

Running head: PARENTS AND PEDIATRIC PALLIATIVE CARE

Exploring What is Important to Parents of Children Receiving Palliative Care: An Integrative

Review

by

Linda Dart

BScN, University of British Columbia, 1995

A Project Submitted in Partial Fulfillment of the Requirements for the Degree of

MASTERS OF NURSING

in the School of Nursing, Faculty of Human and Social Development,

University of Victoria.

© Linda Dart, 2014
University of Victoria

All rights reserved. This thesis may not be reproduced in whole or in part, by photocopy or other means, without the permission of the author.

Supervisory Committee

Exploring What is Important to Parents of Children Receiving Palliative Care: An Integrative
Review

by

Linda Dart
BScN, University of British Columbia, 1995

Supervisory Committee

Dr. Kelli Stajduhar, (School of Nursing)
Supervisor

Dr. Lenora Marcellus, (School of Nursing)
Departmental Member

Abstract**Supervisory Committee**

Dr. Kelli Stajduhar, School of Nursing

Supervisor

Dr. Lenora Marcellus

Departmental Member

Objectives: To identify what is important to parents of children with life-threatening or life-limiting conditions (LTCs) who receive pediatric palliative care (PPC) and make recommendations for improvements for PPC care delivery.

Method: An integrative literature review was conducted with 11 qualitative and mixed-methods studies, published between 2000 and 2013 and retrieved via CINAHL, Google Scholar, Web of Science, and University of Victoria Library. Selected studies met inclusion criteria and reported what was important to parents of children receiving PPC, as identified by parents.

Results: Continuity of care, effective communication between health care professionals and with parents and support through their child's illness and death was important to parents and contributed to the preservation of their roles as parents while receiving PPC. Parents identified bereavement support and pain and symptom management as priority areas for improvement.

Conclusions: Improvements to PPC can be achieved through care coordination, bereavement support, education for PPC and pediatric health care professionals, and further research.

Keywords: children, families, family-centred care, palliative care, parents, pediatric palliative care, pediatrics

Table of Contents

Supervisory Committee	ii
Abstract	iii
Table of Contents	iv
Acknowledgements	vi
Dedication	vii
Introduction	1
Overview of PPC	1
Family-Centred Care in PPC	3
Methods	6
Results	8
Continuity of Care	8
Communication	10
Support	13
Support from staff	13
Sibling support	14
Spiritual support	14
Bereavement support	15
Pain and Symptom Management	16
Role of Parents	17
Summary of Results	18
Discussion	19
Care Continuity and Coordination	19

Communication with HCPs and Parents	19
PPC Support	20
Relief From Suffering	21
Preserving the Role of Parents	21
Recommendations	22
Optimizing PPC Programs	23
Improving Clinical Care	24
Deepening Knowledge Through Education	24
Expanding Knowledge Through Research	25
Limitations	26
Conclusion	27
References	28
Appendix A: Literature Search Flow Chart	34
Appendix B: Critique Table	35

Acknowledgments

This paper marks the end of a four-year long adventure. I am grateful to my family for their ongoing love, support, cheerleading, and belief in me. I could not have accomplished what I have without you! I thank my friends for their support and my colleagues for their patience and participation in late night shift discussions on research and theory. More recently, I thank my project reviewers, Rosella, Cindy, Sara, Ashley, and Krista, for their thoughtful questions and comments. Special thanks are offered to Tracie Northway for her passion, enthusiasm, and support. Lastly, I would like to acknowledge and thank my supervisor, Dr. Kelli Stajduhar, and committee member, Dr. Lenora Marcellus, for their commitment to this work, for pushing me to dig deeper, and for late night revisions so I could hit my goal with a project to be proud of.

Dedication

This project is dedicated to the families with whom I have been privileged to journey.

Exploring What is Important to Parents of Children Receiving Palliative Care: An Integrative Review

It is a desire of many health care professionals (HCPs) to take away the physical and emotional pain dying children and their families experience; to ‘make it all better’. Evidence tells us this is rarely achievable but there are ways to help make their journey a little bit gentler. Providing meaningful quality pediatric palliative care (PPC) requires understanding not only the needs of dying children, but also what parents consider important for PPC in order to have the best possible quality of life with their child. My purpose in this paper is to explore what is important to parents of children with life-threatening and life-limiting conditions (LTCs)¹ receiving palliative care in a pediatric hospital setting. Recommendations will be made regarding care coordination in clinical practice, as well as bereavement support and further research.

Overview of PPC

Approximately 3,500 children² die in Canada each year (Statistics Canada, 2013), while about 44,000 children die every year in the United States (US) (Hamilton, Hoyert, Martin, Strobino, & Guyer, 2013). In Canada, about 1200 of those deaths occurred in infants before their first birthday (Statistics Canada, 2013). The leading cause of death for infants below 12 months old in 2007 was congenital malformations, deformations, and chromosomal abnormalities; the second highest cause was problems of prematurity; and the third was effects of maternal complications of pregnancy (Statistics Canada, 2011). For children aged 1 to 14 years old, the

¹ “Life threatening” and “life limiting” are terms used to describe conditions with which children receiving palliative care are living. A life threatening condition (LTC) is defined as a disease for which curative treatment may exist but may fail, such as cancer (Wolfe, Hinds, & Sourkes, 2011a). A life limiting condition has no reasonable hope for cure and the child will die from the condition, such as a degenerative neuromuscular disease (Wolfe et al., 2011a). Life threatening is the broader term that is used in this paper because, as explained by Wolfe et al. (2011a), “most serious illnesses are characterized by prognostic uncertainty” (p. 3), and even children with life limiting conditions may experience acute events that may be life threatening.

² The terms “child” and “children” are used in this review to refer to the age range of newborn to the teenage years, unless otherwise specified.

leading cause of death in 2007 was accidental injury; followed by malignant neoplasm; and then congenital malformations, deformations, and chromosomal abnormalities (Statistics Canada, 2011). Widger and colleagues (2007) used data from the US and the United Kingdom (UK) to estimate that more than 3800 children are living in Canada with a disease or condition that threatens their life.

Palliative care is an approach to care that seeks to ease pain and suffering caused by LTCs and support patients and their families to live as normally as possible, for as long as possible (Field & Behrman, 2003). Palliative care is defined by the World Health Organization (WHO) as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, n.d. b, para. 1)

The WHO's definition of PPC states that:

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes. (WHO, n.d. a, para. 1)

Wolfe et al. (2011a) added to this definition an emphasis on providing care that is developmentally appropriate and aligns with the values of the family.

PPC is unique from adult palliative care as children themselves are different. Children are growing and developing through physiological, emotional, and cognitive stages and tend to die of rare conditions not present in adults (Field & Behrman, 2003). Specialized knowledge in pediatric anatomy, physiology, growth and development, and diseases of childhood, in combination with concepts associated with palliative care, including grief, bereavement, and pain and symptom management is necessary to care for this unique population (Field & Behrman, 2003).

The first Canadian PPC program was created at Toronto's Hospital for Sick Children in 1986, followed by the establishment of North America's first free-standing children's hospice, Canuck Place Children's Hospice (Canuck Place) in Vancouver, British Columbia (BC) in 1995 (Widger, Cadell, Davies, Siden, & Steele, 2012). Among Canada's 12 specialized children's hospitals there are eight hospital-based PPC programs. There are six freestanding children's hospices, with one more opening this year (Widger et al., 2012). The Canadian Hospice Palliative Care Association standards call for constant access to palliative care for patients who need it, standards these organizations are striving to meet through PPC teams and educating other HCPs to provide palliative care for children and their families (Widger et al., 2012).

Family-Centred Care in PPC

When a child is living with a LTC, every member of the family is affected. The philosophy of family-centred care is predominant in pediatrics, shaping HCPs' approach to caring for children and their families. Family systems theory, a foundation of family-centred care, recognizes strengths of the family unit and the interrelatedness of its members. Each family member is an individual subsystem made up of physical and psychological systems. Placed within a family, each individual has relationships with other family members, creating a system that seeks to maintain equilibrium and stability (Wright & Leahey, 2013). When change occurs

for one member of the family, all other family members are affected and work to adapt to the change. Family systems theory recognizes the major stressors and challenges for parents as the family adapts to having a child with a LTC (Stephanson, Nicholson, & Fletcher Johnston, 2006; Wright & Leahey, 2013).

