PALLIATIVE CARE NEEDS OF PEDIATRIC PATIENTS & THEIR FAMILIES:

A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences

Thesis submitted in accordance with the requirements of the
University of Liverpool for the degree of Doctor of Business Administration
by Lisa A. Crockett

January 2015

ABSTRACT

Title: Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences [Short Title: Pediatric Palliative Care Study]

Author: Lisa A. Crockett, University of Liverpool, Doctor of Business Administration

In the United States, more than 1 million children may be suffering from a life-limiting condition (Ruston and Catlin, 2002, p. 57) for which there is no reasonable hope for cure or long-term survival (Fraser et al, 2012, p. 923). However, less than one percent of these children and their families benefit from the provision of pediatric palliative care (Stayer, 2012, p. 350), which is an innovative health care model designed to address their physical, emotional, psychosocial and spiritual needs from diagnosis through end-of-life. During the last decade, pediatric palliative care has begun to secure a foothold as an emerging health care specialty (Crozier and Hancock, 2012, p. 198), but a dearth of literature has left the lived experience of children and their families poorly understood. Therefore, the Pediatric Palliative Care Study is a qualitative research study that utilizes interpretative phenomenological analysis to address two objectives: (1) understand and articulate the comprehensive lived experience of caring for children with life-limiting conditions and their families and (2) delineate how the collective experiences provide insights into needs that can be addressed by pediatric palliative care. The study was conducted at four research sites within Providence Health & Services. In total, nine major themes emerged from the experiences of 27 multidisciplinary care team providers who participated in the study. The themes have been framed from the perspective of the child and family: 1) Develop an innovative approach to caring for me, (2) Place me at the center of care, (3) Care for me as a whole person, (4) Be my guide, (5) Educate and prepare me for what I need to know, (6) Come alongside me, (7) Cultivate the plan and purpose for my life, (8) Be my voice and help me find my own and (9) Help me thrive. The analysis also contributed to an overarching statement about the experience that articulates the interconnectedness between the themes and creates a story of the phenomenon. The study presents seven implications for future practice related to (1) balancing matters of health care design with the human experience, (2) addressing the aims of health care reform legislation, (3) developing care models for home-based settings, (4) customizing care and developing solutions from the perspective of families, (5) educating about palliative care, (6) understanding the skills needed for palliative care providers and (7) improving data reporting for palliative care. Moreover, the study offers three contributions to extant literature, including: (1) validating and refining the WHO definition of palliative care, (2) completing an assessment of the adult versus pediatric palliative care literature from 2011-2014 and (3) addressing a known gap in the literature by offering the first IPA study to articulate the comprehensive lived experience. Limitations of the study and implications for future research are delineated as a research agenda for those seeking to build upon the study findings.

LIST OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AAHPM	American Academy of Hospice and Palliative Medicine
CAPC	Center to Advance Palliative Care
CITI	Collaborative Institutional Training Initiative
COI	Conflict of Interest
COPD	Chronic Obstructive Pulmonary Disorder
CORE	Committee on Research Ethics
DBA	Doctor of Business Administration
DDP	Doctoral Development Plan
DME	Durable Medical Equipment
DNR	Do Not Resuscitate
ESRD	End-stage Renal Disease
FDA	U.S. Food & Drug Administration
GDP	Gross Domestic Product
HIPAA	Health Insurance Portability and Accountability Act
ICH-GCP	International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use – Good Clinical Practice
ICPCN	International Children’s Palliative Care Network
IPA	Interpretative Phenomenological Analysis
IRB	Institutional Review Board
NICU	Neonatal Intensive Care Unit
NPCRC	National Palliative Care Research Center
OHRP	U.S. Office of Human Research Protections
PICC	Peripherally Inserted Central Catheter
PMRC	Providence Health & Services – Medical Research Center
POLST	Physician Orders for Life-Sustaining Treatment
PPACA	Patient Protection and Affordable Care Act
SBR	Social and Behavioral Research
U.S.	United States of America
WHO	World Health Organization

DEDICATION

For Dayle. Fifteen years ago, you scribed a handwritten note inside one of my favorite Dr. Seuss books that read, “*Oh, the places you’ll go … can I come, too?”* After more than a decade of marriage, I am grateful we have walked alongside one another on this journey though life. You have been my compass while I have chased my lifelong dreams. Indeed, the completion of this doctoral thesis is our achievement, not mine alone.

Twende … let’s go!

ACKNOWLEDGMENT

To the twenty-seven unsung heroes at the Providence Hospice & Home Care of Snohomish County – Carousel Program, Providence Hospice of Seattle – Stepping Stones, Providence Sacred Heart Medical Center & Children's Hospital – Sunflower Program and Providence TrinityKids Care who opened their lives and bore their hearts for this study, I remain inspired by the work you do each day to care for children and their families. Through the stories you imparted with tears in your eyes or tender smiles as you recalled those you have served, it is evident pediatric palliative care is not merely a job to you but rather a deep calling to serve others in their greatest time of need – one child at a time, one family at a time, one day at a time. Thank you for sharing your personal experiences so openly with me.

To my employer, Providence Health & Services, I appreciate the tuition reimbursement that helped fund a portion of my doctoral degree and the support of organizational leaders who have given me a platform to share my research findings with others to advance the field of pediatric palliative care. Working in partnership, I believe we are fulfilling our Mission: "Together, as people of Providence, we reveal God's love for all, especially the poor and vulnerable, through our compassionate service." I also want to acknowledge the Providence Medical Research Center and Institutional Review Board Spokane staff for their expertise in helping me complete the ethical review requirements and become a credentialed medical researcher.

To the Doctor of Business Administration (DBA) faculty at the University of Liverpool, I value the coursework I completed under your guidance and the opportunity to learn from your professional and academic areas of expertise. I feel privileged to have studied at one of the top-rated research universities in the world, as you have shaped me into the scholar practitioner I am today and opened new doors for my future that I would not have previously envisioned. Thank you, as well, for providing me with opportunities to serve in a leadership capacity to help other doctoral students and advance the DBA program. More specifically, I wish to thank Dr. Paul Ellwood, who has served as my dedicated doctoral thesis supervisor; his research knowledge, unwavering commitment to excellence, years of expertise and ongoing encouragement have been pivotal in shaping my research endeavors. I appreciate being able to work with you as a research colleague and look forward to the ways in which our paths will continue to cross in the future.

Finally, to my classmates, I am humbled by your wisdom, inquisitive minds, compassion for others and fervor for making a difference, as these traits have inspired me to push beyond boundaries in order to soar to greater heights. We have come from different walks of life, yet we are bonded as one through the shared experience as University of Liverpool doctoral students. I yearn to see you fulfill your dreams and find success in your chosen professional path and future research endeavors. This world in which we live seems smaller today because of the opportunity I have had to get to know each of you. Without a doubt, this journey has been richer because you were part of it.

AUTHOR'S DECLARATION

The principal researcher, Lisa A. Crockett, hereby declares the *Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences* [Short Title: Pediatric Palliative Care Study] to represent original research that has not been submitted previously for publication. The researcher served as the sole author for the study, which was completed under the thesis supervision of Dr. Paul Ellwood as a requirement for the degree of Doctor of Business Administration from the University of Liverpool. When drawing upon the work of others within the existing literature, the principal researcher has provided appropriate referencing and acknowledgment to the sources. There was no direct funding source for the Pediatric Palliative Care Study. However, the principal researcher is employed by Providence Health & Services, which provides partial tuition reimbursement to employees who are pursuing higher education. While Providence did not fund the study in a direct manner, the organization awarded tuition reimbursement on an annual basis to offset a portion of tuition costs.

CHAPTER 1

Introduction

"In this day and age, it's rare for children to die, and it's not a natural thing. You expect your parents to die ahead of you. You may even have your spouse die ahead of you, and there's a huge community of people who share that experience. Children don't die! We don't even have a word in our language for a person who has lost a child. If you lost your husband, you're a widow. If you lost both your parents, you're an orphan. What do we call somebody who loses a child? We don't have a word for it."

~ Pediatric Palliative Care Nurse

1.1 Accounting for the Presence of Children With Life-limiting Conditions

Written accounts of infant and pediatric deaths can be traced back thousands of years to ancient medical writers and historians. However, the first endeavors to establish a quantitative method of calculating pediatric mortality did not arise until the 17th century when physicians utilizing burial records and bills of mortality estimated one in five children would die before age five (Graunt, 1662; Brosco, 1999, p. 478) and a multitudinous number would fail to reach adulthood. In due course, the sobering statistics that portrayed pediatric mortality as an all-too-common reality for the family unit would prompt a resolute focus and call to action within subsequent generations to curb the trend by concentrating on advances in modern medicine, technology and health care delivery systems (Brosco, 1999, p. 479). According to Dr. S.W. Newmayer, who led the Department of Public Health and Charities in Philadelphia at the start of the 20th century, "The country which first recognizes its responsibilities to the child will receive the recognition of the world as being the foremost civilized nation" (Newmayer, 1911, p. 288). Indeed, the impassioned focus on childhood health and welfare has transformed societal views that pediatric mortality need not be "common" but rather should be a rare exception, thus promoting a modern era tenet within industrialized nations that children today *should* survive their parents and reach adulthood (American Academy of Pediatrics, 2000, p. 351). Regrettably, this is not always the case.

In the United States, an average of 53,000 children die each year, with an additional 400,000 children estimated to be living with a life-limiting condition (Friebert and Huff, 2009, p. 1). Life-limiting conditions are defined as "diseases with no reasonable hope of cure that will ultimately be fatal" (Fraser et al, 2012, p. 923); the most common conditions include genetic or congenital anomalies, neuromuscular disorders, oncology diagnoses, respiratory conditions and gastrointestinal, cardiovascular, metabolic, renal and immunologic problems (Feudtner et al, 2011, p. 1094, 1096). Due to existing limitations in epidemiological data collection,[1] the actual number of U.S. children with life-limiting conditions may be appreciably higher (Friebert, 2009). In fact, other quantitative studies have suggested the annual incidence rate of U.S. children with life-limiting conditions may exceed 1 million children (Rushton and Catlin, 2002, p. 57).

Therefore, the pediatric mortality rate and prevalence of children with life-limiting conditions in the U.S. raises fundamental questions about the lived

---

[1] Current epidemiological data sources present conflicting definitions, age groups and prognosis criteria, including overlapping definitions that make it unfeasible to calculate accurate statistics for children who are eligible to receive palliative care and those who have received services (Friebert, 2009, p. 3).

experience of families who are caring for these children, the overall needs of the children and their families and how best to serve them through the provision of specialized health care services that are reflective of their experience and distinctive needs. Notably, children with life-limiting conditions have diagnoses that would qualify them to receive pediatric palliative care and, eventually, hospice care (Rushton and Catlin, 2002, p. 57). However, only 10-20 percent of the children who die annually are recipients of hospice care (Friebert and Huff, 2009, p. 9), while less than one percent benefit from palliative care that is provided during a longer period of time (Stayer, 2012, p. 350). Pediatric palliative care has been demonstrated to serve as an effective health care delivery model for children and their families. In a 2013 retrospective cohort study of more than forty U.S. children's hospitals and 24,342 pediatric patients, Keele et al (2013) concluded children receiving palliative care experience significantly fewer acute care admissions, complications and invasive procedures, as well as lower median lengths of stay and decreased average daily charges for health care services. Additional benefits acknowledged but not specifically quantified by the researchers include psychosocial and spiritual support, decision-making guidance, sibling and family support, and other factors associated with holistic services that extend beyond basic medical benefits (Keele et al, 2013).

1.2 Definition of Pediatric Palliative Care

The World Health Organization's (WHO) definition of palliative care is deemed the most universally recognized and accepted. WHO has articulated both a general palliative care definition that is germane to all forms of palliative care, regardless of age or diagnosis, as well as a unique subset of qualifications related to pediatric palliative care. The definitions will be utilized as the basis of common understanding for this research (WHO, 2013):

> Palliative care is 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. Palliative care:
>
> - Provides relief from pain and other distressing symptoms;
> - Affirms life and regards dying as a normal process;
> - Intends neither to hasten or postpone death;
> - Integrates the psychological and spiritual aspects of patient care;
> - Offers a support system to help patients live as actively as possible until death;
> - Offers a support system to help the family cope during the patient's illness and in their own bereavement;
> - Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- 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.

As a point of differentiation, the provision of pediatric palliative care should begin preferably at the point of diagnosis (Brook and Hain, 2008, p. 1067) and can occur throughout the progression of the disease while curative treatment is being sought, which may last months or years (Crozier and Hancock, 2012, p. 198). In large measure, it is focused on improving the quality of life from a holistic perspective, regardless of how long or short that time may be. By comparison, hospice care – also known as end-of-life care or terminal care – is prescribed for patients with a prognosis of less than six months to live, who are no longer receiving curative treatments (Centers for Medicare & Medicaid Services, 2013).

