanted information on supporting her daughter and son-in-law. Participant seven had the child approach her and asked if support could be provided to the parents. Participant seven reported that the child asked “help me make them understand that I am okay to die.” Legacy work was also something that participant seven encountered. Funding seems to also be a common request. Including where to look and what is available. Participant six commented, “definitely funding comes up...bills don’t stop coming in, so that is a big concern or stressor the financial piece.” Participant eight stated what she thought would be helpful:

A Kinsmen application like what the Kinsmen Foundation can do for them, was probably the primary one. Make a Wish Foundation, some the more local charities like the Chris Knox Foundation...Also with the parents the EI application for parents of critically ill children.
The needs of families can vary depending on the program or setting from where they are accessing support. Families request emotional support for themselves but funding and financial information were the most common requests. It is not just the families that are requesting and needing support, but also the children with the LLI.

4.7 Impacts on Health Care Professionals

The fourth theme is *impacts on health care professionals* by working with families of children with a LLI. As the literature discussed earlier the number of children dying is low in Saskatchewan due to the population size, so health care professionals may not always feel prepared. Participant eight reported that when she “had to see families with children in our program that I felt much more anxious than other visits with adults.” Participant two stated “I do not have the knowledge and expertise to be able to counsel around that area…It was really hard for me to, how do I? … I have some difficulty in that area honestly” Participant four also reported “I don’t know what to do for this…for self-care and that so I don’t know.” Participant seven stated she “felt a little like a fish out of water. Some developmental stage/issues… With families how do you help?…with siblings how do you help one and keep one a priority because they are sick? …A lot of relations stuff.”

The participants in this research study are left feeling unprepared and ill equipped to work with children with a LLI. Six out of the eight participants reported some sort of negative or difficult experiences. The majority of the participants in this research study are feeling anxious without the knowledge and the tools to support families and their children.
4.8 Effects on the Families

The fifth theme is effects on the families. These are the opinions of health care professionals that provide supports for families of children of a LLI. Families are isolated due to the small populations. Participant one stated “parents are advocates for their children, and at times this can be confusing, exhausting, and challenging...but some families are overwhelmed...the financial burden.” Participant three reported that families “are very distraught.” Participant six stated that “it is just overwhelming for parents...its rare and just not the normal way to go.” Participant four stated;

A lot of families are very resistant. I think it stems from a lot of things but I think mainly stems from “I can do this on my own and I don’t need to ask for help.” I think a lot of parents think if they ask for help they are admitting failure. And in the grand scheme of things they are asking for help and not admitting to failure.

Participant four also commented on how families are affected by discussing palliative care; “Families are resistant to palliative, as soon as families hear the word palliative...don’t talk to me, there is now a wall.” Participant seven also commented on some barriers for families; “I think what the barrier is it is the misunderstanding what the term palliative means and had we been able to have been involved sooner than later may have been a bit more beneficial for them.”

Overwhelmed, withdrawn, confused and isolated are a few of the words that were used to describe the families that these eight participants work with. Families and their children are not always receiving the supports that are needed from health care professionals.

4.9 Suggestions for a Resource Booklet

The last theme is suggestions for a resource booklet. All eight participants stated that a resource booklet would be beneficial and would utilize it once developed, but most
had concerns or suggestions for the resource booklet. Participants one, three and eight thought the resource booklet needs to be quick, simple, clear, short, and practical for it to be beneficial for families. Participant six asked if it would be accessible to all, and participant seven suggested it be used to support professionals too. Participant five had concerns that the resource would get dated and that resources vary from region to region. Lastly, participant two thought the resource booklet should be based on research.

Another piece of information that came out of the data, which was discussed in the literature review, was what palliative care means to different health care providers. This had been a great concern for the researcher from the beginning. The researcher learned early in the interviews to define what life-limiting and palliative meant. In interview number two the researcher stated;

*I know that the terms life-limiting illness, life-threatening illness, medically fragile, and palliative are very similar, and it depends on how you see the definitions. In my [research] I have chosen life-limiting because I felt if I used palliative parents and not only parents but also professionals would not see that it applies to them. Palliative is once you have an incurable disease and it is going to end in death... on our caseload you have children with life-limiting or life-threatening illnesses but no one sees them as palliative.*

Participant two response;

*I am glad that you explained that because I think that changes my answer. Not changed my answer but if you had used palliative I would not have seen all those children that are medically fragile with a gradual decline as we do not see them as palliative... Their health status declines but we would not have looked at them as palliative.*

Participant five addressed why she thought there are not specialized PPC, which has also been addressed in the literature review. Participant five states;

*The challenge is there is such a difference in the level of services or direct services depending where people are located and whether it is in a smaller center or rural community. We do not always know what resources are available. There are more limitations. There is not always the population base to sometimes*
have the specialized services, so then to have something in print or something to give families would be very important.

With the common experience of all the participants not having adequate resources and feeling ill equipped a resource booklet containing a variety of information for all environments would help address this problem.

4.10 Summary and Interpretation

Even though the eight participants worked in the different health regions and agencies throughout a variety of programs, they all have similar experiences working with families of children with a LLI. The participants feel that they do not have the resources that are needed for them to support families. All eight participants also acknowledge they could benefit from a resource booklet either for families or for other health care professionals. A resource booklet might be beneficial for families who are not able to meet or just not ready to meet with health care professionals. Depending on the program or setting, the eight participants found it challenging to have conversations with the families and are left with not knowing what to say or even how to support the families. Many of the participants talked about the families are at times left on their own feeling isolated.
CHAPTER FIVE: CLOSING DISCUSSION

5.1 Introduction

In this research study, data was gathered from eight participants: seven social workers and one registered nurse. Thematic analysis revealed six themes related to families of children with a LLI. The findings from this research study produced valuable information to facilitate the development a resource booklet (see Appendix C). In this section, the themes will be discussed as it relates to the literature and experiences of the eight participants. Lastly, the limitations and strengths will be discussed, as well as the implications for social work practice and future research.