Family-centred care is a philosophy of health care that recognizes the importance of the family in the life of the child (BCCH, 2013). When caring for a child, the health care team acknowledges the strengths of the family and employs the concepts of respect, choice, information sharing, support, collaboration, flexibility, and empowerment (BCCH, 2013). Jones et al. (2011) identify the five key components of family-centred care in the context of PPC as:

- (1) Recognizing and respecting the pivotal role of the family in the lives of children;
 - (2) Striving to support families in their caregiving roles by building upon their unique strengths as individuals and as families;
 - (3) Respecting and encouraging the choices families make for their children;
 - (4) Promoting normal patterns of living in the hospital, at home, and in the community;
- and
- (5) Promoting partnerships between families and professionals to ensure excellence at all levels of healthcare. (Jones et al., 2011, p. 135)

Family-centred care builds on family strengths, increases parental satisfaction with care, and decreases health care costs (Davies et al., 2008). Assessing family needs with a family-centred care approach recognizes the cultural context and developmental stage of the family and each of its members. Stephanson et al. (2006) provided an example, suggesting, for instance, that family needs will be different for families with young children and a large extended family compared with families with a middle-aged single parent with a teenager. Family-centred care

requires that HCPs ask, not assume, what is important to individual families (Contro & Scofield, 2006).

From the research and from family systems theory, we know that parents are significantly affected by the care their dying child receives and events that occur in the palliative period. For example, great emotional distress in parents has resulted from unrelieved pain in their child, poor delivery of difficult news (Contro, Larson, Scofield, Sourkes, & Cohen, 2002), and failure to provide adequate information to parents (Davies, Contro, Larson, & Widger, 2010). Contro and colleagues (2002) interviewed 68 family members, of whom 57 were parents, and found that:

One of the most striking findings was how a single event could cause parents profound and lasting emotional distress. Parents recounted incidents that included insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents' judgment regarding the care of their child, and poor communication of important information. Such an event haunted them and complicated their grief even years later. (p. 15)

These types of experiences provide an impetus for HCPs to examine how we provide PPC and build on our strengths and identify and act upon those areas in which we need to improve.

When I began this paper I knew some Canadian PPC programs employed clinical nurse specialists (CNSs) as PPC team members or program coordinators. My assumption was this role would strengthen the delivery of PPC to children with LTCs and their families by applying specialized PPC knowledge and skill to coordinate care and support families, provide education, mentorship, and support for nursing staff providing direct care, and enhance hospital policies and clinical practice guidelines for quality PPC. However, a preliminary search of the literature to investigate how a CNS might enhance and improve PPC showed that little research has been done in this area. Therefore, for the purposes of this review, I turned my attention to better

understanding the needs of parents of children receiving PPC before being able to determine how a CNS might utilize advanced practice nursing competencies to meet this population's needs. A family-centred approach was important for understanding the needs of parents and considering how the health care system can better respond to those needs (Johnson, 1990). The research question guiding this integrative review was: what is important to parents of children with LTCs in the hospital setting from their perspective?

Methods

An integrative literature review was conducted to investigate the research question. This method was chosen as it contributes to evidence-based nursing practice by investigating both experimental and non-experimental primary research to produce a greater understanding of concepts, theories, and evidence of a particular phenomenon of concern (Whittemore & Knafl, 2005). Whittemore and Knafl's (2005) five stages of an integrative review were utilized: problem identification, literature search, data evaluation, data analysis, and presentation. Initially, the literature was searched for studies regarding the clinical nurse specialist role in pediatric palliative care using the search terms: "pediatric palliative care," "end-of-life care," "pediatrics," "children," "clinical nurse specialist," and "advance practice nurse." However, since only two articles were found, neither of which were primary research, the search was shifted to explore what parents deemed to be important about the care their family received or needed during their child's illness and death. Additional search terms used were: "needs of families," "needs of parents," "perspectives," "parents," and "family-centred care" to find studies that sought the voice of family members, specifically parents, to describe their own perspectives of what is important in PPC.

Computerized search engines utilized were the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Google Scholar, Web of Science, and the University of Victoria

Library. Krainovich-Miller and Cameron (2009) suggested searching back in the literature about 5 years for academic or evidence-based papers or projects, however, since PPC is a relatively new subspecialty with little published research, this search was conducted back to the year 2000. A total of 335 articles were found and reduced to 65 through title searches for applicability to the research question: what is important to parents of children receiving PPC? (See Appendix A – Literature Review Flow Chart). In order to be included in this review, studies had to be in English and focus on: needs or elements of importance to parents of children receiving PPC in the hospital setting in Canada, US, UK, Australia, or New Zealand; perspectives of the parents; and primary research. Articles were excluded that were focused on: PPC in the community; HCP perspectives of parent and family needs; exclusively the bereavement period; editorial or opinion articles; grey literature; and satisfaction surveys or program evaluations. Studies focused on the community and specifically on the bereavement period were excluded because of my interest in the delivery of PPC in the acute care setting.

Abstract reviews excluded 18 more articles and brief text reviews excluded another 34. Ancestry searches were conducted from the remaining 13 articles, which, after removal of duplicates, yielded seven more studies. Twenty articles remained and were evaluated utilizing the Evidence Based Library and Information Practice *Critical Appraisal Checklist (EBLIP-CAC)* (Glynn, n.d.) to interrogate the research regarding its quality, trustworthiness, and validity. Articles were scored by their description of population, data collection, study design and results; those scoring more than 75% were included, resulting in 11 primary source qualitative and mixed-method studies. No purely quantitative studies met the inclusion criteria. Further evaluation of each study was conducted using the *Critical Review Form: Qualitative Studies (Version 2.0)* (Letts et al., 2007) and the *Evaluative Tool for Mixed Method Studies* (Long, 2005) (See Appendix B - Critique Table). Data were extracted and analyzed using the constant

comparative method described by Glaser (1965) and suggested by Whittemore and Knafl (2005).

Data was continuously coded and compared with other data from the research and clustered into categories as relationships between emerging themes were identified.

Results

Seven of the 11 articles included in this review were conducted in the US (Brosig, Pierucci, Kupst, & Leuthner, 2007; Contro et al., 2002; Davies et al., 2010; Gilmer, Foster, Bell, Mulder, & Carter, 2013; Heller & Solomon, 2005; Meyer, Ritholz, Burns, & Truog, 2006; Weidner et al., 2011), one in Canada (Widger & Picot, 2008), one included data from both the US and Canada (Steele, Kaal, Thompson, Barrera, & Compas, 2013), and two were from the UK (Midson & Carter, 2010; Price, Jordan, Prior, & Parkes, 2011). All studies sought to understand what is important to parents regarding the palliative care they received throughout the illness and death of their children. Families were interviewed or surveyed between 3 months and 5 years of their child's death, with most interviews occurring between 6 and 24 months post death. All studies focused on parents, though one study included other family members in the interviews, such as grandparents, aunts, an uncles, a sibling, and foster mothers (Contro et al., 2002) and another included siblings (Steele et al., 2013). The age of the deceased children ranged from newly born to 20 years old. Results were generally not categorized in the research by age group of the child who died, with the exception of one study whose participants were bereaved parents of infants who were less than 1 year old when they died (Brosig et al. 2007). Through analysis and synthesis of the reviewed articles, the following five themes were identified in the literature as being important to parents: (1) Continuity of care; (2) Communication; (3) Support; (4) Pain and symptom management; and (5) Preservation of the parental role.

Continuity of Care

Continuity of care in PPC has commanded much attention in the literature and was specifically mentioned by participants in ten of the 11 reviewed studies. It is regarded as essential to providing high quality PPC (Contro et al., 2002; Heller & Solomon, 2005). Themes identified by bereaved parents interviewed in Heller and Solomon's (2005) study exploring continuity and coordination of PPC affirmed the three components of continuity classified by Ried (as cited in Heller & Solomon, 2005): relational, informational, and management continuity. The need for relational continuity was expressed through parental requests to have a specific HCP assigned to provide all explanations, answer questions (Davies et al., 2010), deliver bad news (Contro et al., 2002; Heller & Solomon, 2005), and be a spokesperson for the health care team (Meyer et al., 2006). One parent in Contro et al.'s (2002) study stated, "having one person follow you throughout is probably the biggest sense of relief" (p. 16).