1.3 Access to Pediatric Palliative Care in the United States

When the American Academy of Hospice and Palliative Medicine (AAHPM) was established in 1988, it became the first professional organization in the U.S. to focus on improving the quality of life for patients with life-limiting conditions and their families (AAHPM, 2013). However, as pioneering palliative care programs began to emerge in limited markets across the country, the scope of services was restricted to adult patients and did not include pediatrics (Froedtert, 2010). While U.S. adults with life-threatening or terminal illnesses have benefited from the growing availability of palliative care services for thirty years, pediatric palliative care has been far slower to secure an industry foothold (Hain, 2004, p. 79). Only in the last decade has the health care industry begun to define pediatric palliative care and recognize it as an emerging specialty (Mellor et al, 2011, p. 115; Crozier and Hancock, 2012, p. 198). As a result, the hindered growth and adoption of pediatric palliative care as a value-added specialty for children with life-limiting conditions and their families has hampered the availability of services in the majority of U.S. markets.

At present, the actual number of pediatric palliative care programs in the U.S. is unknown, although all indications point toward the availability of services being extraordinarily low. In 2011, the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC) teamed to evaluate the availability of adult palliative care within acute care hospitals and concluded the provision of care has increased by 138 percent since 2000, yet it is still woefully lacking in many states across the nation (CAPC and NPCRC, 2011, p. 5). Despite the strong focus on adult palliative care, the availability of services varies across the U.S. and is insufficient in most markets; by comparison, the accessibility of pediatric palliative care is perceived to be far less than adult programs but has never been quantified. The simple fact remains that a substantial unmet need exists for pediatric palliative care services in markets across the U.S. and demand is projected to increase (Marchessault et al, 2012, p. 235). To date, CAPC and NPCRC have not sought to study access to pediatric palliative care in the same manner in which emphasis has been granted to adult palliative care. Moreover, there are no national associations, research centers or similar organizations in the U.S. that maintain a centralized database or comprehensive list of pediatric palliative care facilities, leaving health care providers and those seeking services equally uninformed about the available programs or lack thereof in their communities.

1.4 Purpose of the Research Study: Why This Topic & Why Now?

Overall, the celebrated achievements in modern medicine that have radically reduced infant and pediatric mortality also have contributed to an increase in the incidence rate of children diagnosed with life-limiting conditions, incurable diseases and disabilities who survive for significantly longer periods of time than was once possible (Benini et al, 2008, p. 1, 3). The complexities of caring for these children has given rise to new strategic priorities in determining how best to provide care when definitive cures and recovery are not possible. In these challenging situations, optimizing the quality of life is tantamount to success for health care providers who aim to meet the needs of the children and families they seek to serve. As an emerging pediatric specialty, the holistic aims of palliative care with its ability to address the body, mind and spirit may hold a key to reshaping the approach within the U.S. health care industry to caring for children with life-limiting conditions and their families. However, current research is limited and does not offer a comprehensive understanding of their lived experience and related needs, as well as the manner in which pediatric palliative care can address these factors.

Moreover, following the passage of the Patient Protection and Affordable Care Act (PPACA) in 2010, the implementation of U.S. health care reform legislation has prompted increased dialogue and reinvigorated interest about the optimal ways to increase patient access to care, improve affordability and enhance quality. Health care expenditures as a percent of U.S. gross domestic product

(GDP) increased to 17.9 percent in 2012, which represents one of the highest percentages of health care GDP in the world (World Bank, 2013). Despite the increased expenditures for the provision of health care services, the U.S. does not have quality outcomes or morality rates that are markedly better than other industrialized nations. With the staggering health care GDP trend deemed unsustainable, health care reform legislation is stimulating efforts by U.S. health care providers, government agencies, insurance companies and other key stakeholders to evaluate how best to bend the cost curve through the implementation of innovative health care delivery concepts and payment models that can provide health care to more people with better quality at a lower cost. In this manner, the aim of health care reform legislation may promote interest by health care providers and stakeholders in identifying better ways to provide care for children with life-limiting conditions, designing innovative systems of care to meet their needs and ensuring greater access to these critical, high-quality services.

The following qualitative research study (short title: Pediatric Palliative Care Study) aims to articulate the lived experience of caring for children with life-limiting conditions and their families and define their palliative care needs by examining the experiences of multidisciplinary care team providers (e.g. physicians, nurses, social workers, chaplains) who deliver care in a home-based setting. Before new health care delivery models can be employed, a vital imperative exists to examine the tangible needs of children and their families in order to ensure the provision of care is aligned with the realities of living with a life-limiting condition or caring for someone with these diagnoses. Rather than making assumptions about services that may be helpful or desired, the study yields an intentional focus, first and foremost, to delve into the daily realities of care providers who have worked with multiple families in their homes, local hospitals or ambulatory care settings. By examining the lived experiences of those who work intimately with children and their families, the common themes that emerge from their experiences can raise awareness about what it is like to care for children with life-limiting conditions and how the needs inform the design of health care delivery in the future. As will be demonstrated by the study, the existing literature has proffered limited insights into the emerging field of pediatric palliative care and has neglected to introduce qualitative research about the comprehensive lived experience and needs of this unique patient population when children and families are receiving care primarily in a home-based setting.

CHAPTER 2

Background

“Children are not supposed to die. Children are supposed to live! Children – kind of like women and other minorities – their voices aren’t as well heard. They’re not given a voice in general.”

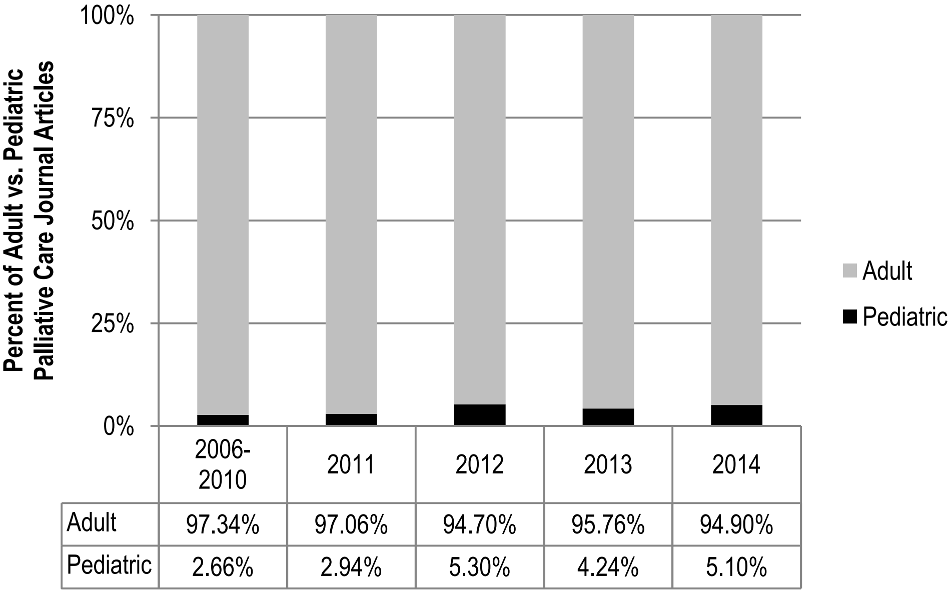
~ Pediatric Palliative Care Physician

2.1 About the Literature Review

While pediatric palliative care represents a promising health care delivery model for children with life-limiting conditions and their families, only negligible attention has been paid within the body of literature to understanding and advancing this specialized health care field. To delineate the parameters for the qualitative Pediatric Palliative Care Study, the following literature review seeks to provide contextual background for five key themes that are interwoven within the aims of the study. In turn, the study endeavors to articulate the palliative care needs of children and their families via an exploration of the comprehensive lived experiences of multidisciplinary care team providers who deliver care primarily in a home-based setting. First, the review addresses the lack of pediatric palliative care research within the literature – also called the “body of knowledge” – and the extent to which additional research is needed to advance the field. While the literature contains copious articles about adult palliative care, the literature review delineates the fundamental differences that exist between the provision of adult and pediatric palliative care and why adult palliative care research is not germane and cannot be generalized to the pediatric population. Next, the literature review demonstrates the vital role of the family in pediatric palliative care and why defining the needs of the child and family should not be separated from one another. Also, the review identifies the locations in which pediatric palliative care can be provided, the merits of focusing on pediatric palliative care in a home-based setting and the gaps that exist in the current literature in terms of understanding the provision of care in the home. Finally, the literature review evaluates the role of the multidisciplinary care team in providing pediatric palliative care in the home and examines why the providers are an effective voice for articulating the lived experience and overall needs of children and their families.

2.2 Lack of Research About Pediatric Palliative Care

First, the emergence of palliative care has proffered significant research about adult palliative care, but the focus on the adult patient population is disproportionate in comparison to the research that has been introduced about pediatric palliative care and cannot be considered transferable. Only in the last decade has research about pediatric palliative care begun to emerge, but the shortfall between adult versus pediatric palliative care literature remains immense. While the adult-focused research has led to better care and ongoing improvements in palliative care, the same level of research is not available to help advance the field of palliative care for the pediatric population (Stevenson et al, 2013, p. 566). In a systematic review and quantitative analysis of the top twelve palliative care journals[2] from 2006-2010, Kumar (2011) concluded only 2.66 percent of the journal articles focused on pediatrics, while more than 97 percent were devoted to adult palliative care. Utilizing the methodology and data synthesis techniques employed by Kumar (2011) to evaluate the literature since 2010, the disparity between adult and pediatric palliative care research in the leading palliative care journals has remained largely unchanged (see Figure 2.1).



	2006-2010	2011	2012	2013	2014
Adult	97.34%	97.06%	94.70%	95.76%	94.90%
Pediatric	2.66%	2.94%	5.30%	4.24%	5.10%

Figure 2.1. Comparative Trend of Adult Versus Pediatric Articles in the Top Twelve Palliative Care Journals, 2006-2014.

While the systematic review completed by Kumar (2011) offers comprehensive insights about the proportion of adult versus pediatric articles in the leading palliative care journals, two weaknesses in the review offer opportunities for future refinement. First, Kumar's (2011) identification of relevant articles was based on the title of the article alone, rather than the content of the journal article. In this regard, the potential exists for valid articles about pediatric palliative care to have been omitted from the tabulation if the articles did not contain "pediatric" or "children" in the title. While it is unlikely that a substantial number of articles related to pediatrics were omitted due to the lack of a pediatric-related identifier in the title, it should be noted that the percentage of pediatric versus adult palliative care articles may vary to some degree if each article was reviewed in detail.

Second, Kumar (2011) limited the systematic review to palliative care journals only, as opposed to including other leading medical or pediatric journals that may represent a more effective conduit for disseminating pediatric palliative care research. For example, *Pediatrics*, which is the leading pediatric journal in the

---

[2] Based on the SCImago Journal & Country Rank, the top twelve palliative care journals from highest to lowest ranking include: (1) *Palliative Medicine*, (2) *Journal of Palliative Medicine*, (3) *Journal of Palliative Care*, (4) *American Journal of Hospice and Palliative Medicine*, (5) *International Journal of Palliative Nursing*, (6) *Palliative and Supportive Care*, (7) *Journal of Pain and Palliative Care Pharmacotherapy*, (8) *BMC Palliative Care*, (9) *Current Opinion in Supportive and Palliative Care*, (10) *Journal of Hospice and Palliative Nursing*, (11) *Journal of Social Work in End-of-Life and Palliative Care* and (12) *Indian Journal of Palliative Care*. Five additional palliative care-related journals with lower journal rankings were not included in the systematic review by Kumar (2011).

world, included 22 articles[3] related to pediatric palliative care from 2006-2010, the time period used by Kumar (2011). While the pediatric palliative care articles represent less than one percent of the total articles published in *Pediatrics*, the research is not insignificant in comparison to the 97 articles published in the top twelve palliative care journals during the same time period.

Ultimately, whether pediatric palliative care research is published within notable palliative care journals or other health care publications, the volume of pediatric palliative care literature is limited. The dearth of literature for pediatric palliative care and, more specifically, the lived experience and needs of children and their families has left the emerging field predominantly undefined and inadequately understood (Stayer, 2012, p. 350). While researchers often seek to locate a gap within the body of knowledge in which to offer a meaningful contribution, the overall lack of pediatric palliative care research represents more than a mere gap but rather a massive chasm of innumerable opportunities for ongoing improvement.