5.2 Discussion of the Themes

The first theme was the expression of the lack of resources. The participants in this study reported that there is a lack of available resources and information to offer families. The participants work with families and children of LLI infrequently, so they are unable to develop their own resources. As already stated, children with a LLI are rare, so few programs and resources are developed to support these families. The participants who are working in palliative care with adults are receiving referrals for children. These children require specialized care, and dynamics working with children and their families are quite different from adults. This leaves the health care professionals not knowing how to support families and their children. Previous studies have found that PPC is vital work that requires specialized skill, and approaches that are based on adult models do not work with children and their families (Levine et al., 2013).

The second theme is that the participants’ expressions of what is needed to support families and their children. All the participants felt a resource booklet would be
useful and would utilize it. The participants thought that addressing Advanced Care Planning in the booklet or at some point in the children’s illness was important. There was no real consensus on whether Advanced Care Planning should be addressed in the resource booklet, but that Advanced Care Planning needs to be addressed with families early on and not done at a time of crisis. Research findings do show that an Advanced Care Planning discussion early on in a child’s diagnosis is beneficial for families (Dussel et al., 2009). Edwards et al. (2012) suggests that health care professionals should even use different scenarios from relative health to deteriorating health to assist the families to articulate their wishes for their children.

The third theme, the needs of families, outlines the supports that families are requesting. Some participants did report that not all families seek out support but are accepting of support when offered. Families need and are asking for different supports. Cadell et al. (2014) had reported that families spent a substantial time researching to find their own services, supports and resources. The most sought out support is funding. Families are faced with financial burdens when they have a child with a LLI. Families need to have access to funding and financial information. Research supports these findings as families face financial burdens with medical cost and employment constraints (Ireys et al., 1997). Families will also need the support of health care professionals to acquire the information and assistance with applications and forms (Weidner, 2011). Respite was another support families are requesting, and for a lot of families it was stated they are not receiving this resource. As the literature shows, respite is an invaluable resource to aid families of children with a LLI. The problem with having sufficient respite is it costs money, and so addressing this lack of resource will not be solved easily.
Research supports that respite is essential for families. Siden and Steele (2015) found that parents can spend up to 85 hours a week providing care to their ill children. That does not leave a lot of extra time for self-care, employment or family time with other children. Respite should be provided for all families (ACT, 2003). Research also shows families may not recognize that they need to take a break and have respite (Eaton, 2008).

The fourth theme is **impacts on health care professionals**. Participants in this study reported they are left feeling frustrated, anxious and ill-prepared to work with these families. One of the participants who works daily with children feels challenged when death is imminent. Health care professionals are not receiving the knowledge and education needed to work with this population. Davies et al. (2008) had reported that caring for a seriously ill child places heavy responsibility on the health care professionals who are often feeling ill-equipped. Jones’s (2005) findings support that health care professionals are not always prepared to work with this population. She had found that social workers are left feeling unprepared to offer bereavement support, about discussions from curative care to palliative care and education on disease process. Jones (2006) reported that social workers possess the skills and the knowledge to work in the field of PPC; they just need the extra training/education.

The fifth theme is the **effects on the families**. Participants reported that they are overwhelmed, confused, exhausted and are not provided services and supports. Previous research supports these findings as in the USA and in Canada the needs of families are not being met by health care systems (Stevenson et al., 2013). Further research needs to be done to examine how the services and supports that are needed can be delivered, as studies show that PPC is able to alleviate caregivers’ distress and burden (Groh, 2013).
In the final theme, *suggestions for a resource booklet*, participants expressed their suggestions and thoughts. For a resource booklet to be helpful to families it needs to be quick, simple and clear. One of the participants thought the resource booklet could also be a tool that is informative for health care professionals. The challenge is to keep the resource booklet updated with current research and resources. Research does support that families want the tools and knowledge to care for their children (Weidener, 2011).

5.3 Limitations and Strengths

In qualitative research, a study’s limitations and strengths come from the trustworthiness of the research itself. Guba (1981) believed that qualitative research should be trustworthy. To be considered trustworthy research, four criteria must be met: credibility, transferability, dependability and confirmability. In this section, the limitations and strengths of this research study will be discussed in the terms of these four criteria.

Credibility examines if a research study has internal validity that is - did this study test what the researcher set out to test (Shenton, 2004)? Credibility is one of the important factors in establishing trustworthiness in a research study (Lincoln & Guba, 1985). There are provisions set out that can ensure that the researcher has accurately studied what they intended on (Shenton, 2004). This research study set out to find what resources were available and utilized by health care professionals who support families of children with a LLI. This research study utilized a case study which is a well-established research method. Procedures were used such as standardized questions during the interviews and the method of data analysis. It is important to incorporate correct operational measures for what is being studied (Yin, 1994). The researcher also followed other provisions to
ensure credibility such as each potential participant was given the opportunity to refuse to participate. The data collection was from participants who were genuinely willing to participate in the research study. During the interviews the participants were encouraged to discuss their own experiences with the researcher and they were aware at any time that they could withdraw from the study.

The research findings of this study are congruent with past studies. The ability of the researcher to relate their findings to an existing body of knowledge is a key criterion for evaluating works of qualitative inquiry (Silverman, 2000). A limitation of this research study is that the sample was not random; it was purposeful. Random sampling may negate charges of researcher bias in the selection of the participants (Shenton, 2004). As mentioned previously the researcher did have pre-existing relationships with some potential participants. This research study also did not utilize different methods in collecting data which can be seen as a limitation.