Informational continuity occurred when team members communicated clearly amongst themselves, passed along information about the child and family, and were on the same page regarding knowing the child and knowing the plan (Steele et al., 2013). Informational continuity was also facilitated when the information provided to families by the health care team was consistent (Heller & Solomon, 2005). For example, a parent in Heller and Solomon's (2005) study described receiving different information about their child's condition and treatment plan from different team members. This kind of inconsistency contributed to confusion, hypervigilance regarding care, and undermined parents' trust in their health care team (Heller & Solomon, 2005). Management continuity was achieved by having a coordinator of care throughout a child's illness (Contro et al., 2002; Heller & Solomon, 2005) leading to improved communication with parents, increased parental participation in informed decision making, improved bereavement support (Midson & Carter, 2010), and improved team communication (Steele et al., 2013). In addition, a PPC coordinator was attributed to relieving parents of sole

coordination of care during stressful times and contributing to parents' sense that staff know their child. Parents also felt confident in the quality of care their child received and relief from feeling the need to ensure that nothing from their child's care was overlooked (Heller & Solomon, 2005).

Continuity of care increased parental confidence and trust in the quality of care they received, supported building relationships between families and HCPs, and decreased parental anxiety and feelings of being abandoned by the health care team (Heller & Solomon, 2005).

Another important aspect of continuity of care related to the ability to achieve continuity across programs serving children and families, and the settings in which care occurred (i.e., pediatric intensive care unit, ward, hospice) (Heller & Solomon, 2005; Steele et al. 2013; Widger et al. 2007). These studies suggest that when continuity is achieved that transcends programs or care settings, communication improves and the transition is smoother for parents and children.

Communication

Essential to successful continuity of care was effective communication. Parents in all 11 reviewed studies stressed the importance of receiving honest and complete information from their health care team (Brosig et al., 2007; Contro et al., 2002; Davies et al., 2010; Gilmer et al., 2013; Heller & Solomon, 2005; Meyer et al., 2006; Midson & Carter, 2010; Price et al., 2011; Steele et al., 2013; Weidner et al., 2011; Widger & Picot, 2008). Improving communication was a major theme for the 99 bereaved parents and siblings of children who had received PPC in Steele et al.'s (2013) study who were asked, "what advice, if any, do you have for us as health care providers and researchers, who work with children and families?" (p. 254). Some parents, while wanting honesty, also wanted staff to deliver news and information in a way that still allowed for some hope (Contro et al., 2002; Steele et al., 2013). Gilmer et al.'s (2013) research team asked 15 parents of children who died in hospital about the end-of-life care their child received. They found that comprehensive information regarding changes in their child's condition, treatment

plans, and setting of care contributed to parents' positive perspectives of their child's end-of-life care in hospital. Parents in this study discussed the importance of communication in the clinical management of their child's care (Gilmer et al. 2013). Some parents in Meyer et al.'s (2006) study of parental priorities for end-of-life care in the pediatric intensive care unit wanted to hear viewpoints of all team members. However, at other times, families wanted to understand the "big picture" and benefited from someone summarizing for them (Meyer et al., 2006; Steele et al., 2013). Effective communication between staff members was also important to parents. Steele et al. (2013) and Widger and Picot (2008) found inconsistent information exchange led to parents getting mixed messages, which contributed to confusion, stress, emotional turmoil (Contro et al., 2002; Davies et al., 2010), anxiety (Widger & Picot, 2008), apprehension, and lack of trust (Heller & Solomon, 2005).

Witnessing the end of a child's life is devastating for parents. In several studies, parents expressed how important it was to them to be better prepared for the possibility of their child's death (Davies et al., 2010; Midson & Carter, 2010) and to know what to expect around the how and what of their child's death (Steele et al., 2013; Weidner et al., 2011). After their child's death, many parents appreciated follow-up meetings with the health care team to affirm their decision to withdraw life-sustaining treatment (Brosig et al., 2007), yet other parents felt frustrated about leaving meetings with unanswered questions, and some just were not ready to relive the experience (Midson & Carter, 2010). Understanding and accommodating individual family communication needs and styles was deemed important to many study participants (Meyer et al., 2006; Steele et al., 2013).

Despite the growth of multiculturalism in the US, Davies et al. (2010) found that few non-English speaking families were included as participants in qualitative studies about their experiences with PPC. Therefore, they sought to understand the challenges of communication for

this population and interviewed 36 Spanish American and Chinese American parents of children who died in two US hospitals. Language was identified as a significant barrier to providing complete information to families (Davies et al., 2010). Few non-English speaking parents in Davies et al.'s study reported receiving adequate information and support, leaving parents feeling ignored, confused, lost, angry, and even guilty for not being able to understand or be understood. Parents needed to know about the availability of interpreters and to have interpreters provided to mitigate this stressor (Davies et al., 2010). Similarly, even English-speaking families requested that staff use accessible vocabulary when providing information at a level and pace that families can handle (Weidner et al., 2011).

When information about their child's condition or plan of treatment was not provided to parents, was incongruent, or was incomplete, parents revealed losing trust in staff (Contro et al., 2002; Davies et al., 2010; Heller & Solomon, 2005). For example, in Brosig et al.'s (2007) study of bereaved parents of infants, most of whom died in an intensive care unit (76%), parents described feeling angry when they were not made aware of the option of a Do Not Attempt Resuscitation order for their child. Parents who were interested in donating their child's organs but were never approached expressed disappointment. Others recommended that the topic be raised to give parents the choice of organ donation or, if ineligible, provide the family with rationale as to why their infant or child is not a donor candidate (Widger & Picot, 2008). Lack of communication or poor communication contributed to frustration (Davies et al., 2010; Midson & Carter, 2010), anger, disappointment (Davies et al., 2010), and mistrust (Contro et al., 2002; Davies et al., 2010; Heller & Solomon, 2005).

In summary, the literature suggests that honest, clear, consistent, and complete information, communicated in their language of origin and with terms they understand, from a team that communicates well with each other was important to parents caring for a dying child.

Support

Families expressed the importance of feeling supported in several forms. Generally, themes of support were gathered in subcategories of support from staff, support for siblings, spiritual support, and bereavement support.

Support from staff. Families who have experienced the death of a child or are actively caring for a dying child need support from their HCPs. That support can look different to every family, so assessment of what each family determines to be supportive is necessary to tailor care. In the literature, parents described elements of emotional support, information support, and instrumental or material support (including respite care and financial assistance) from health care professionals (Price et al., 2011). Participants of Brosig and colleagues' (2007) study of parental perspectives appreciated receiving emotional support from all members of the health care team, including physicians, nurses, social workers, child life specialists, spiritual care chaplains, psychologists, and counselors. Emotional support was often felt by parents who had good relationships with the health care professionals caring for their child (Heller & Solomon, 2005; Widger & Picot, 2008; Weidner et al., 2011). Many parents in Weidner et al.'s (2011) research described how important it was to them that HCPs made time to just be there for and with them. Supportive HCPs were also described as being caring, compassionate (Weidner et al., 2011), sensitive, and empathetic (Widger & Picot, 2008).

It was particularly important to parents to feel supported, empowered, and respected for the decisions they made about their child's care. Price et al. (2011) found that parents received information support through the receipt of pertinent information that allowed them to be more involved in decision making and have a greater understanding of their child's situation. Parents in the same study acknowledged that support received through respite care not only gave them a rest

from caring for their child with a LTC, but also allowed them to focus on other members of their family and regain a sense of normalcy (Price et al., 2011).

Davies et al. (2010) discovered that few non-English speaking parents reported receiving adequate support. Expectations regarding how a family feels cared for may not be met due to cultural differences, leaving parents feeling unsupported (Contro et al., 2002). However, cultural considerations made by physicians were appreciated by participants in Davies et al.'s study. Overall, many parents expressed wanting more support from staff (Davies et al., 2010; Gilmer et al., 2013; Heller & Solomon, 2005; Midson & Carter, 2010), shown through compassion, kindness, empathy, and emotional expression (Meyer et al., 2006; Steele et al., 2013).

Sibling support. Family systems theory includes the philosophy that all family members are affected by a child's LTC (Gilmer et al., 2013; Lewis & Prescott, 2006; Wright & Leahey, 2013). Yet while bereaved parents requested that more support be made available for parents (Gilmer et al., 2013), sibling support was also lacking for many families (Contro et al., 2002; Steele et al., 2013; Weidner et al., 2011). Specifically, there was an identified dearth of information provided to parents regarding how they can better support their ill child's siblings (Davies et al., 2010, Contro et al., 2002). According to Steele et al. (2013), parents and siblings alike felt it important to include healthy siblings in their siblings' medical discussions and decisions (Steele et al., 2013). One father interviewed in Steele et al.'s study felt it important that staff allow siblings to spend as much time as they can with the dying child so they have those last memories.