2.3 Differences Between Adult & Pediatric Palliative Care

In addition, more research is needed to focus on the lived experience of caring for children with life-limiting conditions and the specific needs of children and their families because fundamental differences exist between the provision of adult and pediatric palliative care. While more than 97 percent of the articles in the leading palliative care journals from 2006-2010 were devoted to adult palliative care (Kumar, 2011), the abundance of research is not transferable to the pediatric patient population. Beginning with the basic definition of palliative care, the World Health Organization has identified the importance of offering two definitions of palliative care – one that is generally applicable to all populations and a second description that is specific to children and their families (WHO, 2013). At the core, both adult and pediatric palliative care are focused on improving quality of life and comfort through a holistic approach of caring for physical, psychosocial and spiritual needs (WHO, 2013). However, major differences in needs and practices exist between adult and pediatric patients that extend beyond the common palliative care principles (Spathis et al, 2012, p. 777). Researchers caution that the palliative care methods used to care for adult patients are not suitable for children and their families; pediatric palliative care must be interwoven into the medical management of the child from the identification of the life-limiting condition through the end-of-life in a manner that differs from the structure and aims of adult palliative care (American Academy of Pediatrics, 2000; Field and Behrman, 2002; Knapp et al, 2011, p. 121). Researchers emphasize that “children are not small adults”, so seeking to extrapolate and apply adult palliative care research to a pediatric population is unacceptable and fails to take into consideration the uniqueness of

---

[3] The articles include American Academy of Pediatrics (2010); Davies et al (2010); Thompson et al (2009); Lyon et al (2009); Linton and Feudtner (2008); Pritchard et al (2008); Levetown (2008); McCabe et al (2008); Davies et al (2008); Howell (2007); Santucci et al (2007); McClain and Kain (2007); Feudtner et al (2007); Robinson et al (2006); Hentschel et al (2006); Goldman et al (2006); Kolarik et al (2006); Feudtner et al (2006); Meyer et al (2006); Pousset et al (2009); Lantos and Meadow (2009); and Williams et al (2009).

the life-limiting conditions found in children, the differences in cognitive and developmental milestones and other pediatric physiological considerations (Ullrich and Morrison, 2013, p. 334).

Moreover, Benini et al (2008) identified seven key challenges or differences that reinforce the importance of designating children as a special patient population for palliative care; the findings reinforce that the research contributions for adult palliative care are not broadly applicable to younger patients. First, the number of children who qualify for pediatric palliative care is significantly smaller than the number of adults who are eligible for palliative care. Because of the smaller number of pediatric patients spread across a broad geographic region, the organizational design, educational training requirements and cost structure for pediatric palliative care programs varies in comparison to adult palliative care (European Association of Palliative Care Taskforce, 2007; Benini et al, 2008, p. 2). Second, adults who receive palliative care tend to have similar diagnoses, such as oncology, cardiac disease, chronic obstructive pulmonary disorder (COPD), end-stage renal disease (ESRD) or other terminal diagnoses (Center to Advance Palliative Care, 2013). By comparison, children represent a broad spectrum of diagnoses that vary in their complexity, rarity and duration of care (Benini et al, 2008, p. 2). Given the gamut of diagnoses that necessitate the provision of pediatric palliative care, health care decisions about course of treatment or the optimal structure of palliative care programs cannot be easily generalized or inspired by the adult-focused palliative care research.

Due to the variability and overall complexity of diagnoses for children, the role of the multidisciplinary care providers and family in providing extensive hands-on care, emotional support and monitoring for a continuous period of time is deemed more intensive than the level of care required for adult palliative care patients (Benini et al, 2008, p. 2). As modern medicine and health care technology have advanced, the survival rate of children with life-limiting conditions has increased, which has spurred the growing need to focus on the growth and development of pediatric palliative care programs (Benini et al, 2008, p. 3). The underlying need for adult palliative care has not changed dramatically in recent decades, as the life expectancy rate and mortality rate in the U.S. has remained fairly constant. However, advances in modern medicine have contributed to children with life-limiting conditions living for much longer periods of time than was once deemed possible, which has introduced a new challenge of designing palliative care programs to meet a new patient population that, at one time, would not have lived long enough to require these health care services.

Furthermore, differences exist between the role of the family for adults versus children. In the case of children who are receiving palliative care, the parents or legal guardians serve in a pivotal position to make health care decisions, provide constant care and communicate with health care providers (Benini et al, 2008, p. 3). Siblings and the extended family also tend to play a larger role in the lives of children who are receiving palliative care. Comparatively, the majority of adult patients have the ability to make independent health care decisions, and the role of their family in providing care or participating in the decision-making process is often minimized. In a similar manner, the ethical and legal implications of palliative care can differ between adult and pediatric patients, as children often are unable to articulate their needs or participate actively in decisions about their care, necessitating that a parent or guardian make informed decisions about the type of palliative care services that will be received (Benini et al, 2008, p. 3). The ability of children to participate in their care and understand their illness is a differentiating factor in comparison to adults (Ullrich and Morrison, 2013, p. 334).

Finally, the level of emotional involvement is believed to vary between adult and pediatric palliative care, which also can have implications for the type of health care decisions that are made by care providers and families. When caring for adult patients who have a life-limiting condition or terminal illness, the failure of treatment, inevitability of death or irreversible nature of the disease tend to be more easily accepted (Benini et al, 2008, p. 3). However, the same prognoses for children can lead to over-treatment, greater utilization of health care services and more exhaustive therapeutic efforts because of the emotional involvement of caring for a dying child, thus influencing the role and design of palliative care programs for pediatric patients (Benini et al, 2008, p. 3). Based on the aforementioned reasons, scholars and practitioners should be mindful not to utilize adult palliative care research as a proxy for understanding pediatric palliative care, but rather should recognize the need to offer novel contributions that will advance the emerging field of pediatric palliative care.

2.4 Role of the Family in Pediatric Palliative Care

Furthermore, new research about pediatric palliative care must acknowledge that the needs of the child and their family cannot be separated from one another but rather should be viewed in combination. When articulating the meaning of pediatric palliative care, the World Health Organization offers a definition of holistic care “appropriate for children and their families” [emphasis added] and depicts the multidisciplinary approach to pediatric palliative care as being inclusive of the family (WHO, 2013). From the perspective of providing holistic care that contemplates the needs of the mind, body and spirit, pediatric palliative care is designed to reflect the child and family together as a single entity that has special health care needs before and after death (Himelstein et al, 2004, p. 1752). Because families serve as the primary caregivers for children and bear the ongoing responsibility of providing continuous care (Spathis et al, 2012, p. 777), pediatric palliative care research must be fastidious in reflecting the interconnectedness of the child and their family. With families playing a crucial role in the provision of daily care and health care decision-making, the experiences of children with life-limiting conditions should not be evaluated in isolation since the family is regarded as the unit of care within pediatric palliative medicine (Ullrich and Morrison, 2013, p. 335). In evaluating the literature, Ullrich and Morrison (2013, p. 335) and Steele and Davies (2006) observed more research is needed to understand the experiences of family members in order to design pediatric palliative care in a manner that reflects the needs of the child and entire family.

2.5 Provision of Pediatric Palliative Care in a Home-based Setting

Pediatric palliative care can be provided in a variety of settings across the continuum of care, including acute care hospitals, hospice care centers and family homes (Muckaden et al, 2011). For the majority of children and their families, the home is deemed the optimal setting in which to receive pediatric palliative care since receiving care in the home can be the least disruptive to “normal” daily routines and family life, especially when taking into consideration the needs of the entire family (Benini et al, 2008, p. 1). During the last year of life, the majority of children with life-limiting conditions receive the greater part of their care in the home and do not access acute care services in a hospital (Miller et al, 2012; Ullrich and Morrison, 2013, p. 336). In comparison to other care settings, providing pediatric palliative care in a home-based setting has been demonstrated to benefit children and their families by reducing the need for emergency room or clinic visits (Rogers et al, 2011, p. 164). Similarly, according to a 2012 study about effective pediatric palliative care models, the provision of care in a home-based setting by a multidisciplinary team has been confirmed to improve the quality of life for children and their families, best address and manage the symptoms of illness, improve overall communication and minimize administrative barriers (Vollenbroich et al, 2012, p. 294).

However, despite the preponderance of evidence demonstrating that pediatric palliative care is best delivered in a home-based setting, the body of literature contains limited information that is specific to the home environment. For example, of the 97 articles published about pediatric palliative care from 2006-2010 in the top twelve palliative care journals (Kumar, 2011), only one article referenced pediatric palliative care in a home-based setting, and the qualitative research study was narrowly focused on clinical extubation procedures (Zwerdling et al, 2006). Since 2010, only a small handful of articles referring to care at home have been published in the leading palliative care journals (see Table 2.1), with other articles focusing on acute care or omitting a reference to a care location. Overall, the limited articles about pediatric palliative care in the home tend to address narrow aspects of palliative care, rather than broader themes about the needs of pediatric patients and their families when care is delivered in a home-based setting. When factors such as the location for the provision of care are taken into consideration, the availability of relevant literature becomes substantially more restricted for those seeking to learn about pediatric palliative care.

TABLE 2.1 RESEARCH ABOUT PEDIATRIC PALLIATIVE CARE IN A HOME-BASED SETTING, 2006-2014

Author	Year	Title	Journal	Research Method
Zwerdling et al	2006	Home pediatric compassionate extubation: bridging intensive and palliative care	American Journal of Hospice and Palliative Care	Qualitative
Nayak, M. and Salins, M.	2011	Providing palliative care for a dying teen at home: perspectives and challenges	Indian Journal of Palliative Care	Qualitative
Simpson, E.C. and Penrose, C.V.	2011	Compassionate extubation in children at hospice and home	International Journal of Palliative Nursing	Quantitative
Bradford et al	2013	The case for home based telehealth in pediatric palliative care: a systematic review	BMC Palliative Care	Systematic Review
Groh et al	2013	Specialized pediatric palliative home care: a prospective evaluation	Journal of Palliative Medicine	Quantitative
Niswander et al	2014	End-of-life care for children enrolled in a community-based pediatric palliative care program	Journal of Palliative Medicine	Quantitative
Groh et al	2014	Specialized home palliative care for adults and children: differences and similarities	Journal of Palliative Medicine	Quantitative

2.6 Role of the Multidisciplinary Pediatric Palliative Care Team

In seeking to deliver palliative care that addresses the physical, psychosocial and spiritual needs of children and their families, the role of a multidisciplinary team is deemed critical to the ability to offer holistic care. When defining palliative care, WHO (2013) underscores the use of a “team approach to address the needs of patients and their families” that includes multiple health care providers in a “broad multidisciplinary approach”. Due to the health care complexity of treating those with life-limiting conditions, the needs of children and their families are best served through the devoted attention of multiple disciplines, as opposed to a solitary specialty (Remke and Schermer, 2012, p. 287). While the exact membership of the teams will vary by location and reflect the availability of health care providers in the community, the most common roles include physicians, nurses, social workers and chaplains. Care coordinators, bereavement specialists, child psychologists and child life specialists also may play a routine or ancillary role in delivering care (Himelstein et al, 2004, p. 1752), as well as other support staff and health care professionals (Swinney et al, 2007). Prior literature offers limited insights into the optimal combination of roles for a multidisciplinary team when palliative care is provided in a home-based setting (Vollenbroich et al, 2012), although the findings of the studies are supported by pediatric palliative care research that has not specified a location or that has elected to highlight the structure of multidisciplinary teams in acute care locations (Jennings, 2005, p. 195-198; Ward-Smith et al, 2006; Meier and Beresford, 2007).

Members of the multidisciplinary team often spend extensive time with families in their homes and frequently operate as an extension of the family. The amount of time spent with children and families varies based on need and the condition of the child. For example, a recent pediatric palliative care study concluded nurses often have “frequent, poignant, and intimate relationships with families during the delivery of end-of-life care” (Reid, 2013, p. 541). Overall, the time commitment by care providers on the team makes them an appropriate voice for the research study due to the amount of time spent with families and the insights they are able to proffer about the day-to-day reality of caring for a child with a life-limiting condition.

2.7 Research Study Will Address the Scarcity of Information About the Lived Experience & Needs of Children and Their Families

In closing, the Pediatric Palliative Care Study is positioned to make noteworthy contributions to the body of knowledge by focusing on two research objectives: (1) understanding and articulating the comprehensive lived experience of caring for children with life-limiting conditions and their families and (2) delineating how the collective experiences provide insights into needs that can be addressed through the provision of pediatric palliative care (see Figure 2.2). As exhibited by the literature review, pediatric palliative care is an emerging specialty that has a deficiency of published research in comparison to adult palliative care, and the adult palliative care research findings cannot be considered germane or transferable. While not a panacea for the dearth of information, the Pediatric Palliative Care Study aims to draw scholars and practitioners into the phenomenon of caring for children and families through the lived experiences of care providers with first-hand knowledge of offering care and partnering with families in their home. Undoubtedly, this is a situation many scholars and practitioners might not otherwise have the opportunity to explore. Rather than relying on theoretical constructs or quantitative research results, the Pediatric Palliative Care Study draws inimitable insights from the words and tangible experiences of multidisciplinary care team providers. The study has been designed to balance rigor and objectivity (Annells, 1996, p. 706), with the need for relevant information about pediatric palliative care that is timely, applicable and transferable to decision-making (Tuckett, 2005, p. 31) about the optimal design and provision of health care services for children and their families. With utilization trends for pediatric palliative care projected to increase (Marchessault et al, 2012, p. 135), the study will make known the lived experience and needs associated with this unique population so health care stakeholders can make informed decisions about designing care delivery models that address the attributes that are most important to children with life-limiting conditions and their families.