Transferability looks at whether a study has external validity. To achieve external validity research findings in this study must be applied to other health care professionals’ experiences in Saskatchewan. Lincoln and Guba (1985) state that it is up to the researcher to ensure sufficient contextual information has been provided about the field work sites to enable other health care professionals to relate the findings to their own experiences. The researcher did provide this information in this research report, so whether or not the research has transferability is up to the health care professionals themselves to decide. They need to decide whether the research findings can be generalized to their work environment (Bassey, 1981).
Dependability of a study looks at the reliability that the research can be repeated by another researcher with the same participants and end up with the same findings. The researcher must have sections devoted to the research design and its implementation. The operational detail of the data collection and reflective appraisal of this research has achieved a level of dependability. This research study has addressed these steps in the research report.

Confirmability is the last of the four criteria that a researcher must address to state her research has trustworthiness. Confirmability is the qualitative researcher’s comparable concern with objectivity (Shenton, 2004). It is difficult to get true objectivity in this research as the researcher has her own bias as she is a social worker in the health care system who has worked with families of children with a LLI (Patton, 1990). The research questions were designed by the researcher. As mentioned the researcher did not utilize triangulation in gathering data. The data was gathered by 8 interviews, and from no other sources.

5.4 Implications

The objective of this research study was to develop a resource booklet from the best practices needs of social worker/health care providers that work with families of children with a LLI. From this research, it is apparent that social workers and other health care providers do not have the resources needed to provide full support to these families and their children. Not only do they not have the resources to provide full support to the families, they also reported feeling ill equipped to provide support or even knowing what to say to the families and their children.
Education institutions that have social work programs offer courses in death and dying, but how much time is spent with the population of children who are dying? It is my position that a course in death and dying does not fully prepare one to work in the field of death and dying. One introductory course does not prepare a person to work with dying children. Education in curative care to palliative care, and disease progression for health care professionals are needed along with education in communication.

5.5 Recommendations

The findings suggest that a follow-up study that looks at educating the health care professionals and how that can be possible in Saskatchewan. It is not feasible to have pediatric programs specializing in LLI in each region of the province as the population it would be serving is limited. However it may be possible to have certain individuals across the province trained in this area so the rest of the province could access their expertise. Research looking at training modules that an individual could have access to is one means to educate health care professionals spread across the province that could be available on-line. The modules could be specific to the discipline.

5.6 Conclusion

The number of children dying from a LLI is small in Saskatchewan but the impact is significant. A child’s illness and impending death has emotional, social and financial impacts on his/her family and their communities. These low numbers do affect the reasons that our province does not have pediatric palliative care programs. The numbers do not support having an entire program in each region dedicated to the care of this population. In our larger centers, social workers and other health care professionals will encounter families and their children who have a LLI. When families are taking their
children home to die to smaller centers or urban areas, they will need the support of trained health care professionals.

The goal of this study was to explore the development of a resource booklet for families of children with a LLI. In interviewing the eight health care professionals, study data indicated that a resource booklet for this population would be a valuable and welcoming tool. Findings show health care professionals are impacted both personally and professionally because of the lack of resources to support them. This lack of resources has a negative effect on families as well. Health care professionals provide a variety of supports to families, and having a resource booklet benefits all those involved. Our health care professionals do their absolute best in providing limited resources and services to these special families. A little more, such as a resource booklet might go a long way in helping make healthier families and communities.
REFERENCES


Appendix A

**Interview Guide**

**Questions and Probes**

Explain why the term life limiting and not palliative was chosen for this project.

1. Please share with me your experience of working with families with children with a life limiting illness. For example what setting and population (urban and rural).

2. Do you feel you have adequate information to give to families of children with LLI? If not what types or sources of information do you believe would assist you in your position of supporting families of children with life limiting illnesses?

3. What sorts of information do you provide for your families for support? Emotional and practical.

4. What information do you find is most helpful for families? Siblings support, self-care…

5. Do you find that the families that you provide support to request certain information? Respite, funding, support…

6. Would it assist you in supporting families if you had access to a support booklet to give the families, especially if for any reason you could not speak with them directly? After word hours or unavailable. Leads to next question then…

7. Would it be useful to you to have material/supportive information to leave with other professionals (when you are not available) on your team for families?

8. Have you had experiences when you were unable to connect with the families, and it would have been beneficial to have had a supportive booklet that could be offered? What I am looking for in this question is that sometimes as professionals we are unable to connect with the clients/families we work with for many reasons. Sometimes they are not ready to let us in or hear what we have to say, but if we had a support booklet/information to offer them they would have the information when they were ready for it.

9. In your position do you ever have to discuss medical issues regarding the children? For example no CPR? Do you feel it would be beneficial to have information explaining what it means to have a CPR order in place and what a no CPR means? Discuss what research shows.
Table 1.0 – Participants One Through Four