Spiritual support. Receiving spiritual care from professionals and having faith supported in an accepting environment was of particular importance to parents of children who died in three US pediatric intensive care units who experienced spiritual distress (Meyer et al., 2006). Other parents preferred to receive spiritual support from friends, family, and their own place of

worship, as well as from pastoral care providers on the health care team (Weidner et al., 2011).

Some families were able to make meaning of their child's death through their faith and the spiritual support they received (Brosig et al., 2007).

Bereavement support. Bereavement support was highlighted in many studies as important to parents and a priority area for improvement. Parents interviewed in Widger and Picot's (2008) study indicated how important it was for them to wash or bathe their child after death and create and collect memories during that time. Tangible memorabilia was described and shown to interviewers, including photographs (Brosig et al., 2007; Midson & Carter, 2010; Widger & Picot, 2008), hand and footprints (Midson & Carter, 2010; Widger & Picot, 2008), hospital bracelets, and locks of hair (Widger & Picot, 2008).

Continued contact from HCPs via cards or calls on significant dates was reportedly important to many parents (Brosig et al., 2007; Contro et al., 2002; Weidner et al., 2011). As one parent stated, "when your child is sick like that, it becomes your life and the doctors and nurses become your extended family" (Contro et al., 2002, p. 17). Loss of the support they received during the child's illness and connection with staff after their child's death added to some parents' grief (Heller & Solomon, 2005). Many parents reported that bereavement support was neither offered nor available after the death of their child, leaving them feeling abandoned and compounding their grief (Heller & Solomon, 2005; Widger & Picot, 2008).

When asked what was helpful to them in their bereavement, some parents thought support groups were helpful while others did not (Brosig et al., 2007; Steele et al., 2013); some parents wanted individualized support (Steele et al., 2013). Brosig et al., (2007) reported that there were parents whose infant died who perceived parents in their support group "who lost older children... have the attitude that our loss is not as great as theirs" (Brosig et al., 2007, p. 514), so did not feel validated in their grief in the group setting. Contro et al. (2002), who interviewed 68

family members of 44 deceased children for a PPC needs assessment at a children's hospital, noted that parents who participated in their study were grateful to have the opportunity to tell their child's story, possibly indicating an unmet need to do so. Being part of research or knowing that research was continuing in order to improve the quality of PPC was comforting to many families and could be viewed as "making meaning" of their experience (Steele et al., 2013).

Pain and Symptom Management

Witnessing children in pain was identified as a major stressor for parents. Pain and symptom management was a priority area for improvement (Contro et al., 2002; Gilmer et al., 2013; Weidner et al., 2011; Widger & Picot, 2008). Weidner and colleagues (2011) interviewed 29 bereaved parents of 20 children who died to ask what was important to them in their child's end-of-life care. Parents described struggling between wanting their child to be comfortable and alert enough to interact with family members and happy (Weidner et al., 2011). Freedom from physical (e.g., pain, breathing difficulties, constipation) and emotional symptoms (e.g. anxiety, fright) was paramount for parents (Weidner et al., 2011). Parents reported their child experienced substantial pain throughout the dying process and expressed anguish and feelings of helplessness over seeing that. However when asked about how well the pain was managed, many of those same parents stated the pain was managed adequately (Contro et al., 2002). Pain relief was identified as important but not discussed in detail (Widger & Picot, 2008). Quantitative data regarding pain and symptom management in Gilmer et al.'s (2013) study revealed that most parents were satisfied with their child's relief of symptoms (93%) and pain (87%); qualitative themes were not disclosed. One mother described to researchers in Heller & Solomon's (2005) study that she felt very upset and distressed when an unfamiliar physician discounted her daughter's complaints of significant pain just before she died. Contro et al. (2002) argued that

pediatric pain management is often ineffective. Surprisingly, pain and symptom management did not appear as a theme in any of the other seven studies in this review.

Role of Parents

Parents of children with LTCs were concerned with maintaining their parental role throughout their child's illness. Parents identified the importance of maintaining a sense of parental authority over their ill child's care and their family life (Price et al., 2011; Weidner et al., 2011). In order to do so, some parents asked to be taught how to care for their child, even as their child's needs changed, so they could be better advocates (Weidner et al., 2011). Heller and Solomon (2005) found that parents who participated in their child's care and received consistent information were less stressed and experienced greater trust in staff than parents who were less involved and received less information. Being able to do as much as they could for their child, both physically and emotionally, was significant to many parents (Brosig et al., 2007; Davies et al., 2010; Price et al., 2011; Weidner et al., 2011). Protection of the family unit happened by meeting family needs to spend private time with their child in the time leading up to death (Meyer et al., 2006; Weidner et al., 2011) and after (Meyer et al., 2006; Midson & Carter, 2010), including being offered the opportunity to be involved in post-death care of their child's body (Widger & Picot, 2008).

Involvement in decision making was identified in eight of the reviewed studies (Brosig et al., 2007; Davies et al., 2010; Gilmer et al., 2013; Meyer et al., 2006; Midson & Carter, 2010; Price et al., 2011; Steele et al., 2013; Weidner et al., 2011). As discussed previously, parents needed complete information in order to be involved in informed decision making (Steele et al., 2013; Weidner et al., 2011). Davies et al. (2010) stressed that information be provided in families' own languages to ensure understanding and to empower families to participate in decision making. Bereaved parents of 16 children who died revealed how emotionally draining

and difficult it was to be involved, but how much they appreciated the support of HCPs who ensured they understood what was happening so they could “competently navigat[e] through an otherwise difficult situation” (Price et al., 2011, p. 1387).

The concept of families’ level of participation in end-of-life decision making has been discussed widely (Brosig, et al. 2007; Meyer, et al, 2006; Steele et al., 2011; Weidner et al., 2011). Some parents described feeling an ownership for difficult decisions about withdrawal of life-sustaining treatment and feeling supported by the team when their participation was facilitated (Brosig et al., 2007). Feelings of anger and resentment were prevalent when parents were not included or not respected during the end-of-life decision making process which negatively affected their overall perception of the quality of care their child received (Brosig et al, 2007). Parents wanted to be respected in their decisions and recognized as knowing what is best for their child (Steele et al., 2011; Weidner et al., 2011). However, most parents in Meyer et al.’s (2006) study clarified their need for involvement by saying they wanted to have a voice in decision making, but not complete control over each life-sustaining treatment decision.

Summary of Results

In summary, care delivery leading up to and including at the end of life should be driven by what is important to children and their families. While there was not universal consensus on the following themes in each study reviewed, the majority of parents who have experienced the death of a child or have a child with a LTC identified the importance of providing continuity of care, effective communication, support for all family members throughout the child’s illness, death, and the bereavement period, relief of pain and symptoms for their child, and preservation of the role of parents.

Discussion

Care Continuity and Coordination

This integrative review investigated what is important to parents of children with LTCs who require PPC. While there is still much to be understood about families' experiences with PPC, this review highlights frequently shared elements as identified by parents. PPC encompasses complex clinical situations in which maintaining continuity of care is of great importance. The Institute of Medicine's (IOM) Committee on Palliative and End-of-Life Care for Children and Their Families recommended a single HCP as point of contact for families (Field & Behrman, 2003). Appointing care coordinators or advanced practice nurses to individual patients and families has the potential to provide management continuity through their PPC journey, builds relationships that foster trust and reduces stress and anxiety, and enables consistent and coordinated sharing of information (Heller & Solomon, 2005), meeting the need for continuity of care identified by families in eight reviewed studies.

Communication with HCPs and Parents

The consistent element described as important by parents in all 11 studies was that of honest and complete information from the health care team. Any member of a child's health care team, regardless of discipline and specialty, can contribute to meeting this need. Consultation and collaboration among health care team members that includes parents is paramount for creating a cohesive and comprehensive picture of the child's condition for the child and family (Mack & Hinds, 2011; Meyer et al., 2006). Quality family-centred PPC includes providing education and information for patients, as developmentally appropriate (Johnson, 1990), and their families about diagnoses, trajectories of illness, decision making, pain and symptom management, and anticipatory guidance for what to expect at the end of life (Kane, Joselow, & Duncan, 2011). Sharing with parents about what PPC services can provide for families may reduce fears and increase knowledge regarding palliative care and allow for earlier support from a PPC team. In

her description of the nine elements of family-centred care, Johnson (1990) advocated for not only sharing comprehensive information in a supportive manner with parents, but also including them in the collaboration process as part of the health care team. Opportunities for families to meet with various HCPs to have specific questions answered are important to ensure their understanding of their child's condition and to enable informed participation in making decisions about plans of treatment. This is especially important for families for whom English is not their spoken language (Davies et al., 2010).