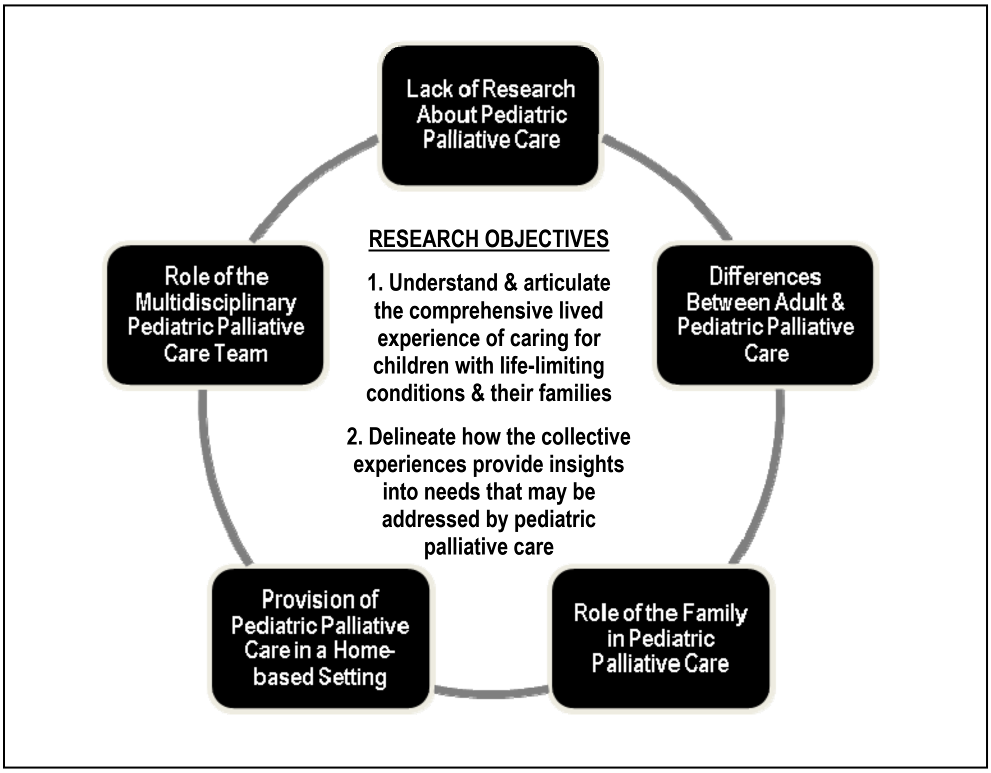


Figure 2.2. Conceptual Diagram of the Five Facets of the Literature Review that Influenced the Research Objectives & Methodological Design of the Study.

CHAPTER 3

Methodology

“By doing research, really what you’re ending up doing is giving us one of the greatest new open doors.”

~ Pediatric Palliative Care Community Liaison

The Pediatric Palliative Care Study has been designed to utilize an interpretative phenomenological analysis (IPA) research methodology in order to address the aims of understanding the lived experience of caring for children with life-limiting conditions and their families, as well as the inherent needs associated with this phenomenon. The following chapter delineates the methodological basis of the qualitative research study and the overall research design parameters, including specificity about the research setting, ethical approval of the study, sampling methodology, recruitment process, research participants, interview process and questions, data collection and retention, confidentiality and anonymity of research participants, risk management, data analysis and review process.

3.1 Interpretative Phenomenological Analysis

At its core, phenomenology means “to bring into light” (Pringle et al, 2011b, p. 8), which is fitting of the manner in which the methodology can be employed to offer insights into a phenomenon with which others may have limited to no familiarity. In such instances, “phenomenon” carries the meaning of an experience or occurrence, as opposed to the alternative societal definition of something at which others marvel with wonder or view as a spectacle. With scarce information available in the body of literature for pediatric palliative care, a qualitative research methodology, such as IPA, that allows for explanatory study of the lived experience is appropriately aligned with the research aims. It seeks to surpass perfunctory descriptions of the phenomenon to tender more advanced explanations of the holistic experience, as well as richer details that can benefit academia and professional practice (Maxwell and Mittapalli, 2008, p. 324-346). In IPA, research participants are recognized as experts whose personal experiences and viewpoints are regarded with authority (Biggerstaff and Thompson, 2008, p. 215), with verbatim excerpts from research interviews deemed a hallmark of IPA studies so that the voice of participants remains central to the research findings (Reid et al, 2005, p. 22).

IPA represents one of the more contemporary variations of phenomenology, as it was introduced by Dr. Jonathan Smith, Birkbeck University of London, in the 1990s (Birkbeck University of London, 2011). IPA builds upon Husserlian (or transcendental) phenomenology, which is a qualitative research methodology developed by Edmund Husserl that aims to explore the lived experiences of research participants and define an essence or universal knowledge of the phenomenon that can serve to illuminate the experience for others (Schacht, 1972). In order to do so, Husserl calls for researchers to set apart their assumptions and pre-understanding of the phenomenon and remove themselves in totality through an effort called “bracketing” so as not to influence the interpretation of the lived experience (Schacht, 1972). However, Smith diverged from Husserl by observing that researchers cannot fully remove themselves from the research, as they have an interpretative role in listening, analyzing and making sense of the lived experience that is conveyed to them by research participants (Biggerstaff and Thompson, 2008, p. 215). In this manner, IPA features a double hermeneutic quality, meaning both the research participants and the researcher have a function in interpreting the lived experience (Birkbeck University of London, 2011). For these reasons, IPA remains rooted in Husserlian phenomenology but acknowledges the central role of the researcher in the analysis (Pringle et al, 2011a, p. 20).

In general, IPA is considered germane for researchers conducting studies related to health, human and social sciences (Birkbeck University of London, 2011). In a systematic literature review of 65 IPA articles published from 1996 to 2004, Reid et al (2005, p. 21) concluded the use of IPA has increased and that the methodology is having an influence on 11 research areas, one of which is palliative care.[4] Nonetheless, it is worth noting that no pediatric palliative care articles were identified during the review by Reid et al (2005); the Pediatric Palliative Care Study serves as the first of its kind to examine the comprehensive lived experience using IPA.[5] During the last decade, qualitative research and IPA, in particular, have established a foothold in the health care industry, which has been dominated historically by the rigors of quantitative research and evidence-based medicine (Biggerstaff and Thompson, 2008, p. 214; Pringle et al, 2011a, p. 20). While the quantitative research contributions remain vital, these methodologies engender a disparity in the literature in terms of “understanding healthcare and illness from the patient or service user perspective” and utilizing researchers to bear witness and make sense of these personal experiences (Pringle et al, 2011a, p. 20). Jasper (1994, p. 313) also concludes that researchers who utilize phenomenology can explore the experiences of patients and use the results of the study to pinpoint the optimal services or approaches to care delivery that address their needs. Overall, IPA is especially advantageous when researching a phenomenon about which little is known or understood (Reid et al, 2005, p. 23), which was an influential factor when selecting the methodology for the Pediatric Palliative Care Study.

3.2 Purposeful Exclusion of a Theoretical Construct

Unlike other quantitative or qualitative research, phenomenological studies abstain from applying theoretical constructs or relying on existing theories, as utilizing such frameworks would detract from the focus on the lived experience of research participants and the ability to describe the overarching essence of a phenomenon (van Manen, 1990). According to Reid et al (2005, p. 23), “bypassing

---

[4] The 11 research areas in which IPA is having an influence include: (1) new genetics, (2) health professionals / therapists, (3) dementia / degenerative disease, (4) sexual identity and sexual health, (5) chronic illness, (6) quality of life measurement, (7) spirituality and bereavement, (8) palliative care, (9) mental health / addiction / eating disorders, (10) reproductive decision-making and adoption and (11) personal and cultural identity (Reid et al, 2005, p. 21).

[5] An examination of the body of literature reveals two pediatric palliative care studies that have been conducted using IPA. They are the “Psychological impact of working with patients with cystic fibrosis at end-of-life, pre-transplant stage” (Clisby et al, 2013) and “Qualified clinical psychologists’ experiences of working with children with life-limiting conditions: a qualitative study” (Davenport, 2012). Neither study was designed to focus on the totality of the lived experience.

the closed systems of borrowed hypotheses and theories, [IPA] can instead provide meaningful and unexpected analysis of psychosocial issues." Therefore, this study has intentionally excluded the use of theoretical constructs to inform its design, data analysis or articulation of research findings. To overlay a theoretical construct would be counterintuitive to the quintessence of the methodology and benefits it prescribes by being able to explore and make sense of a phenomenon without the bias of existing theories. Phenomenology also is not intended to proffer new theories at the conclusion of the study, per se (Thorpe and Holt, 2008, p. 115). While some critics contend this is a methodological weakness, others note that "while 'Theory' with a capital 'T' is not the purpose or remit of IPA studies, findings can nevertheless influence and contribute to theory in a broader 'lower case' sense" (Pringle et al, 2011a, p. 21). As evidenced by Chapter 5: Discussion, the Pediatric Palliative Care Study has fulfilled its research objectives and offered both implications for future practice and contributions to extant literature without producing unnecessary "Theory".

3.3 Bracketing Framework

IPA differs from Husserlian phenomenology in its supposition that researchers cannot fully remove themselves from the interpretation of the lived experience and ability to express an overall essence of the phenomenon. Nonetheless, IPA still utilizes a bracketing framework to promote reflexivity and encourage researchers to take inventory of potential areas of influence to the extent that is feasible. While researchers cannot achieve absolute objectivity (Crotty, 1996), those who utilize phenomenology are expected to suspend their personal beliefs and values to the degree that is possible in order to minimize their influence on providing an accurate account of the lived experience (Ahern, 1999, p. 407). Scholars contend that bracketing should seek to set aside or bring heightened cognition to the assumptions (Crotty, 1996), biases (Dowling, 2004), prior knowledge of the experience (Beech, 1999) and other factors that may influence the study. Following the recommendations of Hamill and Sinclair (2010, p. 20-21), the principal researcher adopted a continuous approach to bracketing for the duration of the Pediatric Palliative Care Study, as opposed to limiting it to the more common junctures of data collection and analysis.

For example, the principal researcher wrote a bracketing analysis paper prior to commencing with the data collection in which she documented her pre-understanding and knowledge of pediatric palliative care, the rationale for selecting the research topic and her three primary roles as an individual, working professional and student. The bracketing paper included descriptions about the degree to which these roles may influence the study design. The paper was reviewed and discussed with her thesis supervisor in order to establish transparency about areas of potential bias. In addition, the principal researcher limited the scope of the literature review at the beginning of the research study to ensure the extant literature did not influence the data analysis and identification of themes for the phenomenon (Hamill and Sinclair, 2010, p. 20). Prior to undertaking the research interviews, the principal researcher shared the proposed questions for the semi-structured interviews with her thesis supervisor and representatives within Providence Health & Services to assess whether any leading questions or biases were being introduced. Throughout the study, the principal researcher practiced reflexive writing to capture her thoughts and perceptions at each step of the study. The process allowed her to think reflectively about her position in relation to the emerging themes and the extent to which she may be introducing bias to the analysis of the lived experiences. More specifically, the principal researcher wrote reflective notes and observations following each research interview to continue bracketing her own experience and composed weekly progress reports for the duration of the study. The reflections served as a way of documenting key research observations, while ensuring the voice of the research participants was not muddled with the voice of the researcher.[6]

3.4 Ethical Approval of the Study

Ethical approval of the Pediatric Palliative Care Study was granted by the Providence Health & Services – Institutional Review Board Spokane (IRB)[7] on August 15, 2013 and September 26, 2013, followed by approval from the University of Liverpool – Committee on Research Ethics (CORE) on October 9, 2013 (see Appendix A. Ethical Approval of Research Study). The principal researcher also was required to become a credentialed researcher through the Providence Health & Services – Medical Research Center (PMRC), which reviewed the proposed study, assessed the qualifications of the researcher to execute the study and mandated the successful completion of 38 training modules and exams (see Appendix B. Ethical Research Training Requirements). The research and data collection for the study did not begin until the extensive credentialing process was completed and ethical approval was obtained from both institutions.