<table>
<thead>
<tr>
<th>About the Participants</th>
<th>Participant One</th>
<th>Participant Two</th>
<th>Participant Three</th>
<th>Participant Four</th>
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<tbody>
<tr>
<td>Themes</td>
<td>Social Worker</td>
<td>Social Worker</td>
<td>Social Worker</td>
<td>Registered Nurse</td>
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<td></td>
<td>Pediatric Acute</td>
<td>Pediatric</td>
<td>Pediatric</td>
<td>Pediatric Home</td>
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<td>Care Inpatient</td>
<td>Outpatient</td>
<td>Outpatient Cancer Centre</td>
<td>Care Program</td>
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<td>Expressions of</td>
<td>No adequate</td>
<td>Feels not</td>
<td>No resources</td>
<td>Does not know</td>
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<td>Lack of Resources</td>
<td>information</td>
<td>always has</td>
<td>available,</td>
<td>where to look</td>
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<td></td>
<td></td>
<td>adequate</td>
<td>nothing to give</td>
<td>for supports</td>
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<td>information or</td>
<td>families, nothing</td>
<td>and does not</td>
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<td>it is</td>
<td>specific about</td>
<td>have adequate</td>
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<td></td>
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<td>inaccurate</td>
<td>LLI, no local</td>
<td>information to</td>
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<td></td>
<td>information</td>
<td>give</td>
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<tr>
<td>Expressions of</td>
<td>Need written &amp;</td>
<td>Needs</td>
<td>It is important</td>
<td>Families need</td>
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<td>What is Needed</td>
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<td>information to</td>
<td>to have information</td>
<td>to receive</td>
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<td>information,</td>
<td>send out to</td>
<td>to give to</td>
<td>Advanced care</td>
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<td></td>
<td>resource</td>
<td>families and a</td>
<td>families to</td>
<td>planning early</td>
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<td>resource</td>
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<td>to hand out by</td>
<td>booklet</td>
<td>needs/ Advanced</td>
<td>resource booklet</td>
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<td>care planning, a</td>
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<td>professionals</td>
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<td>resource for to</td>
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<td>other professionals to</td>
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<td>hand out</td>
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<td>The Needs of</td>
<td>Families want</td>
<td>Families want</td>
<td>Families ask</td>
<td>Families do not</td>
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<td>Families</td>
<td>support and</td>
<td>emotional</td>
<td>occasionally for</td>
<td>ask for support</td>
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<td>respite and</td>
<td>support and</td>
<td>support and</td>
<td>or information,</td>
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<td>information,</td>
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<td>some not aware</td>
<td>in other</td>
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<td>they could ask,</td>
<td>programs</td>
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<td>psycho-social</td>
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<td>support for</td>
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<td></td>
<td>siblings</td>
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<tr>
<td>Impacts on</td>
<td>Hard to have</td>
<td>Feelings of</td>
<td>Feeling of</td>
<td>Feels it is</td>
</tr>
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<td>Health Care</td>
<td>conversations</td>
<td>no knowledge</td>
<td>frustration when</td>
<td>difficult to</td>
</tr>
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<td>Professionals</td>
<td>with families</td>
<td>and expertise,</td>
<td>no resources</td>
<td>connect with</td>
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<tr>
<td></td>
<td>and</td>
<td></td>
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</table>

Appendix B
<table>
<thead>
<tr>
<th>Effects on the Families</th>
<th>don’t know what to tell parents</th>
<th>feelings of difficulty and challenged to reach families</th>
<th>families, does not feel knowledgeable in this area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed, caregivers are burnt out, confused, exhausted, challenged, information is received at a crisis</td>
<td>Families withdrawing from services</td>
<td>Some families do not even recognize they need the supports, families distraught</td>
<td>Families feeling they need to do it on their own, isolated</td>
</tr>
</tbody>
</table>

| Suggestions for the Resource Booklet | Booklets need to be quite and simple and practical | Would be a challenge to keep booklet updated and contains material based on research | A resource booklet needs to be simple and clear | A booklet needs to be updated |

Table 2.0 Participants Five through Eight

<table>
<thead>
<tr>
<th>Participants</th>
<th>Participant Five Social Worker Pediatric</th>
<th>Participant Six Social Worker Pediatric Acute</th>
<th>Participant Seven Social Worker</th>
<th>Participant Eight Social Worker Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes</td>
<td>Outpatient Program (Serving Northern Saskatchewan)</td>
<td>Care- Inpatient Palliative Home Care Program</td>
<td>Program Home Care and Acute Care</td>
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<td>---------------------------------------------</td>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Expressions of Lack of Resources</td>
<td>Gaps in resources, no written materials, don’t know what resources are available</td>
<td>No adequate information and no written information</td>
<td>Absolutely no information, rare so don’t develop resources, dynamics differ from adults, unnecessary delays</td>
<td></td>
</tr>
<tr>
<td>Expressions of What is Needed</td>
<td>Need written information that can be read later, ACP, resource for team to hand out, visible to families</td>
<td>Written material would be helpful, yes to a resource booklet to families who do not want to talk and information to hand out when no SW</td>
<td>Need a way to make it easier, yes to a resource booklet for when families won’t talk, to be involved with families early on in illness</td>
<td></td>
</tr>
<tr>
<td>The Needs of Families</td>
<td>Want information on how to talk to family members, the child and siblings, end of life, funding anticipator grief, financial or practical information</td>
<td>Funding, self-care, emotional, and practical information, who to reach out to, and support groups</td>
<td>Want legacy and support group information, relationship information, children themselves asked for support for their parents</td>
<td></td>
</tr>
<tr>
<td>Impact on Health Care Professionals</td>
<td>Feels comfortable working with families</td>
<td>No comment</td>
<td>Feels like a fish out of water, don’t know how to support siblings, frustrated, and struggle to find resources, just do not know how to help, not doing justice for the families</td>
<td></td>
</tr>
<tr>
<td>Effects on the Families</td>
<td>Families do not always have the knowledge of how</td>
<td>Families do not understand CPR orders so not able to make decisions, over-</td>
<td>Barriers to receiving supports as do not understand palliative care,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parents do not know what to ask for, not aware there were supports for their</td>
<td></td>
</tr>
</tbody>
</table>