PPC Support

Collins et al. (2011) argued that support and information from the health care team received during the child's illness facilitates the grieving process for parents and is valuable for the bereavement period. Bereavement care was highlighted as a priority for parents (Widger & Picot, 2008) and should be provided for all families, whether they had received palliative care services or not before or at the time of their child's death (Field & Behrman, 2004). As described in the IOM Report, circumstances surrounding the death of a child affect the parents' and family's bereavement (Field & Behrman, 2004). Parents of a child with a LTC that had an prolonged illness may experience anticipatory grief and may have some supports in place before the death, while other families whose child dies suddenly in the emergency room have had no preparation and need immediate bereavement interventions (Field & Behrman, 2004). While Contro et al. (2011) stated that research on bereavement interventions in pediatrics is in its early stages, we know from this review that bereavement support is an important and necessary element for parents in PPC. The importance of participating in post death care of the child (Widger & Picot, 2008), staying in contact with HCPs (Brosig et al., 2007; Contro et al., 2002; Weidner et al., 2011), and receiving either group or individual bereavement support (Contro et al., 2002; Heller & Solomon, 2005) is documented in the literature (Collins et al., 2011; Field &

Behrman, 2004; Stephanson et al., 2006). Bereavement support and memorabilia that is offered can be standardized; families can choose what support best fits their needs. This would hopefully reduce feelings of abandonment experienced by some families (Heller & Solomon, 2005).

Relief From Suffering

Parents in only four of the 11 studies discussed pain and symptom management (Contro et al., 2002; Gilmer et al., 2013; Widger & Picot, 2008; Weidner et al., 2011), possibly due to the nature of questions asked in interviews and on questionnaires. However, easing suffering is identified in literature as the primary responsibility of the PPC team (Wolfe, Hinds, & Sourkes, 2011b). Current PPC practices of opioid dosing escalation, opioid switching, and improved side effect management has been shown to reduce palliative pain in children, however research is still showing that improvements in pain and symptom management are acutely required (Collins et al., 2011). Some parents revealed their need for education regarding pain and symptom management options, by reporting their child experienced substantial pain throughout the dying process, while at the same time also stating that the pain was managed adequately (Contro et al., 2002). This could suggest a parental belief that either the pain could not be reduced any more, or that they “could not tolerate that everything possible to reduce pain was not done” (Contro et al., 2002, p. 18). The team’s purpose is not only to relieve pain and other physiological and psychological symptoms of the child and suffering of the family, but also to preserve or help to re-establish family integrity (Wolfe et al., 2011b).

Preserving the Role of Parents

The philosophy of family-centred care highlights the importance of parents in the life of the child and their role as partners with HCPs (Johnson, 1990; Jones et al., 2011). The major themes in this review of continuity of care, communication, support, and even pain and symptom management are intertwined with parents’ need to continue to be a parent to their child, in spite

of a LTC. When parents have a solid understanding of their child's LTC and have a trusting relationship with the health care team, they are able to participate in making decisions for their child's plan of care or levels of intervention to the degree they desire (Meyer et al., 2006). Heller and Solomon (2005) concluded from their study findings that parents were more trusting in the quality of PPC being provided for their child when they were encouraged and empowered to be involved in all aspects of their child's care. PPC professionals can preserve the integrity of the parent-child relationship by "honor[ing] the rightful place and privilege of parents, and support[ing] them in their efforts to be the best parents they can be" (Meyer et al., 2006, p. 654) by involving parents in decision making and caregiving, and supporting them as protectors of their child.

Recommendations

Based on what parents in these reviewed studies have identified as important for PPC, recommendations are presented here to inform improvements in how we can best support parents of children with a LTC. Specialized pediatric hospitals across Canada provide PPC with models for care that serve their populations. Whether hospital-based, hospice-based, or part of an adult community program, teams work to provide care to children with LTCs and their families. Due to lack of funding, most Canadian PPC teams, aside from the development of two new children's hospices, have been unable to greatly expand (Widger et al., 2012). Creative thinking is required to consider models of care that will provide continuity not only for the hospital setting, but also for children and families receiving PPC as they move between hospital, hospice, and their home communities. Advanced practice nursing domains of practice will be used as a framework for recommendations for program level changes, clinical care, education, and research in PPC (Canadian Nurses Association [CNA], 2008).

Optimizing PPC Programs

Contro et al. (2002) highlighted the need for “comprehensive [PPC] programs that incorporate all aspects of care and family support, in the hospital and at home, from diagnosis to bereavement follow-up” (p. 18), which is in line with a family-centred care approach to providing PPC (Johnson, 1990). Hospital PPC teams are often physician-led, may have an advanced practice nurse (either a CNS or nurse practitioner) and a chaplain, and then consult unit-based social workers, child life specialists, and therapists as required (Kramer, Remke, & Sehring, 2011) without utilizing specific PPC funding (Widger et al., 2012). Other programs began their PPC program with a dedicated team that is inclusive of the above roles (Kramer et al., 2011). When considering implementing or improving a hospital-based PPC program, it is essential to engage stakeholders early in the process, take time to complete a needs assessment, and create a comprehensive business plan. The Center to Advance Palliative Care (CAPC) published *A Guide to Building a Hospital-Based Palliative Care Program* to assist hospitals in this process (CAPC, 2003).

The designation of a care coordinator to follow PPC families (Heller & Solomon, 2005) and the appointment of a hospital liaison to community hospices, home care agencies, and families (Contro et al. 2002) were recommended to improve continuity of care. Ideally, the PPC coordinator should bridge organizations and collaborate with interdisciplinary PPC teams to optimize clinical care through meeting the child’s and family’s needs for consistent communication among HCPs and parents. By utilizing a family-centred approach the PPC coordinator would initiate conversations about and guide families through difficult decision making, keep the child and family at the centre of care with a focus on their information and psychosocial needs (Field & Behrman, 2003), assess and meet patient and family learning needs (LeGrow et al., 2010), enhance communication, and improve bereavement support (Midson &

Carter, 2010). Coordination and continuity of care assists families to navigate complex health care systems during a highly stressful time.

Improving Clinical Care

A significant aspect of clinical care is effective PPC pain and symptom management. A PPC coordinator would require advanced knowledge of palliative pain and symptoms, focused assessment skills, an understanding of the most current pain and symptom management research and practices, along with advance care planning and communication skills (Collins et al., 2011). Access to consultation with hospital pain teams for pain and symptom assessment, management and HCP education regarding current research and practice is essential for best clinical care.

Bereavement support was identified as a high priority for parents whose children have died. A PPC coordinator would collate and assess resources currently available to families at the place of the child's death (hospital, hospice, or community). Knowledge of available resources in families' home community will be important to provide referrals for support in the immediate and long term. Smaller communities may have private psychosocial practitioners that can be available for families, but might not offer bereavement support groups. Larger communities and cities may have several different groups for bereaved siblings, bereaved parents of children who died suddenly, or those whose child died of a protracted illness, as well as available individual counselling. In keeping with family-centred care, attempts should be made to connect newly bereaved parents with other bereaved parents in their community or region for support and networking (Johnson, 1990). Coordinated bereavement follow-up is an essential component of PPC.

Deepening Knowledge Through Education

The IOM (2003) report includes recommendations to improve PPC, end-of-life care, and bereavement care education for all HCPs caring for children, especially those caring directly for

children with LTCs and their families (Field & Behrman, 2003). Several education initiatives have recently focused on PPC including the Initiative for Pediatric Palliative Care (Browning & Solomon, 2005) and Workshops in End-of-Life Training for Health Professionals in Children's Hospitals (Pituch, Trudeau, Keefer, Azim, & Murphy, 2011). Continued education is recommended to improve knowledge about pain and symptom management (Widger & Picot, 2008) and to enhance communication among health care teams and with families (Davies et al., 2010; Midson & Carter, 2010). A team that communicates well and is well informed about a child and their family can collaborate with the family to create a palliative care plan that supports their needs, values, and wishes. Steele et al. (2013) also suggested advanced training be provided for HCPs and recommended that hospital policies, procedures, and clinical practice guidelines be improved for PPC. Modern technology has enhanced organizations' and programs' abilities to economically provide education and share knowledge through Telehealth and video sessions for smaller communities who are supporting children with LTCs at home.