3.5 Setting

The study was conducted at four research sites: (1) Providence Hospice & Home Care of Snohomish County – Carousel Program in Everett, Washington, (2) Providence Hospice of Seattle – Stepping Stones in Seattle, Washington, (3) Providence Sacred Heart Medical Center & Children's Hospital – Sunflower Program in Spokane, Washington and (4) Providence TrinityCare Hospice and TrinityKids Care in Torrance, California (see Appendix C. Background of Research Locations). The sites represent the only pediatric palliative care programs in Providence Health & Services, based on an inventory completed by the principal

---

[6] The bracketing analysis paper, reflexive writing and progress reports were shared with the thesis supervisor to help monitor potential areas of bias or influence by the principal researcher. However, they have not been included within the thesis so as not to detract from the Pediatric Palliative Care Study, lived experiences and phenomenon that remain central to the study.

[7] Consistent with requirements to conduct research at an overseas location, the principal researcher obtained local permission from the IRB to ensure the research study complied with organizational and U.S. ethics standards for research. The IRB is composed of technical experts, administrators, lay people and clergy, who review research projects involving human subjects to ensure the studies adhere to regulations and guidelines provided by the U.S. Food & Drug Administration (FDA) and the U.S. Office of Human Research Protections (OHRP). The researcher remained subject to ongoing reviews and audits for the duration of the study.

researcher in partnership with the System Director, Nursing Clinical Strategies, in August 2013.

3.6 Sampling Methodology

Per IRB and CORE approval, the study was approved for enrollment up to 30 research participants, which is consistent with the suggested range for phenomenological studies. For example, Cresswell (2007, p. 121), quoting Polkinghorn (1989), recommends conducting interviews with five to 25 people. Similarly, a systematic review of 52 health psychology IPA studies by Brocki and Wearden (2006, p. 94) concluded the number of participants may extend up to 30 people. Overall, IPA studies are marked by smaller sample sizes in comparison to other research methodologies, with no optimal sample size existing for all studies since multiple factors can inform the decision-making by researchers about the number of participants to include (Smith and Osborn, 2003, p. 54; Brocki and Wearden, 2006, p. 94). Due to the geographic distribution of the research sites across multiple states and the number of distinctive roles within a pediatric palliative care team, a sample size at the upper threshold of the recommended limit was adopted for this study. The sample size ensured the study was large enough to encompass representation from two states, four research settings and multiple employment roles within the teams. If the study had been limited to a smaller sample size, the representation for each state, setting and employment role may not have been feasible.

A purposive sampling methodology was used to recruit participants from the four research sites, which led to identification of a research base of participants who shared the common lived experience. Purposive sampling is most commonly used for IPA studies (Smith and Osborn, 2003; Brocki and Wearden, 2006, p. 95) because it aids the researcher in identifying research participants “who have expertise with the phenomenon being studied by virtue of its being an integral part of their life experiences” (Wagstaff and Williams, 2014, p. 9, reflecting on Cohen et al, 2007). To participate in the study, research participants were required to fulfill three inclusion criteria: (1) be employed by Providence Health & Services or an affiliated provider, (2) be employed as a pediatric palliative care physician, nurse, social worker, chaplain or other palliative care role, and (3) be providing pediatric palliative care at this time, preferably in a home-based setting. The aim of the inclusion criteria was to identify individuals who had experienced the phenomenon in order to generate research findings that would depict a common understanding of the lived experience (Creswell, 2007, p. 62). Those individuals serving in palliative care leadership roles, such as program directors or administrators, were not invited to participate in the interviews if they were no longer providing direct patient care since their current expertise was not aligned with the aims of the study; they would not be able to share timely insights from their lived experiences of caring for children and their families. Otherwise, no exclusion criteria were delineated for the selection of participants.

3.7 Recruitment & Selection of Research Participants

Once ethical approval was granted to commence with the research, the principal researcher contacted the program director at each pediatric palliative care facility to request their assistance in distributing an e-mail solicitation to all pediatric palliative care employees who met the inclusion criteria for the voluntary research study (see Appendix D. Recruitment Advertisement). Per the IRB, U.S. FDA, and U.S. OHRP guidelines, the principal researcher was not allowed to identify or make direct contact with potential research participants until the participants elected to contact the researcher, hence the necessity of the program director at each location serving as the conduit for distributing the initial e-mail solicitation. Responses to the e-mail solicitation were sent directly to the principal researcher so employee participation in the study could remain confidential and anonymous. Those who responded affirmatively to the request for research participants and provided their contact information to the researcher were contacted to schedule an interview at a time and place of their convenience. For some research sites, a second e-mail solicitation was distributed by the program director to remind employees of the opportunity to participate, as the first solicitation was unsuccessful in reaching the desired enrollment for the study.

In total, 27 employees consented to participate in the study, with participants representing the employment diversity commonly found within palliative care teams. The participants included 13 nurses, five social workers, two chaplains, two community liaisons, two nurse practitioners, one physician, one nurse / social worker and one program coordinator / child life specialist. Of the participants, 25 were female and two were male. At the time of their interviews, the participants ranged in palliative care experience from four months to 24 years, with a mean of 6.1 years of experience, respectively. Approximately 63 percent of participants had less than five years of experience in pediatric palliative care, which is reasonable since it did not begin to achieve recognition as a specialty until a decade ago (Mellor et al, 2011, p. 115; Crozier and Hancock, 2012, p. 198). Beyond their palliative care experience, the majority of participants had significantly longer health care careers, including experience in adult and pediatric acute care, hospice care, trauma care and other relevant experience.

Due to the difference in size of the palliative care programs, the number of participants varied by research site. In total, the study included 16 participants from TrinityKids Care, four participants from Stepping Stones, four participants from the Carousel Program and three participants from the Sunflower Program. The inclusion of diversified employment roles elicited insights from various perspectives in caring for children and their families, as these team members work closely with families in unique capacities and have in-depth understanding of their needs. Participants did not receive financial remuneration, inducements or other direct benefits for participating in the study.

3.8 Informed Consent & Voluntary Participation

An Informed Consent for Research Participants and a Statement of Informed Consent were reviewed and approved by the IRB, CORE and Providence

Health & Services – Department of Legal Affairs (see Appendix E. Informed Consent for Research Participants & Statement of Informed Consent). In accordance with IRB guidelines, potential research participants were informed their participation was voluntary and that they may withdraw from the study at any time. The principal researcher obtained informed consent from participants via a three-step process. First, the informed consent documents were provided in writing as part of the e-mail solicitation, which allowed prospective participants to review the information at length, ask questions and make an informed decision about whether to participate in the voluntary study. Second, the documents were reviewed verbally at the beginning of each research interview, and participants were asked if they had questions about the informed consent for the study. Finally, participants were given a written copy of the documents and asked for their signature prior to commencement of the research interview; the document also required signature by the principal researcher. Following the interview, a photocopy of the signed Statement of Informed Consent was e-mailed to participants for their personal records. The researcher archived the original documents in accordance with Providence Health & Services policy (Providence Health & Services, 2014g).

3.9 Interview Process & Questions

To collect data for the study, the principal researcher conducted semi-structured interviews, which encouraged the collection of comparable data from research participants and provided the flexibility to ask follow-up questions to explore the concepts and examples shared by participants. Semi-structured interviews serve as the most common interviewing technique for IPA because of the benefits researchers find in being able to ask open-ended questions to gather information from participants about a common lived experience (Thorpe and Holt, 2008, p. 116, contributed by Dunworth). While the semi-structured interviews leverage a common interview guide for key questions or themes to explore, the researcher has the benefit of being able to change the order of the questions or remain fluid in response to the lived experiences that are delineated by participants (Lewis-Beck et al, 2004). According to Pringle et al (2011a, p. 23), “Expansive, honest and reflective accounts may be less forthcoming and more difficult to access from participants if a rigid set of questions or a more structured interviewing technique are used.” In total, the interview guide for the study included 10 questions (see Table 3.1).

On average, each research interview lasted 60-90 minutes, with the majority of interviews conducted in-person and a small quantity occurring via phone when an in-person interview was not feasible. During the interviews, participants were not required to answer the questions and had the right to refuse to answer for any reason; they also had the right to retract answers after they had been provided, although none chose to do so. Participants were informed that additional questions or clarifications may be sought from them during the 12 months following the initial interview while the data analysis was under way.

TABLE 3.1 INTERVIEW QUESTIONS

Category	Question
Background About Research Participants	• What is your current title and role in the organization? • How long have you served as a pediatric palliative care [physician, nurse, social worker, chaplain, etc.]? • What led you to work in pediatric palliative care?
Insights About the Lived Experience and Child & Family Needs	• As you reflect on your personal experiences as a [physician, nurse, social worker, chaplain, etc.], can you describe a time that stands out as an example of providing effective pediatric palliative care? Using as much detail as you are comfortable sharing, what happened from start to finish when providing pediatric palliative care for the child and family? • What are the key problems or challenges faced by children and their families? In what ways are pediatric palliative care services addressing these issues? • Based on the time you spend with children and their families, what are the key questions or requests that are expressed to you? • To what extent are you able to address these needs? Are there barriers that get in the way of meeting the needs of children and their family? • Have you encountered any experiences in which your aims in providing pediatric palliative care differed from the needs of the child and family? • From your perspective, what do children and/or their families hope that pediatric palliative care will provide for them?
Closing Comments	• Is there anything else you would like to share that would be helpful for me to understand about your personal experiences as a pediatric palliative care [physician, nurse, social worker, chaplain, etc.] or the needs of the children and their families?

3.10 Data Collection & Retention

With permission from each research participant, a digital audio recording of the interview was made for subsequent analysis, with additional notes and observations scribed on paper. At the conclusion of the study, the paper files will be scanned into electronic records for archival purposes. All audio recordings, data and project files associated with the study were stored electronically on an encrypted, password-protected Providence Health & Services laptop. As the data owner, the researcher maintained responsibility for determining the appropriate access levels for the electronic information and ensuring access control procedures were in place based on the level of sensitivity of the information (Providence Health & Services, 2014e). Confidential data and research files were not stored on a shared workstation or network drive in accordance with organizational policy (Providence Health & Services, 2014c). As requested, the IRB has the authority to obtain access to study records for audit and quality improvement purposes. Providence Health & Services also has Record Retention Standards, which govern the length of time files must be stored (Providence Health & Services, 2012). While the policy provides guidance for clinical studies, it does not specify requirements for data generated during non-clinical academic research. Using the Record Retention Standards for clinical research as a proxy, the informed consent documents will be stored permanently (Providence Health & Services, n.d.). Because the study involves non-human experimentation – meaning this is not a clinical intervention study involving medical treatment, experimental pharmaceuticals or devices – the research data and related paperwork must be stored for 10 years (Providence Health & Services, n.d.). In the event that the researcher leaves the organization prior to 10 years from the completion of the study, the researcher will transfer the files to an encrypted, password-protected device and take the files with her to ensure they are disposed at the appropriate time.

3.11 Confidentiality & Anonymity of Research Participants

One of the attributes of IPA is the extent to which the research findings incorporate explanations about the lived experience and use representative quotations from research participants so that the researcher can generate an “insider perspective” (Thorpe and Holt, 2008, p. 115, contributed by Dunworth). In order to draw upon the voice of participants, the researcher has included direct quotations from the research interviews in the study, which have been de-identified to preserve the anonymity of participants. The quotations provide relevant examples from genuine experiences in order to allow others to see the situation through the lens of those with first-hand knowledge. By providing transparency into the spoken words of participants, the study stands apart from other forms of qualitative or quantitative inquiry by permitting others to hear directly from those with personal expertise of the phenomenon.

All information collected from participants has been kept confidential and stored in an anonymous manner, and the identity of the participants has not been shared within Providence Health & Services or other outside entities. Following each interview, the researcher assigned a unique four-part code to the interview recording, transcript, research notes and analysis. The code provided the researcher with important details at a glance while otherwise being obscure to others, with the code identifying the profession of the research participant, research location, participant initials and year in which the interview was conducted. The researcher has maintained the solitary key to identifying the research participant name and corresponding code, with the key stored in a separate location from the coded data files. Any direct quotations utilized within the study have been made without attributing them to the names of the participants or disclosure of their identity. In addition, any child and family names shared during the interviews also have been omitted from the findings in order to protect the identity of past or current recipients of pediatric palliative care within Providence Health & Services.

3.12 Risk Management

The study provided research participants with an opportunity to share their professional expertise and personal experiences in order to help advance the field of pediatric palliative care. While speaking about palliative care is a sensitive subject, the level of sensitivity is comparable to other health care topics and every day professional dialogue that takes place within the health care industry. Prior studies have demonstrated that caregivers who participate in qualitative research studies about their experiences find the interviews to be empowering and that sharing personal stories emboldens participants to feel like their insights can make a difference in helping others (Gysels et al, 2008, p. 1). While the study was designed to involve no more than minimal risk, any minor emotional or psychological effects posed to research participants by the study were outweighed by the anticipated benefits of empowerment and ability to make a difference in the field of palliative care. Prior to commencing with the interview, participants were reminded to share only the level of detail with which they were comfortable, thereby allowing them to self-monitor their level of comfort with the dialogue. Participants also were reminded that specific patient information would not be solicited, nor should they share identifiable patient information with the researcher. In the event that a participant became emotional while answering the interview questions, the researcher asked if the participant would like to pause or discontinue the interview; however, none elected to stop their participation in the study.