The Needs of Families

Families do not understand CPR orders so not able to make decisions, over-

Barriers to receiving supports as do not understand palliative care, Parents do not know what to ask for, not aware there were supports for their
| Suggestions for the Resource Booklet | Resource booklet needs to be update, resources vary in regions | A booklet that is accessible to all | A booklet to be informational for other professions | A booklet needs to be short and simple ideas |
Appendix C

Resource Booklet - Draft

Resource Booklet for Caregivers

And Their Children With A Life-Limiting Illness
Information completed by
Lynn McKenzie, BA, BSW, RSW

Illustrated
By
Braeden, Austin and Josie McKenzie

Dedicated to Ellysa and her Mom, Stacey
For inspiring the creation of this booklet

LIFE IS NOT MEASURED BY THE NUMBER OF BREATHS WE TAKE, BUT BY THE MOMENTS THAT TAKE OUR BREATH AWAY
Funding Information

Kinsmen Foundation – [www.telemiracle.com](http://www.telemiracle.com) – 1-877-777-8979
Financial assistance for equipment and medical expenses available. Application with financial and medical documents required.

President’s Choice Children’s Charity – [www.presidentchoice.ca/pccharity](http://www.presidentchoice.ca/pccharity) - 1-888-495-5111
Financial assistance for children under 18 years old for equipment, housing modifications and medical expenses. Application with financial and medical documentation required.

Canadian Cancer Society – [www.cancer.ca](http://www.cancer.ca) - 1888-939-3333
Financial assistant provided for transportation and accommodations when travelling to other cities for treatment. Application with financial documentation required.

Cognitive Disability Strategy (CDS)
Contact your local health region representative for more information. CDS may provide individuals who have a cognitive impairment with funding for which there is no alternative source of funding.

Orange Benevolent Society of Saskatchewan – [www.obsociety.com](http://www.obsociety.com) - 1-877-522-8257
Financial assistance is for travel, treatment and devices to improve the quality of life. Application process requires a letter outlining the need, medical and financial documentation.
Compassionate Care Benefits – Employment Insurance – [www.servicecanada.gc.ca] - A benefit paid to an individual who needs to provide care to a family member who is ill and at risk of dying in the next six months.

Parents of Critically Ill Children – Employment Insurance – [www.servicecanada.gc.ca] – For parents of children with a life-threatening illness or injury who need to be away from work to care for their child up to 35 weeks.

Disability Tax Credit Certificate – Canada Revenue Agency – [www.cra.gc.ca/disability]
A tax credit used to reduce income tax payable on your tax return. The application form must be completed by practitioner listed on the application. The practitioner must certify that your child has a severe or prolonged impairment.

Child Disability Benefit – Canada Revenue Agency – [www.cra.gc.ca]
Once your child has been approved for the Disability Tax Credit and you are receiving the Child Tax Benefit you may be eligible to receive money through the Child Disability Benefit. You will receive this money at the same dates as your Child Tax Credit.

Registered Disability Savings Plan – Canada Revenue Agency - [www.cra.gc.ca]
Once your child has been approved for the Disability Tax Credit this saving plan allows funds to be invested tax-free.

Saskatchewan Rental Housing Supplement (SRHS) – 1-888-488-6385 - SRHR is a monthly payment that helps families with low to moderate incomes.

Saskatchewan Employment Supplement (SES) - 1-888-488-6385 – SES provides a monthly payment to families of low to moderate incomes.

Saskatchewan Family Health Benefit Program - 1-888-488-6385 – If families meet the income text for SRHR and SES they will receive a range of health benefits.

Ministry of Social Services – 1866-221-5200 – To apply for social assistance call contact center with number provided.

Palliative Care Drug Program – 1-800-667-7781 -
[https://www.saskatchewan.ca/residents/health/accessing-health-care-services/palliative-care-programs] This program covers the cost of drugs for an individual who is in the later stages of a terminal illness.

Accommodations – Ask your health care provider for information on which hotels in the area have a discount for families who have a loved one in the hospital.

Wascana Rehabilitation Centre Hostel – Regina – 306-766-5797
available for patients and their family members with Regina Qu’Appelle Health Region. Open 7 days a week.


**Ronald McDonald House** – Saskatoon – 306-244-5700- [www.rmhc.ca](http://www.rmhc.ca) – Ronald McDonald House provides accommodations for families of children under the age of 18 years who are receiving treatment at a medical facility. There is a minimal fee. Reservations recommended.

### Travel

**Hope Air** – [www.hopeair.org](http://www.hopeair.org) – Hope Air is a registered, national charity that provides free flights to people who cannot afford the cost of an airline ticket to get to medical expertise or specialized medical technologies that usually exist only in larger urban centers.

**Disability Travel Card Program** – [www.abilitiescouncil.sk.ca](http://www.abilitiescouncil.sk.ca). This card provides the identification to a person with a permanent disability, and this will allow an adult attendant to travel at no cost or at a reduced cost.

### Wish Foundations

**Children’s Wish foundation of Canada** – 1-888-822-9474- [www.childrenswish.ca](http://www.childrenswish.ca) - Grants wishes for children between the ages of 3-17 who are diagnosed with a life-threatening illness.

**Dreams Take Flight** – 1-204-479-5267 – [www.dreamstakeflight.ca](http://www.dreamstakeflight.ca) Children between the ages of 6-11 years must meet specific criteria to receive a trip to Disneyland or Disney World.


**Starlight Children’s Foundation of Canada** – 1-905-752-7827- [www.starlightcanada.org](http://www.starlightcanada.org) - Grants wishes to critically and chronically ill children between the ages of 4-18 years.