Expanding Knowledge Through Research

Parents in this review shared how important it was for them in their bereavement to participate in ongoing research with the purpose of improving PPC (Contro et al., 2002). When approaching parents to participate in research, sensitivity to timing and the situation surrounding their child's death is required (Steele et al., 2005). Areas of suggested research included investigating parents' desire to be more involved in decision making at their child's end of life, pain and symptom management, and quality of life from the child's perspective at end of life (Gilmer et al., 2013). Heller and Solomon (2005) encouraged further study of continuity of care and how it relates to outcomes and occurrence of errors. While Price et al. (2011) stated that the relevance of the identified themes in their study were not impacted by characteristics of participants, there appears to be gaps in the literature specifically exploring the impact of these

factors, especially the age of the deceased child, on what bereaved parents valued about the palliative care.

In summary, it is recommended that pediatric hospitals without established PPC programs conduct a needs assessment. This will determine the level of services required and guide creative planning to utilize available resources. A CNS is one recommended HCP that has advanced practice competencies to enact many of the recommendations in this review in the program (systems), clinical, education, and research domains (CNA, 2008)

Limitations

Many authors of the reviewed articles considered their sample sizes to be small, possibly affecting the generalizability of their findings (Brosig et al., 2007; Contro et al., 2002; Gilmer et al., 2013; Heller & Solomon, 2005; Meyer et al., 2006; Steele et al., 2013; Widger & Picot, 2008; Weidner et al., 2011). Another commonly identified limitation of these studies was the presence or risk of self-selection bias when parents chose to participate or not in the study (Brosig et al., 2007; Contro et al., 2002; Gilmer et al., 2013; Heller & Solomon, 2005; Price et al., 2011; Steele et al., 2013; Widger & Picot, 2008; Weidner et al., 2011). The sensitive nature of the topic and the proximity of time from the death of the participants' child were suggested to be factors that may increase self-selection bias (Davies et al., 2010; Gilmer et al., 2013; Steele et al., 2010; Weidner et al., 2011). A significant limitation of this integrative literature review is the lack of published research, as only 11 studies specifically asked bereaved parents about what was important to them when their family received PPC in the hospital for their dying child. To be truly family-centred in this review, considerations of elements of importance to other family members (e.g. siblings) and related literature could have been included. Finally, my interest in the CNS as a care coordinator for PPC may have introduced a bias that had potential for influencing

my interpretation of the literature, which may have been mitigated by partnering with one or more other researchers.

Conclusion

It is a great privilege to journey with families through their experience of raising a child with a LTC, to advocate for and assist them to navigate the strange world of the health care system, and to accompany and support them through the devastation of their child's death. Providing meaningful family-centred PPC contributes to the quality of life of children and their families for the time they have together. This review highlights the most frequently reported aspects of PPC that are important to parents of children who received PPC. It is a starting point in further discussions of how to best allocate resources in models of care, clinical care, education, and research regarding PPC delivery for children with LTCs and their families. Suffering can be reduced through improvements to HCP knowledge and skills in communication, support, and pain and symptom management. While we may not be able to change their child's outcome, by effectively supporting families through their PPC journey, we can strive positively affect their experience.

References

- British Columbia's Children's Hospital (BCCH) (2013). *Family-centred care*. Retrieved <http://www.bcchildrens.ca/YourVisit/Family-centredcare/default.htm>
- Brosig, C. L., Pierucci, R. L., Kupst, M. J., & Leuthner, S. R. (2007). Infant end-of-life care: the parents' perspective. *Journal of Perinatology*, 27(8), 510–516.
- Browning, D. M., & Solomon, M. Z. (2005). The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational Approach for Healthcare Professionals. *Journal of Pediatric Nursing*, 20(5), 326–334. doi:10.1016/j.pedn.2005.03.004
- Canadian Nurses' Association (CNA) (2008). *Advanced nursing practice: A national framework*. Ottawa, Ont.: Canadian Nurses Association. Retrieved from www.nanb.nb.ca/PDF/practice/ANP_National_Framework_e.pdf
- Collins, J. J., Berde, C. B., & Frost, J. A. (2011). Pain assessment and management. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary paediatric palliative care* (pp. 284-299). Philadelphia, PA: Saunders, Elsevier Inc.
- Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics & Adolescent Medicine*, 156(1), 14. doi:10.1001/archpedi.156.1.14
- Contro, N., & Scofield, S. (2006). The power of their voices: Child and family assessment in pediatric palliative care. In A. Goldman, R. Hain, & S. Liben (Eds.). *Oxford textbook of palliative care for children* (pp. 143-153). Oxford, UK: Oxford University Press.
- Davies, B., Contro, N., Larson, J., & Widger, K. (2010). Culturally-sensitive information-sharing in pediatric palliative care. *Pediatrics*, 125(4), e859–e865. doi:10.1542/peds.2009-0722

Davies, B., Larson, J., Contro, N., Reyes-Hailey, C., Ablin, A. R., Chesla, C. A., ... Cohen, H.

(2008). Conducting a Qualitative Culture Study of Pediatric Palliative Care. *Qualitative Health Research, 19*(1), 5–16. doi:10.1177/1049732308327346

Downing, M. (2006). Introduction. In G. M. Downing & W. Wainwright (Eds.). *Medical Care of the Dying (4th ed.)*, (pp. 1-26). Victoria, BC: Victoria Hospice Society.

Field, M. J., & Behrman, R. E. (Eds.). (2003). *When children die: Improving palliative and end-of-life care for children and their families*. Washington, DC: Institute of Medicine, National Academies Press.

Gilmer, M., Foster, T. L., Bell, C. J., Mulder, J., & Carter, B. S. (2013). Parental perceptions of care of children at end of life. *American Journal of Hospice & Palliative Medicine, 30*(1), 53–8. doi:10.1177/1049909112440836

Glaser, B. G. (1965). The constant comparative method of qualitative analysis. *Social Problems, 12*(4), 436–445. doi:10.2307/798843

Glynn, L. (n.d.). *Evidence Based Library and Information Practice (EBLIP) Critical Appraisal Checklist*. Memorial University of Newfoundland Retrieved from http://www.goums.ac.ir/files/deputy...52bc8/critical_appraisal_checklist.pdf

Hamilton, B. E., Hoyert, D. L., Martin, J. A., Strobino, D. M., & Guyer, B. (2013). Annual summary of vital statistics: 2010–2011. *Pediatrics, 131*(3), 548–558. doi:10.1542/peds.2012-3769

Heller, K. S., & Solomon, M. Z. (2005). Continuity of care and caring: What matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing, 20*(5), 335–346. doi:10.1016/j.pedn.2005.03.005

Johnson, B. (1990). The changing role of families in health care. *Children's Health Care, 19*(4), 234–234. doi:10.1207/s15326888chc1904_7

- Jones, B. L., Gilmer, M. J., Parker-Raley, J., Dokken, D. L., Freyer, D. R., & Sydnor-Greenberg, N. (2011). Parent and sibling relationships and the family experience. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary paediatric palliative care* (pp. 135-147). Philadelphia, PA: Saunders, Elsevier Inc.
- Kane, J. R., Joselow, M., & Duncan, J. (2011). *Understanding the illness experience and providing anticipatory guidance*. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary paediatric palliative care* (pp. 30-40). Philadelphia, PA: Saunders, Elsevier Inc.
- Krainovich-Miller, B., & Cameron, C. (2009). Literature review. In G. Lobiondo-Wood, J. Haber, C. Cameron, & M. D. Singh, *Nursing research in Canada: Methods and critical appraisal for evidence-based practice (2nd Canadian ed.)*, (pp. 84-112). Toronto, ON: Elsevier Canada.
- LeGrow, K., Hubley, P., & McAllister, M. (2010). A conceptual framework for advanced practice nursing in a pediatric tertiary care setting: The SickKids' experience. *Nursing Leadership*, 23(2), 32–46. doi:10.12927/cjnl.2013.21831
- Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007). *Critical review form: Qualitative studies* (Version 2.0). Hamilton, ON: McMaster University.
- Lewis, M. & Prescott, H. (2006). Impact of life-limiting illness on the family. In A. Goldman, R. Hain, & S. Liben (Eds.), *Oxford textbook of palliative care for children* (pp.154-178). Oxford, UK: Oxford University Press.
- Long, A. (2005). *Evaluative Tool for Mixed Method Studies*. Leeds, UK: School of Healthcare, University of Leeds. Retrieved from http://www.usir.salford.ac.uk/.../1/Evaluative_Tool_for_Mixed_Method_Studies.pdf