3.13 Data Analysis

An advantage to using IPA is the methodological flexibility that may be adopted by a researcher to analyze data and generate research findings that align with the aims of the study. Pringle et al (2011a, p. 22), reflecting on the work of Giorgi (2000) and Smith et al (2009), note the methodology is intended to be adaptable to the research study and that attempting to follow a single rigid, prescriptive set of steps for all phenomenological studies is ill-advised. Following the conclusion of the research interviews, the principal researcher commenced with the data analysis, which was informed by the recommendations and practices of multiple scholars. In total, the data analysis for the study engendered three levels of research findings that progress along a continuum from granular to conceptual reflections of the lived experience. With the study being firmly rooted in the words of the research participants, IPA surpasses a standard thematic analysis (Brocki and Wearden, 2006) to provide insights into the lived experience of families who are caring for children with life-limiting conditions. For the purposes of the study, the three thematic levels were optimal, as they allowed for suitable transparency into the personal experiences of care providers while transitioning to broader generalizations and collective expressions of the phenomenon.

As the initial step in the data analysis, the principal researcher fully transcribed the digital audio recordings of each interview by listening to the digital audio recordings, transcribing the files and listening to the recordings again while reading the transcripts to double-check the accuracy of the transcription. Filler words, such as “umm” or “ah”, were not transcribed since they did not provide value or change the meaning of the statements. The transcription files were formatted to include continuous line numbering and an ample right margin to allow space for electronic comments and data coding. Next, the researcher sought to establish an order in which the transcripts should be analyzed. The researcher printed a hardcopy of each transcript, grouped the transcripts by profession (e.g. one stack of transcripts for the nursing interviews, one stack for the social worker interviews and so forth) and read the transcripts in each group to place them in a hierarchical order based on the interviews that were perceived to introduce the greatest number of unique themes to those that offered the fewest new elements. The ranking process was completed for each group of transcripts. Once the overall priority by profession was determined, the transcripts were collated so the final order for the data analysis would begin with the most comprehensive nursing interview, followed by a social worker interview, then a physician interview and so forth until the final sequence of transcripts was identified for the data analysis. Rather than analyzing all transcripts for a particular profession before transitioning to the next profession, the researcher elected to blend the professions in order to hear from the multidisciplinary palliative care team early in the analysis process and be able to reflect on the themes across all professions.

The researcher used a multi-step process to analyze and assign initial codes to each transcript, starting with re-reading the transcript to understand the information shared by the research participant. Next, the researcher read the transcript over again but this time highlighted phrases or sentences in the transcript and inserted an electronic comment to identify an “initial code” for each excerpt, which included a few brief words to encapsulate the concept of the highlighted statement. The initial codes aligned with the spoken words of the interview participants or reflected terminology that would be recognizable to them. This served to ensure the initial codes were grounded in the language of the participants, as opposed to more abstract or conceptual language from the principal researcher. The interview excerpts and codes were reviewed again to discern whether the labels were reasonable. This form of manual coding is recognized as an effective means by which to develop an intimacy with the data to a degree that would be unlikely to arise through an alternative means of data analysis (Clarke, 2009, p. 72). Once this process was completed for a transcript, the phrases or sentences that were highlighted and assigned an initial code were recorded in a spreadsheet for ongoing analysis. At the initial stages of analysis, additional observations, initial impressions and other reflective comments also can emerge, which Smith et al (2009, p. 82) describe as ‘noise’ during the data analysis and recommend recording these comments in a dedicated place so the focus can remain on the raw data. Therefore, the principal researcher prepared a reflective journal and used weekly progress reports to document reflective comments that arose from listening and reading the transcripts multiple times.

After the initial coding was completed for each transcript and the excerpts were added to the spreadsheet, the principal researcher grouped initial codes into categories that were identical or analogous in order to standardize the name of the “core element”.[8] For example, the initial coding of the interview transcripts led to terms such as “multidisciplinary care”, “multidisciplinary team-based care” and similar variations of the same concept. Therefore, the researcher reviewed the initial codes and identified the optimal name for the core element, being attentive not to disregard subtle thematic nuances. At the most detailed level, the core elements serve as the elementary facets of the data analysis, as they articulate the

---

[8] The principal researcher selected the labels of “core elements”, “sub-themes” and “major themes” to delineate the three levels of thematic analysis in the study.

basic codes assigned to statements made by participants during the interviews. The core elements are grounded in the verbiage of the participants in a manner that preserves the concrete, distinctive qualities of their personal experiences.

After the core elements were identified, the principal researcher began an iterative coding process to group the core elements and assign each cluster of core elements a sub-theme label. At the sub-theme level, threads of commonality were identified between core elements, with the thematic elements beginning to transition from concrete to summarized units of meaning. The discrete sub-themes function as building blocks to define the lived experience. Next, the sub-themes were clustered into major themes. At the highest level, the major themes represent a compilation of sub-themes to provide an abstract, comprehensive account of the lived experience, which has the benefit of generalizing the collective experiences of the pediatric palliative care providers to make the experience more accessible and easier to understand.

With IPA being a cyclical process, the principal researcher revisited and refined the thematic codes through multiple iterations of the analysis (Biggerstaff and Thompson, 2008, p. 218). The researcher maintained an electronic spreadsheet for the interview excerpts that were coded, with each excerpt identifying the name of the core element, sub-theme and major theme so that the excerpts could be sorted, evaluated and analyzed to understand the essence of the lived experience and needs of those who require pediatric palliative care services. To facilitate the development of research findings, the researcher also wrote a definition for each core element, sub-theme and major theme, which formed the basis for the Chapter 4: Research Findings. In addition, quotations were selected that best represented each core element and captured the essence of the lived experience (Biggerstaff and Thompson, 2008, p. 218). As Chapter 4 was prepared, the number of quotations was further honed and summary tables were developed to provide transparency into the core elements and sub-themes that comprise each major theme. See Figure 3.1 for a summary of the key steps undertaken during the coding process to proffer the three thematic levels of core elements, sub-themes and major themes.

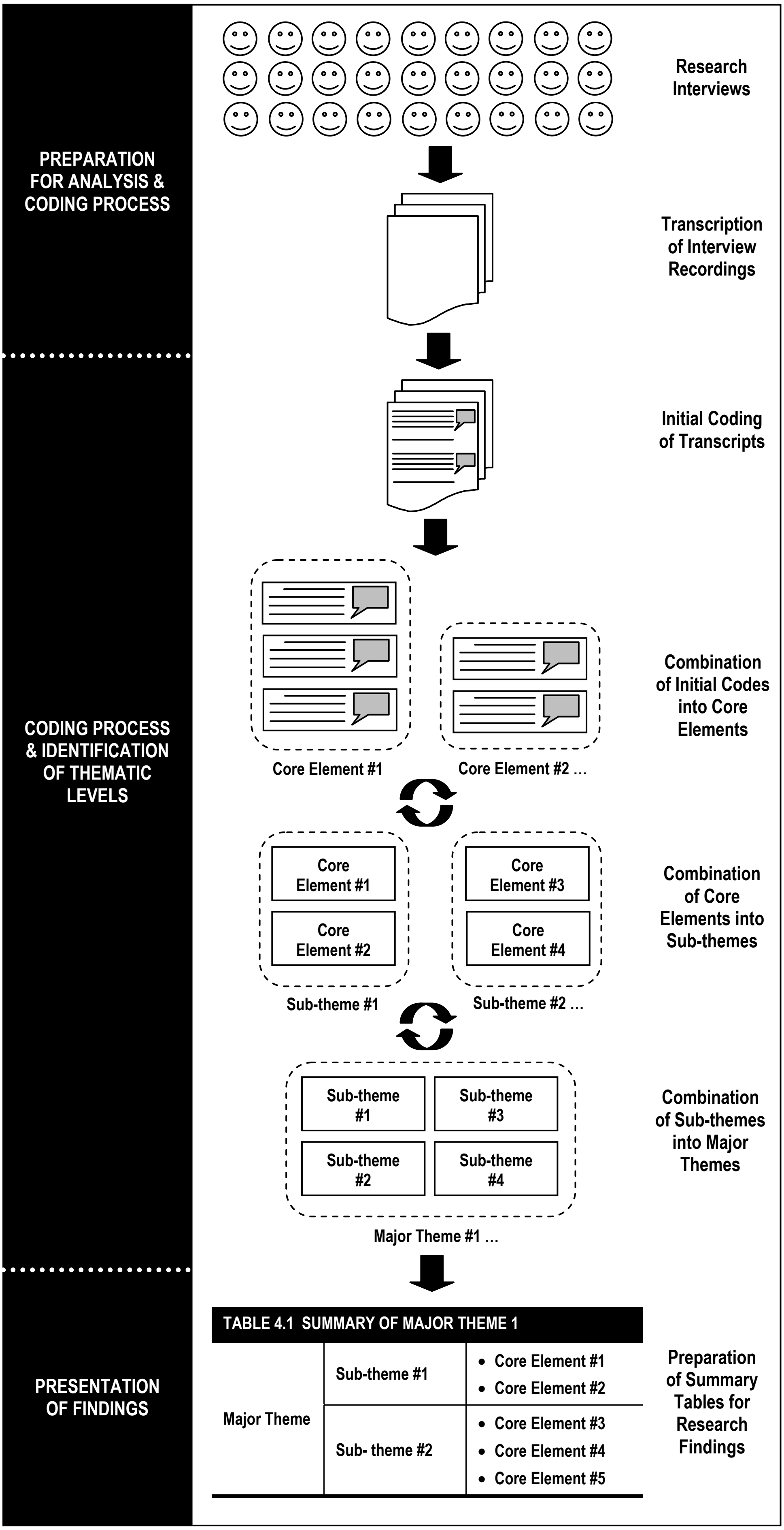


TABLE 4.1 SUMMARY OF MAJOR THEME 1

Major Theme	Sub-theme #1	• Core Element #1 • Core Element #2
	Sub- theme #2	• Core Element #3 • Core Element #4 • Core Element #5

Figure 3.1. Summary of Coding Process.

3.14 Review Process

As part of the informed consent for the research interviews, participants were informed they would have an opportunity to review the thesis prior to its completion and publication by the University of Liverpool. This was perceived to bolster the candor and transparency of responses during the interviews since participants understood they would have an opportunity to evaluate the excerpts and overall essence drawn from their lived experiences. The opportunity to review and validate the data interpretation is consistent with steps commonly pursued in qualitative research and, in particular, phenomenological analysis (Hammill and Sinclair, 2010, p. 20). The participants received an electronic copy of the draft study in November 2014 and were asked to review the document to ensure the thesis was an accurate representation of their responses, the context in which the responses were framed and the overall depiction of the phenomenon. The review process also provided an opportunity for participants to see the manner in which their responses to the interview questions and personal examples were de-identified. Research participants were asked to contact the principal researcher with any suggested changes. Because no personal identifiers were included in the research findings and interview excerpts, the ultimate authority to make revisions of the study remained the discretion of the researcher. In total, more than one-third of the research participants provided written feedback to the principal researcher (see Chapter 5: Discussion for more information and excerpts from the feedback that was offered).

3.15 Summary of the Methodology

Ultimately, the selection of the research methodology and design of the Pediatric Palliative Care Study align with recommended practices for IPA studies and are documented in Chapter 3: Methodology in order to create a "decision trail" or audit process that can be followed by those seeking to validate the rigor and quality of the study (Pringle et al, 2011a, p. 23). One of the most important measures of rigor and validity for an IPA study is whether "the account produced is *a* credible one, not the *only* credible one" [emphasis added] (Smith et al, 2009). In this regard, the research findings emerging from application of the IPA methodology aim to reveal the lived experience and overall essence of the phenomenon by remaining attentive to the words and first-hand encounters of research participants so that a coherent, legitimate account that resonates with scholars and practitioners can be proffered (Pringle et al, 2011a, p. 23-24).

CHAPTER 4

Research Findings

"If it's good research, you're just collecting what's there. You're asking in the right sorts of ways to collect what's there and look at it, so it's great that you have several different people from the team, different influences, different reasonings, getting back to the child. I've been interviewed often, more and more, but you see the difference here is I trust that reasoning … it's the story, it's the heart. Because there's more and more people beginning research, but it's for the "stuff" … that's important, believe me. But with palliative care with children, there's something sacred that you can't divide them. You cannot. It just doesn't happen."