**Sunshine Dreams For Kids** – 1-800-461-7935- [www.sunshine.ca](http://www.sunshine.ca) - Grants individual dreams and dream trips to children between the 7-18 years with a severe physical disability or life-threatening illness.

**The Chris Knox Foundation** [www.chrisknoxfoundation.ca](http://www.chrisknoxfoundation.ca) - Grants opportunities for children and young adults, up to the age of 30, who are currently in cancer treatment, remission or palliative care, to attend sporting, cultural or fine arts events within the province of Saskatchewan.
**Respite**

Respite is a short relief or break from caring for your ill child. It is encouraged that caregivers and families take some time to rest or attend a special event or even a vacation. It is important that caregivers take care of themselves. Being a caregiver is tuff and demanding. Respite can also give caregivers a change to spend time with other children in the family.

**Regina Respite Registry** - Regina and Area - [www.rdacl.ca](http://www.rdacl.ca)
- A list of individuals who are interested and available to provide respite.

- Hope’s Home provides day and extended hours respite for medically fragile children.

**Supporting Your Ill Child and Siblings**

**Children’s Understanding of Death and Dying**

Developmental Understanding of illness and death

Hospice of Denver

Children grieve differently during an illness or after they experience a death of a loved one depending on their age. The following information is to assist you in providing support and understanding with what your child/children are experiencing.
Birth – 2 years

Concept of Illness and Death

- Separation/absence
- Reacts to change in routine and emotional climate

Feelings

- Miss and ach for sound, smell, sight or feel of someone
- Fear of being abandoned
- General anxiety

Behaviors

- Trashing, rocking, throwing
- Crying
- Sucking, biting
- Sleeplessness
- Sickliness
- Indigestion

How to Help

- Physical contact and reassurance
- Attend to immediate physical needs
- Maintain routines
- Include the child in the mourning process when possible and appropriate

2-5 years

Concepts of Illness and Death

- Death is temporary and reversible
- Finality of death is not evident
- To be dead is to be sleeping or on a trip
- May wonder what deceased is doing
- Magical thinking and fantasies, often worse than realities
- Understanding is limited

Feelings

- Sad, anxious
- Insecure, withdrawn
- Confused
- Angry, Scared
- Cranky
- Agitated

Behaviors

- Crying
- Fighting
- Interested in dead things

- Acts as if illness or dead never happened
- Regressive behaviors
- Repetitive questions
- Expressing strong feelings in her/his sleep and dreams
- Expressing feelings through play

**How to Help**

- Answer repetitive questions
- Give simple truthful answers to questions
- Include child in family rituals and in mourning process

**6-9 years**

**Concepts of Illness and Death**

- Thinks about the finality of death
- Thinks about the processes of death
- Death is associated with bodily harm
- Personify death – a spirit, monster
- Who will care for me if my caregiver dies
- My actions or words caused the illness or death

**Feelings**

- Sad
- Sad
- Anxious
- Withdrawn
- Confusion
- Angry
- Scared
- Cranky

**Behaviors**

- Aggressive acting out
- Withdrawal
- Nightmares/sleep disturbances
- Acting as if the illness or death never happened
- Lack of concentration
- Grade changes
- Regressive behaviors
- Specific questioning, looking for details

**How to Help**

- Answer questions truthfully
- Look for confused thinking
- Encourage expression of feeling
- Offer physical outlets
- Encourage drawing, reading, playing, art, music, dance, acting, sports
- Physical contact
- Have intentional times to grieve during an illness or after a death
- Let the child choose how to be involved in the death or mourning process
- Find peer support for the child
- Work with the school to adjust workload if needed
- Talk
9-12 years

Concepts of Illness and Death

- Understanding of the finality and universality of death
- Death may happen again
- What will happen if my caregiver dies
- My action and words caused the illness and death

Feelings

- Vulnerable
- Anxious
- Scared
- Lonely
- Confused
- Angry, sad
- Shock, denial
- Isolated
- Abandoned
- Emotional turmoil heightened by physical changes

Behaviors

- Aggressive acting out
- Withdrawal
- Talks about the physical aspects of illness or death
- Acts like illness or death never happened
- Does not show feelings
- Nightmares/sleep disturbances
- Lack of concentration
- Change in grades
- Regressive behavior
- Acting out role confusion

How to Help

- Answer questions
- Expect and accept mood swings
- Give choices about how to be involved in death and mourning rituals
- Find peer support groups
- Encourage expression of feelings
- Encourage reading, writing, art, music, sport
- Talk
- Encourage reading, writing, art, music, sports
- Talk

12 years and up

Concepts of Illness and Death

- Understanding of the finality of death
- Can sense own impending death
- Self-centered and thus have an exaggerated sense of their own role in regards to the illness and death
Feelings

- Vulnerable
- Anxious
- Scared
- Lonely
- Confused
- Angry
- Sad
- Abandoned
- Guilty
- Fearful
- Worried
- Isolated
- Shock, denial
- Depression
- Highly self-conscious about being different

Behaviors

- Impulsive behavior
- Fighting, screaming, and arguing
- High risk behaviors
- Grieving for what might have been
- Acts like illness or death never happened
- Lack of concentration
- Changes in grades
- Sleep disturbances
- Changes in eating pattern
- Acting out role confusion
- Conflict within teen about moving to independence and remaining dependent

How to Help

- Expect the thought and feelings of the teen to be contradictory and inconsistent
- Allow their coping behavior in covering up their grief if it is basically harmless to themselves and others
- Encourage expression of feelings
- Look for high risk behavior
- Encourage relationships with other supportive adults
- Answer questions truthfully
- Display honest grief, share in discussions
- Give choices about involvement in death and mourning rituals
- Encourage peer support groups
- Talk
School

Attending school gives children a sense of normal in their lives. Attending school as much as possible is important to their well-being. It shows the child they are valued and have a purpose. With your permission members of your child’s health care team can be contacted to work with or educate the school staff in supporting your child and their siblings and classmates.