- Mack, J. W. & Hinds, P. S. (2011). Practical aspects of communication. In J. Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary paediatric palliative care* (pp. 179-189). Philadelphia, PA: Saunders, Elsevier Inc.
- Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics*, *117*(3), 649–657. doi:10.1542/peds.2005-0144
- Midson, R., & Carter, B. (2010). Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences. *Journal of Child Health Care*, *14*(1), 52–66. doi:10.1177/1367493509347060
- Pituch, K., Trudeau, C., Keefer, P., Azim, J., & Murphy, T. (2011). Pediatric Advanced End-of-Life Support (P7). *Journal of Pain and Symptom Management*, *41*(1), 169-170.
doi:<http://dx.doi.org.ezproxy.library.uvic.ca/10.1016/j.jpainsymman.2010.10.011>
- Price, J., Jordan, J., Prior, L., & Parkes, J. (2011). Living through the death of a child: A qualitative study of bereaved parents' experiences. *International Journal of Nursing Studies*, *48*(11), 1384–1392. doi:10.1016/j.ijnurstu.2011.05.006
- Siden, H., Miller, M., Straatman, L., Omesi, L., Tucker, T., & Collins, J. (2008). A report on location of death in paediatric palliative care between home, hospice and hospital. *Palliative Medicine*, *22*(7), 831–834. doi:10.1177/0269216308096527
- Statistics Canada (2011). *Leading cause of death by age group, Canada, 2007*. Retrieved from <http://statcan.gc.ca/pub/91-209-x/2011001/article/11525/tbl/tbl-eng.htm#a2>
- Statistics Canada (2013). *Number of deaths by age and sex, Canada, 2011*. Retrieved from <http://www.statcan.gc.ca/pub/91-209-x/2013001/article/11867/fig/desc/desc03-eng.htm>

- Steele, A., Kaal, J., Thompson, A. L., Barrera, M., & Compas, B. E. (2013). Bereaved parents and siblings offer advice to health care providers and researchers. *Journal of Pediatric Hematology/oncology*, 35(4), 253–9. doi:10.1097/MPH.0b013e31828afe05
- Stephanson, E., Nicholson, K., Fletcher Johnston, M. (2006). Pediatric palliative care: Conceptual frameworks for psychosocial care. In G. M. Downing & W. Wainwright (Eds.). *Medical Care of the Dying (4th ed.)*, (pp. 1-26). Victoria, BC: Victoria Hospice Society.
- Stevenson, M., Achille, M., & Lugasi, T. (2013). Pediatric palliative care in Canada and the United States: A qualitative metasummary of the needs of patients and families. *Journal of Palliative Medicine*, 16(5), 566–577. doi:10.1089/jpm.2011.0076
- Weidner, N. J., Cameron, M., Lee, R. C., McBride, J., Mathias, E. J., & Byczkowski, T. L. (2011). End-of-life care for the dying child: What matters most to parents. *Journal of Palliative Medicine*, 27(4), 279-286.
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. doi:10.1111/j.1365-2648.2005.03621.x
- Widger, K. & Picot, C. (2008). Parents' perceptions of the quality of pediatric and perinatal end-of-life care. *Pediatric Nursing*, 34(1), 53–58.
- Widger, K., Cadell, S., Davies, B., Siden, Hl., & Steele, R. (2012). Pediatric palliative care in Canada. In C. Knapp, V. Madden, & S. Fowler-Kerry (Eds.), *Pediatric palliative care: Global perspectives* (pp. 301-321). New York, NY: Springer.
- Widger, K., Davies, D., Drouin, D. J., Beaune, L., Daoust, L., Farran, R. P., ... Bishop, M. (2007). Pediatric patients receiving palliative care in Canada: Results of a multicenter review. *Archives of Pediatrics & Adolescent Medicine*, 161(6), 597. doi:10.1001/archpedi.161.6.597

Wolfe, J., Hinds, P. S., & Sourkes, B. M. (2011a). The language of pediatric palliative care. In J.

Wolfe, P. S. Hinds, & B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (pp. 3-6). Philadelphia: Elsevier/Saunders.

Wolfe, J., Hinds, P. S., & Sourkes, B. M. (2011b). Easing suffering. In J. Wolfe, P. S. Hinds, &

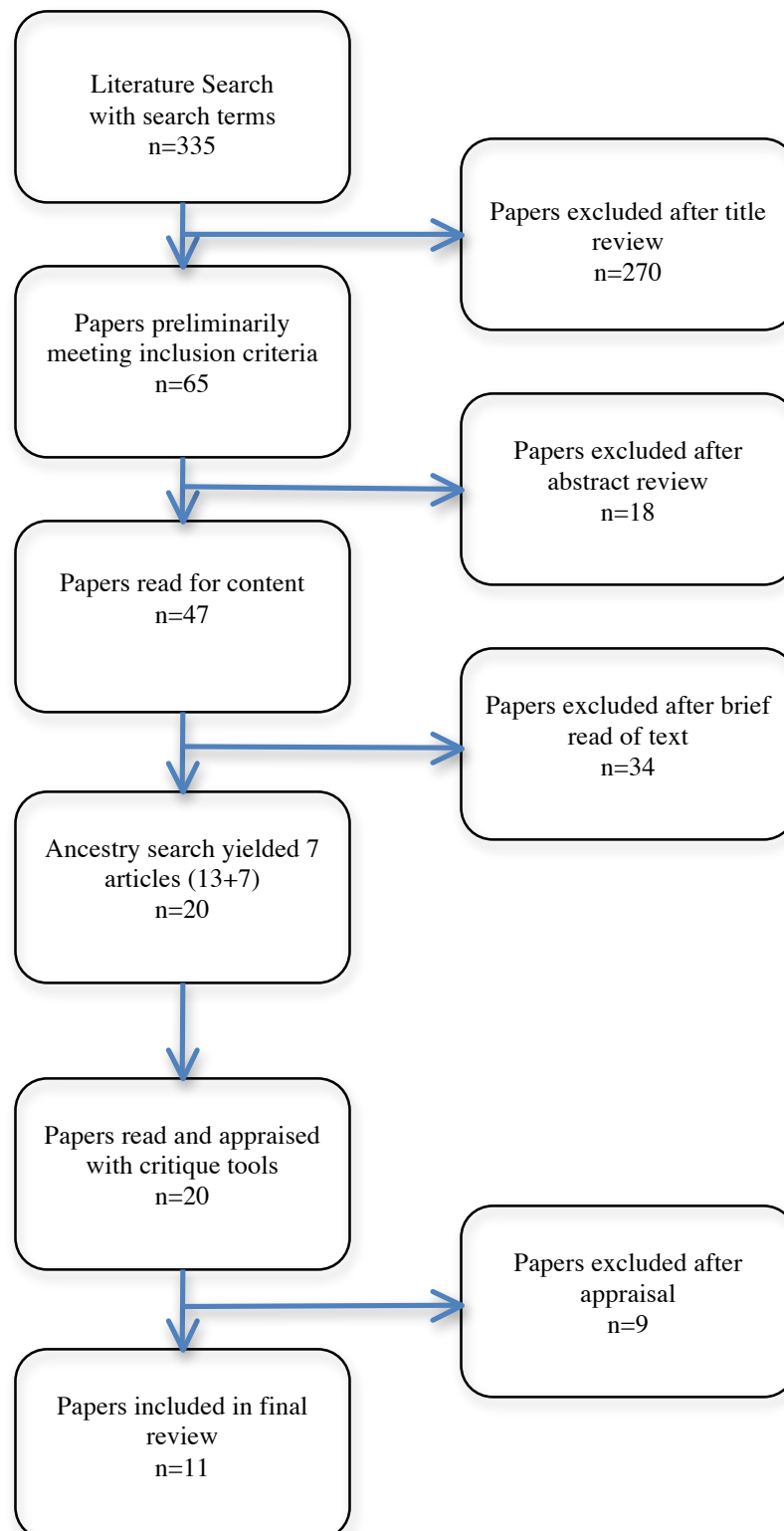
B. M. Sourkes (Eds.), *Textbook of interdisciplinary pediatric palliative care* (p. 227). Philadelphia: Elsevier/Saunders.