~ Pediatric Palliative Care Community Liaison

During the last 20 years, the overall utilization and popularity of interpretative phenomenological analysis (IPA) has grown (Smith et al, 2009), with health care professionals recognizing the value of IPA to "understand[] healthcare and illness from the patient or service user perspective" (Biggerstaff and Thompson, 2008, p. 214) and serve as witness to the experiences of research participants (Barbour, 2007). According to van Manen (1990, p. 62), the research findings of phenomenological studies are intended to describe "other people's experiences and their reflections on their experience in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience". To more fully understand the experience, one of the differentiating factors of IPA in comparison to other research methodologies is the use of direct quotations from research participants to validate the findings and offer poignant insights into the lived experience (Pringle et al, 2011a, p. 22). In this manner, IPA illuminates "'the wholeness and uniqueness of the individual' with the aim of giving a complete and in-depth picture" of the lived experience (Pringle et al, 2011a, p. 21, quoting Malim et al (1992)).

The following research findings for the Pediatric Palliative Care Study are designed to allow scholars and practitioners to become immersed in the lived experience of caring for a child with a life-limiting condition, while simultaneously gaining insights into the overarching needs of these children and their families. In total, nine major themes emerged from the lived experiences of care providers who participated in the study, including: (1) Develop an innovative approach to caring for me, (2) Place me at the center of care, (3) Care for me as a whole person, (4) Be my guide, (5) Educate and prepare me for what I need to know, (6) Come alongside me, (7) Cultivate the plan and purpose for my life, (8) Be my voice and help me find my own and (9) Help me thrive. The titles of the major themes have been composed with the voice of the child and family in mind, as framing the thematic titles from their perspective complements the aims of interpretative phenomenology by characterizing the analysis in words they may use (Pringle et al, 2011a, p. 21). The study seeks to offer tangible insights into the lived experience and present the palliative care needs of children and their families, so the major themes underscore the importance of scholars and practitioners looking through the eyes of children who are battling a life-limiting condition and the families who are caring for them.

In alignment with the data analysis (see Chapter 3: Methodology), the research findings focus on telling the story of the phenomenon by delving into the meaning of the core elements, sub-themes and major themes. Throughout the chapter, the description for each major theme is supported by a summary table of the sub-themes and core elements that serve as building blocks for the theme. The summary tables provide transparency into the details drawn from the research interviews and data analysis, which led to the identification of the major themes. In addition, each major theme is bolstered by illustrative quotations from the research interviews in order to continue bringing the voice of the pediatric palliative care providers and their experiences with the families to the forefront of the research. The quotations from the care providers aim to capture the richness of the lived experience in a manner that cannot be conveyed or fully appreciated through descriptive summaries of the themes alone.

4.1 Major Theme 1: Develop an Innovative Approach to Caring for Me

When the personal examples of pediatric palliative care providers are aggregated, they reveal caring for children with life-limiting conditions and their families is far from traditional or routine health care. In truth, pediatric palliative care elicits novel considerations surrounding the overall scope and location of care, as well as the role of an interdisciplinary care team and partner organizations, which can be considered unique and innovative in comparison to other forms of conventional health care services. Therefore, the first major theme to emerge from the research reflects a calling by children and families to “Develop an innovative approach to caring for me” (see Table 4.1).

TABLE 4.1 SUMMARY OF MAJOR THEME 1: DEVELOP AN INNOVATIVE APPROACH TO CARING FOR ME

Major Theme	Sub-theme	Core Elements
Develop an innovative approach to caring for me	Scope of care	• Care for child and family • Care for extended family
	Location of care	• Home-based care • Minimized care outside home • 24-7 support
	Interdisciplinary care team & partner organizations	• Interdisciplinary care team approach • Partnership with referring providers • Partnership with acute care providers • Partnership with primary care providers • Partnership with other community resources

The optimal manner in which to care for these children differs from standard health care solutions, beginning with the need for a distinctive scope of care since innumerable lives are touched through the life and death of the child. As a result, the “patient” for pediatric palliative care includes the combination of the child and family,[9] with care encircling the family as a single unit due to the breadth of issues that must be addressed. Acknowledging the scope of care as inclusive of the child and family aligns with the WHO definition of pediatric palliative care, which highlights this nuance as a fundamental difference in comparison to services for adults (WHO, 2013). Beyond the immediate family, the role of the extended family also reinforces the imperative for innovative solutions about how best to care for an expanded complement of individuals and groups who are connected to the child, including those involved in the child's care or acting in support of family members. Indeed, when children have a health care diagnosis that may not yield long-term survival, family and extended family members yearn for palliative care solutions that are cognizant of their preferences for the scope of care they would like to receive and reflective of the role they must serve in caring for the child.

> A family is a unit, and it's not just the patient. The patient is the family, and the family is the patient. That's pediatrics for you, though. That's just the way that pediatrics works a lot of times. The whole family revolves around the patient. The complex kiddo is the hub of the wheel that the whole family's life revolves around, so when a kiddo dies in that situation, the whole family's life has been centered on that one person. What are you going to do? It's always in the background or the forefront of your mind.
>
> Nurse

Furthermore, while pediatric palliative care can be provided in acute, ambulatory or continuing care settings, many children and families express a preference for being at home. Their partiality toward receiving care in the home necessitates innovative solutions for ensuring the appropriate level of care and continual support can be made available in the location most desired by families. A decade ago, the notion of offering palliative care in a home-based setting would have been deemed unfeasible in the minds of many health care providers. However, ongoing advances in home-based care have made the provision of complex care and treatment viable for the majority of children, as opposed to limiting such care to hospitals (Samwell, 2012, p. 14). Aside from aligning with family goals or personal preferences, home-based care also allows care providers to understand how families operate in their own space, which can proffer beneficial insights into critical needs that may not be discerned in an acute care setting.

> You're in their space, rather than they're in your space. Right away, you're meeting them on the terms where they live life every day. You see where the patient's bed is at or if they have a bed or if they're in the middle of the living room. You see how things function or if there are healthy kids in the home and how they interact, when they go off to school and how the family functions. When you start to see a family, you're able to know and help a family in that context. You're able to provide something that doesn't exist at all if the patient is seen in the hospital.
>
> Nurse

---

[9] For the purpose of this research study, a distinction is drawn between "family" and "extended family." The family refers to the immediate family (e.g. parent(s) / legal guardian(s)), while the extended family is inclusive of non-immediate family members (e.g. grandparents, other relatives). Alternative family arrangements and cultural differences add complexity to the definition of family, as members of an extended family or non-family members may be present in the home. However, it is necessary to separate the immediate and non-immediate family members due to the differences in legal authority for health care decision-making for the child.

For families caring for children with life-limiting conditions, the ability to reduce the frequency with which health care services must be sought outside the home remains tantamount to success and promotes stability for the child and family as a whole. In many instances, the home-based setting affords children the greatest opportunity to thrive, as they are surrounded by things that are familiar and comfortable. Nonetheless, without continual support from care providers who can offer in-home care and medical assessments, families are more apt to seek care from emergency rooms, hospitals or other external care settings. In this manner, pediatric palliative care offers an innovative solution to help children maintain a healthier state since care providers can see families and children on a frequent basis, and regularly scheduled visits can be supplemented by on-call and telephonic support that is available 24 hours a day, seven days a week. The constant support afforded to families offers an innovative solution to caring for their child safely, confidently and effectively at home. Based on provider experiences, the steady support serves as a safety net and comfort for families who can contact the palliative care team for assistance, request urgent home visits, discuss symptom or condition changes, receive guidance in administering medications or treatments, and more.

> [The mother] said that since Carousel has been involved in the home, [the child] rarely has to go to the hospital or the emergency room; he just has to go for appointments. That stability in their family has allowed them to really focus on the other kids and just keep him comfortable and at ease at home and how important that is to the family health.
>
> Social Worker

Moreover, pediatric palliative care reflects a complementary partnership between interdisciplinary palliative care team members,[10] as well as external organizations and medical providers, with the majority of referrals coming from acute care providers. Each family situation is unique and may evolve as the child's condition or home environment changes, so the construct of the interdisciplinary team typifies an innovative yet highly effective approach for managing the changing dynamics. Working with an interdisciplinary focus, palliative care providers break down the traditional silos of their individual disciplines and combine their expertise to care for children and families in a seamless fashion.[11] Nevertheless, recognizing they cannot care for children and families in isolation, palliative care providers also work in partnership with referring providers, primary care and acute care providers, and other community resources to ensure children and families receive the care necessitated by each step of their journey.

---

[10] According to Jessup (2007, p. 330-331), a distinction can be drawn between interdisciplinary versus multidisciplinary team approaches, with the former reflecting an integration of team member disciplines into a holistic approach for patient-centered care; by comparison, multidisciplinary care teams reflect individuals from various disciplines involved in caring for the patient, but often separate from one another. While pediatric palliative care teams can operate from an interdisciplinary or multidisciplinary perspective, the aim remains for teams to become interdisciplinary in their approach to care.

[11] The composition of the pediatric palliative care team varies by program, with the most common roles including physicians, nurses, social workers and chaplains. Other members may include, but are not limited to, community liaisons, nurse practitioners or ancillary resources dedicated to pediatric palliative care (e.g. pharmacy, nutrition).

Without a referral, many families would remain unaware of pediatric palliative care and the benefits it can offer, which can promulgate drawbacks for the child and family. For example, families who are not receiving palliative care often must travel to physician offices for routine health checks or medication management appointments, which are no simple feat since children may be difficult to transport and appointments can be disruptive to daily family routines. By comparison, when pediatric palliative care providers serve as an extension of primary care providers and perform aspects of routine care in the home, they can restore balance to the family and minimize the volume of care that must be sought outside the home. Upon reflection of their experiences, providers also note the role of the broader community that surrounds the children and families. To thrive at home, families often need assistance from resources beyond the palliative care team, including schools, community agencies, mortuaries and other local resources. Caring for children with life-limiting conditions espouses the necessity for innovative palliative care solutions that acknowledge the breadth of issues that must be addressed, which are atypical in comparison to families who do not have children with these diagnoses.

> So now what do you have to teach in the community? All the mortuaries. Now they have to understand what to do with the death of a child because they're used to going to the hospital and picking somebody up from the morgue. So the two people driving this car – a younger man and an older man – they got [to the family's house]. They had been told it was a child. They said to me, "We don't know if we can do this …". Serious. And here we have mom and dad and the baby. Okay, so now we have to work that out so that their memories and the lives of these two people in the van are impacted. One of them [from the mortuary] consented to hold the child. So there's all of that of now what we do for families. They took her little body and made arrangements that they were going to have a memorial next week.
>
> Community Liaison

In total, the scope of care, location of care and role of the interdisciplinary pediatric palliative care team and partner organizations reflect the core building blocks necessitated by caring for children with life-limiting conditions and their families. Overall, these facets form a foundation for addressing how they would prefer to receive care in an innovative manner that differs from traditional health care services.

4.2 Major Theme 2: Place Me at the Center of Care

Building on the concept that pediatric palliative care should be innovative and adopt a distinctive approach that is differentiated from traditional health care delivery models, the second major theme to emerge from the lived experiences of care providers can be framed as an appeal to "Place me at the center of care" (see Table 4.2). The theme represents an innate plea from children and families to care for them in a manner that is informed by their individual qualities and preferences. To answer the call, pediatric palliative care is most effective when it reflects the children and families who are being served, rather than positioning the health care delivery system itself as the central focus with families being asked to access standard services that are being offered.

TABLE 4.2 SUMMARY OF MAJOR THEME 2: PLACE ME AT THE CENTER OF CARE

Major Theme	Sub-theme	Core Elements
Place me at the center of care	Individuality of family	• Family norms • Cultural diversity & customs • Spiritual diversity & customs • Care in own language
	Child-led care	• Prioritizing the child • Presence with child • Child independence • Helping child go home • Involving child in care • Child preferences for pain management • Answering questions for child • Listening to child • Discussions about illness & death • Fulfillment of last wishes
	Family-directed approach to care	• Individualized care plan • Customized frequency of home visits • Customized team member involvement • Flexibility of visit design • Preferences for medication usage • Medical treatment decision-making • DNR / POLST decision-making

Pediatric palliative care is not focused myopically on “one size fits all” but rather “one size fits one”, as no two families are identical in their orientation toward life, death and the provision of health care services. They want care to reflect who they are, what they believe and how they want to care for their child, which is informed by their family norms, cultural and spiritual diversity, as well as the desire to receive care in their own language. When care is approached with an individual family in mind, it represents a crucial step toward ensuring the child and family are positioned at the center of care and respects that families differ from one another. Upon reflection, the need for a particular health care service – in this case, pediatric palliative care – does not define a family, but rather the family maintains the pivotal role in delineating their individual desires and how they envision caring for their child. In this manner, a conscious effort occurs in building appropriate services around each family, rather than expecting families to fit themselves into a pre-designed health care system that may not reflect their individuality.