Attending school for the siblings of your ill child will also give them a sense of normalcy. It may be a place children can have periods of distraction from home concerns. School can also be a source of pressure. Children may not be able to focus their attention on school. Speaking with your children’s teachers and/or counsellors can get them added support and understanding.

Websites

  - Using the movie “Inside Out” to explore emotions


Books

- About Dying: An Open Book for Parents and Children Together, by Sara Bonnett and Dick Fran
- Gentle Willow, by Joyce Mills
- The Next Place, by Warren Hansen

- What About Me? When Brothers and Sisters Get Sick, by Allan Peterkin
- Special Brothers and Sisters: Stories and Tips for Siblings of Children with a Disability or Serious Illness, Annette Hames and Monica McCaffery
Self-Care

It is important that caregivers take care of themselves. Remember this whole thing does not work if you are not taking care of yourself. Whether that means to have someone to talk to, journal, or to take time to have a long bath or walk it is important that you have a chance to recharge. Take time for the other relationships in your life whether you have a partner or other children it is important to spend that time together. It can be a night out or a weekend away. Depending on what options are available and what is needed for you and your family.

- Shelter from the storm: Caring for a child with a life-threatening condition, by Joanne Hilden, Daniel Tobin, and Karen Lindsey
- Giving Care, Taking Care: Support for Helpers, by Sherokee Ilse

Websites
- Lotsa Helping Hands – is a care calendar website and a way to organize meals and other help that is needed.
  http://lotsahelpinghands.com/-

Books
- Shelter from the storm: Caring for a child with a life-threatening condition, by Joanne Hilden, Daniel Tobin, and Karen Lindsey
- Giving Care, Taking Care: Support for Helpers, by Sherokee Ilse

Legacy Work

Legacy work is about sharing precious moments and gifts with the special people in your life. There are many ways a person can complete legacy work. The following are just a few suggestions;
Scrapbooking:
- Using photos
- Drawings by the child. For example, draw a picture of your favorite vacation. Many pages can be set up with different titles/memories.

Finger prints
- Done in colored clay - Fingertip prints are taken in clay and bake in the oven at 275 for 10 to 15 minutes. Clay can be purchased where craft supplies are sold.
- Jewelry - Certain jewelry outlets. Thumbprints can be taken and made into jewelry.

Handprints
- Moldings — Molding kits can be purchased.
- Drawings – Trace the child’s hand.

Memory Boxes
- Select a box, jewelry box or a box from a craft store. It can be decorated, and anything that is important to your child can go inside the box. It could include pictures, drawings, jewelry, ticket stubs and cards to name a few.

**Health Care Directives - Advanced Care Planning**

Regina Qu’Appelle Health Region

Anyone who has capacity and is 16 years or older can make their own advance care directive. An advance care directive is there to speak for you when you are unable to do so. It directs your health care team and family with what your wishes are if you cannot speak. Children under 16 years of age cannot make a legal health care directive. The custodial parent is responsible for health care decisions for their children. The following is intended to provide you with information you may need to make decisions for your child;

**Antibiotics for Infections** – Antibiotics are drugs used to treat infections by bacteria or other organisms. When a person is dying, antibiotics may or may not prolong life.

**Blood Transfusions** - Generally a blood transfusion is given to replace a part of the blood that is low due to bleeding, illness, or medical treatment such as chemotherapy. Red blood cells are given to correct anemia (low hemoglobin level). Platelets or plasma are given to prevent or stop bleeding.

**Feeding Tubes and Intravenous Fluids** – Artificially administered nutrition is the provision of liquid and food through the use of tubes such as intravenous (IV) which may include fluids only or Total Parenteral Nutrition (TPN), and/or a feeding tube in the stomach. When a person is dying they will not feel thirst or hunger, and at this stage artificial feeding tubes do not improve a person’s quality of life and can cause discomfort.
**Cardiopulmonary Resuscitation (CPR)**- is a medical intervention used to try to restart a patient’s heart and breathing when they stop. CPR may involve;

- Mouth-to-mouth breathing and pumping on the chest.
- Inserting a breathing tube into the mouth to the lungs to help the person breathe artificially.
- Using electric shock to try to get the person’s heart to beat more effectively.

**Comfort Measures Only** – Comfort care is when a person receives maximum comfort and control of their symptoms.

**Palliative Care** - A holistic approach to care which focuses on relieving the physical, social, psychological and spiritual suffering experienced by children and the families who face a progressive, life-threatening condition, and helping them fulfill their physical, psychological, social and spiritual goals (Canadian Hospice and Palliative Care Association, 2006). The following are workbooks that you may want to use with your child to learn about their wishes.

https://agingwithdignity.org/shop/product-details/pediatric-my-wishes
https://agingwithdignity.org/shop/product-details/voicing-my-choices

**Websites**


Websites in this booklet were last viewed in March 2016.

**YOU NEVER KNOW HOW STRONG YOU ARE UNTIL BEING STRONG IS THE ONLY CHOICE YOU HAVE**
Appendix D

Consent Form

 PARTICIPANT CONSENT FORM

Project Title: Exploring and developing resources for families of children living with life limiting illnesses.

Researcher: Lynn McKenzie
Graduate Student
Faculty of Social Work
University of Regina
1-306-630-2170
Goalen11@uregina.ca

Supervisor: Dr. Randy Johner
Faculty of Social Work
University of Regina
1-306-585-4549
1-306-664-7131 (f)
Randy.Johner@uregina.ca

Purpose(s) and Objective(s) of the Research: The purpose of the research is to explore the best practices in supporting families of children living with a life limiting illness, and to develop a support booklet for these families.