World Health Organization (WHO) (n.d. a). *Effective palliative care for children*. Retrieved from <http://www.who.int/cancer/palliative/en/>

World Health Organization (WHO) (n.d. b). *WHO definition of palliative care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

Wright, L. M. & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia, PA: F. A. Davis Company.

Appendix A
Literature Search Flow Chart



Appendix B
Critique Table

Author	Purpose	Participants	Research Method	Results/Conclusions	Critique
Brosig et al. (2007) (USA)	To identify what is important to parents in their infant's EOLC	19 families (30 parents/caregivers) of infants who died under 1 year of age - 18 babies died in hospital (76% in NICU or PICU) and 1 died at home - 8 families had hospice or PPC services - interviews occurred 6 months to 2 years after death	Mixed methods: Quantitative (Revised Grief Experience Inventory and Post-Death Adaptation Scale), and qualitative exploratory study through semi-structured interviews	7 themes emerged from interviews for what is important to parents: honesty from staff, involvement in decision making, being cared for as a parent, trust in staff, physicians' time, environment, and support from staff	Mixed method study that collected different types of data. Results are consistent with other studies with common themes, but this study may not be generalizable due to small sample size and limitations (interviews conducted with parents together, parents who participated may be coping better than those who chose not to). CAC Validity Score: 83%
Contro et al. (2002) (USA)	To learn parent experiences with PPC to learn how to improve PPC	68 participant family members/ caregivers for 44 children who died, ages birth to >15 years old. - 27/44 children died in hospital, 17 died at home - interviews occurred 6 months to 2.5 years after death	Exploratory and descriptive interviews. Standardized measures were not used.	Parents identified the importance of positive relationships with staff, adequate pain management, coordination / continuity of care, bereavement follow-up, and culturally sensitive care. Community hospice care was viewed as inadequate for pediatrics.	The authors addressed quantitative validity, but not qualitative trustworthiness. Neither a literature review nor a background sections was included in the article and research only mentioned in comments section without detail. Positioning this study in what is already known about needs of families would have been helpful. No theoretical or philosophical perspectives were identified. CAC Validity Score: 83%
Davies et al. (2010) (USA)	To learn about how non-English speaking parents of palliative children experience communication with HCPs	36 non-English speaking parents (26 Mexican American and 10 Chinese American) of 28 children who have	Retrospective design of grounded theory	Language and cultural differences are barriers to effective communication with parents of children receiving PPC and can negatively impact parental well-being.	Same centre as Contro's 2002 study (Contro was an author on this one). Excellent description of study methods in Davies et al. (2009) paper.

		died. - interviews occurred 6 months to 5 years after death			The sample size is reported as smaller than the Davies et al. (2009) paper. CAC Validity Score: 88%
Gilmer et al. (2013) (USA)	To describe parental perceptions of their child's PPC, and identify needs of parents for establishing PPC services	15 parents (14 mothers, 1 father) of children who have died between infancy and 14 years old - interviews occurred less than 2 years after death	Mixed methods: quantitative (adapted FAMCARE Likert scale survey) and qualitative (retrospective, semi structured telephone interviews)	Parents can have positive perspectives about their child's EOLC in hospital. More research is recommended regarding parents' desire for greater involvement in EOL decision making.	The sample size and return rate was low, but is judged by authors to be representative. The discussions were vague in regards to this study's results and referred to the literature more than their own results. CAC Validity Score: 83%
Heller & Solomon (2005) (USA)	To explore perceptions of parents regarding continuity and coordination of care their children received before they died, and to identify what needs of families are who require PPC services	36 parents of 34 children who died (32 in hospital, 2 died at home) - children were 7 days to 18 years old - interviews occurred 3 to 10 months after death	Qualitative descriptive study, interviews	Continuity of care builds relationships, reassures that staff "knows" the child, encourages sharing knowledge about child among staff and with family, reduces confusion and frustration, and supports family through death and bereavement.	Strong literature review showing themes and recommendations that have been published to date as well as gaps in the literature. This article is part of a bigger study, and concentrates on continuity and coordination of care. Their inductive process supports theoretical findings of Reid et al. who identified the three aspects of continuity: relational, information, and management continuity, that are important to families. Heller et al. link their findings to previous research. CAC Validity Score: 83%
Meyer et al. (2006) (USA)	To describe the priorities and recommendations for PPC and EOLC from families with children nearing the end-of-life	56 parents of children who died in three Boston PICUs - children were newly born to 18 years old - interviews occurred 12 to 45 months after death	Qualitative study of open-ended questions on questionnaires	Parents identified 6 priorities for improving PPC/EOLC: honest and complete information, access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith.	The authors included the questions of the questionnaire in the article. Questionnaires were anonymous, checking themes was challenging. Also, as it was a questionnaire, investigators were unable to probe answers more deeply. CAC Validity Score: 91%

Midson & Carter (2010) (UK)	To explore parents' experiences of their child's EOLC in the hospital setting and subsequent evaluation/exploration of implementation of EOLC Pathway	28 families in 2006 and 27 families in 2008 were interviewed 1 year to 18 months after death - children were 3 days to 17 years old at time of death	Qualitative survey via telephone interview, face-to-face interview, and paper/postal questionnaire, all asking the same questions.	Three groups of themes were identified: environmental context, communication and information, and feelings and emotions.	They shared their EOLC Pathway, the EOLC Pathway Tool, and identified barriers to PPC in their article. The authors focused their recommendations on education (of staff), raising awareness about resources, and empowerment of families through communication and information. CAC Validity Score: 79%
Price et al. (2011) (Ireland, UK)	To explore parents' experiences of caring for their dying children	25 recently bereaved parents of 16 children who died, aged 2 months to 20 years old - interviews occurred at 6 to 24 months after death	Cross-sectional qualitative study via semi-structured interviews	Parents have a strong need to "do" for their dying child, which is important for their ability to cope with the stress associated with caring for a dying child	The authors included a good description of the methods they used in data analysis. Descriptions of population and data collections were sparse. Discussed how they paid careful attention to rigour and validity. CAC Validity Score: 75%
Steele et al. (2013) (Canada and USA)	To ask bereaved families their advice for improving the quality of PPC	99 family members of 40 children who had received PPC and had died (36 mothers, 24 fathers, and 39 siblings) - children were the average age of 12 years old - interviews occurred 6 to 19 months after death	Cross-sectional qualitative data obtained via face-to-face interviews as part of a longitudinal study of bereaved families of children who died from cancer.	5 themes were identified: improve communication, more compassionate care, increase access to resources, ongoing research, and offering praise. There was an interwoven subtheme of continuity of care.	This study analyses answers to one question on a larger interview questionnaire. The question is included in the study, however addressing only one question may pull it out of context of the greater interview. Offered areas for further research – and ideas from the families, too. CAC Validity Score: 92%
Widger & Picot (2008) (Canada)	To describe perspectives of bereaved parents on the quality of EOLC they and their child received	38 bereaved families of children who died - children were newly born to > 10 years old - interviews occurred	Qualitative: interviews (open and closed questions)	Results show the following areas can be improved: communication, bereavement follow-up, information about autopsy and organ/tissue	Sample questions – could have been open-ended to go deeper with families as questions were asked in an interview. Yes/no questions justified in article, but

		12 to 24 months after death		donation, and pain management. Every parent could relate an event or person that had a negative impact.	limitations are acknowledged. Authors suggest using “always, sometimes, never” instead in future interviews. CAC Validity Score: 88%
Weidner et al. (2011) (USA)	To identify and define elements of PPC and EOLC that are important to parents, to provide guidance for the provision of care	29 parents of 20 children who died and received PPC services	Qualitative: semi-structured interviews and a focus group	7 dimensions: respect for the family role in caring for their child, comfort, spiritual care, access to care and resources, communication, support for parental decision making, and caring/humanism.	Data collection scored low on the Critical Appraisal Checklist due to the lack of information about their tool (questions asked of participants) and about validity. However, authors did argue for the development of a validated measurement tool. CAC Validity Score: 79%

Terms

CAC – Critical Appraisal Checklist (Glynn, n.d.)

EOLC – end-of-life care

HCPs – health care professionals

PPC – pediatric palliative care