Funded by: This research project is not funded.

Potential Risks: There are no known or anticipated risks to you by participating in this research. If for any reason you experience feelings of discomfort while or after participating in this research the researcher can make appropriate referrals for counseling.

Potential Benefits:
The potential benefits of this research are to provide Social Workers with knowledge and tools to assist families of children living with a life limiting illnesses along with providing supportive information to these families during their children’s illnesses.

**Compensation:**
There is no compensation for participants of this study.

**Confidentiality:**
Due to the nature of this study, confidentiality will be limited. To ensure as much confidentiality as possible, your name will not be used and a pseudonym (false name) will be assigned when the interviews are transcribed and reported. The research will done in Saskatchewan and that the sample size is small therefore confidentiality cannot be guaranteed.

**Procedures:** Your participation in the study will involve one 60 minute interview face-to-face or over the telephone at a time and place that are convenient to you. Once your interview has been transcribed you will receive a copy to review.

I give permission:

Individual interview (audio-recorded and transcribed)

YES………………    NO………………

**Storage of Data:**
The data will be stored in a locked cabinet by the researcher and computer files are protected by a password. Once the study is complete, data will be stored in a locked cabinet by Dr. Randy Johner, at the University of Regina for five years. After the required five years, the audio-recordings will be erased and destroyed, and the transcripts, including computer files, will be deleted or shredded and discarded.

**Right to Withdraw:**
Your participation is voluntary, and you are free to withdraw from the research project at any time. If you withdraw, and if desired, your data will be deleted from the research project and destroyed. Your right to withdraw data from the study will apply until the research project’s paper is in its final draft.

**Follow up:**
To request a copy of the paper and resource booklet please contact researcher.

**Questions or Concerns:**
Contact the researcher using the information at the top of page one (1). This project has been approved on ethical grounds by the University of Regina, the University of Saskatchewan, Regina Qu’Appelle Health Region and Saskatoon Health Region Research Ethics Board. Any questions regarding your rights as a participant may be addressed to the committee at 585-4775 or research.ethics@uregina.ca. Out of town participants may call collect.
**Consent**

In-Person Individual:

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

A copy of this consent will be left with you and a copy will be taken by the researcher.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
<th>Date</th>
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**Researcher’s Signature**

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Oral Consent:
I read and explained this consent form to the participant before receiving the participant’s consent, and the participant had knowledge of its contents and appeared to understand it.

A copy of this consent will be sent to the participant and one kept with the researcher.

<table>
<thead>
<tr>
<th>Researcher’s Signature</th>
<th>Date</th>
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Appendix E

February 18, 2015

Ms. Lynn McKenzie
University of Regina
1141 11th Ave. NW
Moose Jaw, SK S6H 4L7

Dr. Randy Johner
3737 Wascana Pkwy
Faculty of Social Work
Regina, SK, S4S 0A2

Dear Ms. McKenzie and Dr. Johner,

RE: REB-15-21; U of R 2014-210
Title: Exploring and developing resources for families of children living with a life limiting illness

Your application for research ethics review has undergone a harmonized review by the Regina Qu’Appelle Health Region (RQHR) and University of Regina (U of R) Research Ethics Boards (REBs). In accordance with the Research Ethics Review Reciprocity Agreement signed by the University of Saskatchewan, University of Regina, and Regina Qu’Appelle Health Region, the RQHR REB accepts the Certificate of Approval issued by U of R REB. This letter is issued to you in lieu of a Certificate of Approval by the RQHR REB. This letter permits you to conduct research activities as approved by the U of R REB, provided that you maintain a valid and up-to-date Certificate of Approval.

All continuing ethics review will be conducted by the U of R REB. The U of R is authorized to share all communications pertaining to this file with the RQHR REB at their discretion. The RQHR REB may provide input into continuing ethical review activities, as agreed upon by both REBs.

The RQHR REB reserves the right to revoke the privileges described in this letter at any time in order to conduct their own independent research ethics review of your project. Such a decision would be communicated to you and the U of R REB in writing.

This letter also serves to acknowledge that you have obtained all necessary departmental approvals within the RQHR and are permitted to proceed with this research on operational grounds. Approval for this study has been received from the following:
- Sharon Garrett (Women’s & Children’s Health)

If at any time you will require resources, participants, or data from any additional departments, you must provide the RQHR REB with the required signatures before proceeding.

Best wishes for your continuing research endeavours.

Sincerely,

Michelle McCarron, Chair
Research Ethics Board
Regina Qu’Appelle Health Region

cc. University of Regina Research Ethics Board
Research Ethics Board
Certificate of Approval

PRINCIPAL INVESTIGATOR
Lynn McKenzie
1141 – 11th Avenue NW
Moose Jaw, SK S6H 4L7

DEPARTMENT
Social Work

REB#
2014-210

SUPERVISOR
Dr. Randy Johnson
FUNDER(S)
Unfunded

TITLE
Exploring and Developing Resources for Families of Children Living with a Life Limiting Illness

APPROVAL OF
Application for Behavioural Research Ethics Review
Letter of Invitation
Participant Consent Form
Interview Guide Questions and Probes

APPROVED ON
December 22, 2014

RENEWAL DATE
December 22, 2015

Full Board Meeting ☐
Delegated Review ☒

CERTIFICATION
The University of Regina Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol, consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion.

Please refer to the following website for further instructions: http://www.uregina.ca/research/REB/make.shtml

Dr. Larena Hoeber, Chair
University of Regina
Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4693
research.uregina.ca