For example, the experiences of care providers reveal learning about family norms is essential; these norms include the values, customs, characteristics and behaviors that define how a family operates on a daily basis. The efforts to learn about family norms help care providers understand who they are placing at the center of care. Similarly, attention must be paid to understanding the family from a holistic standpoint of what they draw from their spiritual or religious traditions if such factors exist. The spiritual or faith-based traditions of a child or family can influence preferences for pain management, dietary restrictions, modesty of dress, beliefs about life-sustaining treatment and other nuances of care. A family's values, beliefs and customs also may be informed to a nominal or significant extent by cultural or ethnic heritage. Cultural differences may influence communication styles, gender-based acceptance of care providers and other factors, so the ability to understand cultural diversity can inform the degree to which care providers are able to partner with families in customizing pediatric palliative care to align with their customs. Finally, when placing children and families at the center of care, consideration must be paid to providing care in their own language, as opposed to asking them to receive care in a language they do not fully understand. Language barriers can impede the ability of a family to grasp information shared by health care providers and add stress to the ability to make informed decisions in the care of their child, whereas providing care in one's own language can remove obstacles and allow providers to forge strong working relationships with children and families.

> I'm Hispanic; I came from Cuba to this country when I was nine years old. I am really satisfied that I'm able to help my people, my community, even if they might not be Cuban, even if they're from Mexico or wherever, I feel like they're my people. With Hispanic people, their culture is so different. I think I'm able to connect with that. I can see where they're coming from. They have a lot of taboos and things, and I'm able to understand that. I think it makes a big difference.
>
> Nurse

Next, care providers underscore the need for child-led care to the extent that is feasible based on the child's age, developmental and cognitive ability in order to keep the voice of the child central to the aims of palliative care. While parent(s) or guardian(s) have the legal authority to serve as health care decision-makers, children remain the focal point for the palliative care team when entering a home, with children being given the opportunity to see and feel that they are being treated as the primary concern. For example, children desire to have people serve as witnesses to their personal experience of battling a life-limiting condition. In this sense, being present with children as a witness and prioritizing their needs means being fully in the moment, whether in silence or vocal support in relation to what is happening at that time. During these moments, care providers join children at the center of care to see the experience and effects of the illness through their eyes, as opposed to making assumptions about what the experience is like for the child.

> We had this 19-year-old girl who was told in September that she had Stage 4 cancer – a rare one. We were there last week with her, and she thought her chemo was going into her for four days. She has a pump at home, and she was lying at home and feeling awful. We get there and find out that she hasn't had any chemo; the chemo was never on, so it wasn't going into her. The devastation in her at that moment that she found out was huge. We allowed her to have that – the nurse and I – and we just normalized the feelings of disappointment, the anger that she expressed and all these things to us. There were long periods of quiet, too. Okay, wow, so we just sat there and we said to her, "You know, this is really difficult we know, but we're here for you."

> Then to see her face look up – because it was down a lot – and to look up, smile and say, "I know." ... She had all this hope … has a lot of hope, but what it represented to her was that, "The chemo wasn't working, but I'm getting forgetful. I'm extremely fatigued. I am all these things, so it must be the tumor because the chemo's not in me to cause all of this." We saw how this is all going on in her brain all at once. "Okay. Oh, my God. This must be the tumor, not the chemo. Oh, my God, I'm so angry right now because [the hospital] sent me home with a pump that wasn't on, and I've been lying in bed for four days, and now I have to go through this all over again." Then for her to look up and smile when she hears how difficult it is and that we're here for you, that was just huge.
>
> Social Worker

One of the most common challenges experienced by children is the change in independence they have enjoyed or would have experienced in life as a healthy child. Common childhood activities may be usurped by physical limitations, uncomfortable tests and treatments, frequent medical appointments, hospitalizations or invasive procedures. Nonetheless, independence can be bolstered by offering suitable avenues for children to exercise control, have choices and feel empowered to make decisions in their life, as opposed to taking action on their own accord to the detriment of their health. For example, when children are positioned at the center of care, palliative care providers report common ways to promote child-led care and appropriate independence include supporting the location where children want to receive care. Reflecting on their personal experiences, palliative care providers recounted examples of children who voiced a personal goal to their parents, palliative care team or other providers to transition home, which aligns with the preferences surrounding the location of care in Major Theme 1. In addition, the care team seeks to listen, understand and support children's preferences for pain management, how they want to feel on a daily basis and symptoms they want to tolerate in lieu of taking additional medication. In some situations, this includes advocating for the preferences of the children with other health care providers or family members so their voice is heard. Similar to longing for independence, children also often desire to adopt a hands-on role in their care, as this involvement bolsters feelings of personal control and accountability for the state of their health.

> I had one patient that I took care of. She was turning five, or she was six years old. It was last year. She had a tumor in her liver, but they didn't diagnose her until later because it wasn't hurting her … When I have to change her PICC line, she would direct me how to clean. "No, not there. I'm not done yet. Wait for me." "Okay, okay, I'll wait for you" and then she would slowly, slowly remove her Tegaderm™, and she would clean from the inside to the outside, circling, and paint a little bit on the side like this. It takes about 30 minutes for her to change, but she would not let anybody do it. She has to do it. So she did it, and she would even introduce our social worker, Henry.[12] "Henry, you hold this part, and I do this part," so the whole team is involved in changing her PICC line dressing.
>
> Nurse

---

[12] Pseudonym.

As the relationship grows between children and palliative care providers, the depth and intimacy of the child-led care may expand to encompass a role for providers as trusted partners who will listen, learn about the things that are most important and address the deepest fears and questions of children in a truthful manner. The role of answering questions about their diagnosis or prognosis, medical treatments or issues they may feel uncomfortable broaching with their families represents a critical facet of understanding the top-of-mind matters for children, which must be prioritized in the plan of care in order to keep their wishes central to the actions that are pursued. The care provider experiences reveal children often seek someone who can serve as a sounding board and respond to their questions with honesty and transparency. On a related note, by listening to children, substantial details are revealed about how they are experiencing their condition and the type of care experience they wish to have. One of the more challenging dynamics of caring for children, especially for some family members, is being part of discussions about their illness and imminent death. Care providers, family members or other participants must remain open to engaging in the dialogue children want to have, as opposed to shying away or dismissing the desire of children to talk about their illness and end-of-life. Listening and talking to children about their last wishes also is important, with efforts made to fulfill their last wishes, whether these are personal wishes for themselves or wishes for others (e.g. parents, siblings, friends). The last wishes represent one of the final conduits for children to write the closing chapter of their life and feel in control of the events that are taking place. Often times, the fulfillment of last wishes involve partnerships between the family, pediatric palliative care team and other community resources.

> He had specific things he wanted to do. He wanted to take his family to Wolfgang Puck. He wanted to buy gifts for his immediate family and his best friend. There was money from Make-a-Wish® that was helping him with that. He wanted to be at home in his living room in his dad’s recliner. So specific. I remember reading all of his stuff and at this time, it was hard to get the team under the mentality of "Don’t say ‘no’, say ‘how can we?’" because it was scary. I have always had a mentality of if the family’s in it and they’re vested and this is really important to them, how do we make this happen? This was one of those kids. How do we make this happen?
>
> Nurse

Next, even when faced with the complexity and inherent challenges of caring for their child, families desire to adopt a family-directed approach to care that begins with an individualized care plan. The plan is not colored by goals of the palliative care providers but rather serves as the *family’s* plan of care; it builds on the notion of pediatric palliative care being “one size fits one”. The plan empowers families by providing a tangible way to articulate and document the most important priorities so they can be referenced by the care team and other providers. Within the plan of care, families inform the timing and frequency of home visits and can increase or decrease the visits based on their needs. In many ways, placing the decision about visits into the hands of the family allows them to maintain control of their household, without feeling as though the visits are an intrusion into their personal space or an unwanted disruption. Conversely, if children and families were not held at the center of care, the tendency could be for health care providers to structure in-home visits to fit conveniently with their schedule instead of focusing on when and how often the family wants to receive care. Within a family-directed approach to care, families also may accept or decline the services of care providers at any time, with the exception of some nursing and social work visitations that are compulsory for insurance companies to maintain the palliative care status of the child. The control remains in the hands of the family as to whom they will permit into the home and the type of services they wish to accept from each care provider. By and large, palliative care team member experiences demonstrate an open agenda for home visits that is guided by the priorities, concerns or issues of the family at that particular time. The flexible visit design allows families to guide how they wish to experience pediatric palliative care and the extent to which it becomes a facet of their life, thus positioning the family at the center of care.

> I never know what I'm going to get into. Once you get in there, they may be at a space where they're ready to talk about something big, or they may be in a space where they are playing and running around the room and they're like, "We love that you came over and met with us, but if you can just check our meds, you can check and then be gone, that's cool, too." And I'm like, "Great, let's do it" and I'm out of there. It just kind of depends. I don't ever try to go in with any certain expectations.
>
> Nurse

Families also want to voice preferences for medication usage and pain management goals, which must be considered in relation to preferences voiced by children. Medication usage may be informed by spiritual beliefs, preferences for natural or homeopathic approaches, or acceptance of pharmaceutical interventions. Regardless of their views, such preferences vary by family and must be approached on an individual basis. In addition, informed decision-making about medical treatments must be made by families, rather than exclusively by the palliative care team or other providers. The family is placed at the center of care when they are informed of medical treatment options, including the benefits, risks and alternatives. With this information in hand, families can make informed decisions about how aggressively they wish to pursue treatment or if treatment options conflict with goals for the child's life. This includes decisions pertaining to DNR (Do Not Resuscitate) and POLST (Physician Orders for Life-Sustaining Treatment). While the palliative care team or providers can broach the subject of DNR and POLST decisions, families remain at the center of care in terms of their personal timetable for discussing, adopting or declining to make these decisions.

> I need to make sure that once that child is safely tucked into God's arms that they're going to go forward feeling really good about how they parented their child during this horrible time and really believe that they were the best parents they could possibly be. What I think is of no importance. My job is to educate, guide, offer options and support the family in their journey, no matter how long or short it is or how much I agree or disagree with it. I think if you do that well in this work, really any work in health care, that you've achieved the most important objectives for the child and for the family.
>
> Nurse

Overall, by placing children and families at the center of care, the emerging specialty of pediatric palliative care demonstrates an unparalleled attentiveness to upholding the individuality of the family and the desire for child-led and family-directed care as pivotal priorities. The reflection of the child and family at the center of palliative care shifts the focus of service delivery to be most concerned about the "patient" – the child and family, their needs and their personal experiences, rather than the provision of health care services, care team preferences or even external care delivery settings as the focal point.

4.3 Major Theme 3: Care for Me as a Whole Person

The third major theme to be derived from the lived experiences of pediatric palliative care team members reflects a petition by children and families to "Care for me as a whole person" (See Table 4.3). Rather than defining and caring for a person in parts, such as adopting a limited focus on a medical diagnosis or symptom of suffering, whole person care epitomizes that a child and family must be viewed in totality as the sum of their parts with an approach to palliative care that addresses their needs in a holistic manner. Therefore, the totality of care that is required spans their basic needs, as well as their physical, medical, emotional, psychosocial, spiritual and end-of-life care, with a hierarchical construct being present within the dimensions of whole person care.

TABLE 4.3 SUMMARY OF MAJOR THEME 3: CARE FOR ME AS A WHOLE PERSON

Major Theme	Sub-theme	Core Elements
Care for me as a whole person	Basic needs	• Food • Safety • Shelter • Electricity & utilities • Compounded basic needs • Poverty & socioeconomic status
	Physical & medical care	• Perinatal care • Physical assessment • Routine medical care • Pain & symptom management • Medication changes & management • Comfort care • Crisis management
	Emotional & psychosocial care	• Parental / family emotional support • Child emotional support • Sibling emotional support • Counseling & therapy • Grief & bereavement support • Psychosocial support • Addressing isolation • Ability to cope
	Spiritual care	• Individualized spiritual support • Connections to spiritual traditions • Faith-based questions • Prayers & blessings
	End-of-life care	• Acceptance of end-of-life • Proactive end-of-life preparations • Presence during end-of-life journey • Validation of end-of-life • Child's recognition of end-of-life • Emotional support through end-of-life • Support for end-of-life decision-making • Sacred space for goodbyes • Death visits • Feelings of abandonment

Traditionally, holistic care has typified a mind-body-soul approach of caring for the physical, emotional and spiritual needs of a child and family. While these elements are vital in whole person care, a fourth dimension related to life-sustaining, physiological needs is even more fundamental. Without first focusing on the basic needs of food, safety, shelter, utilities and the effects of poverty, more conventional elements of caring for a whole person cannot be addressed successfully by care providers.[13] Regrettably, families rarely struggle with a single basic need but rather tend to have multiple unmet needs that inhibit the ability to care for their child at home. When confronted by compounded basic needs, families face difficulties in partnering with providers to focus on the palliative care needs of their child and family. Overall, the extensive list of unmet basic needs offers evidence of the disproportionate share of families living in poverty, either due to their socioeconomic status prior to the child's illness or poverty that is generated as a result of the child's diagnosis. To be expected, it becomes difficult for families to have two parents working outside the home since one parent often must remain at home to care for the child. Due to the corresponding decrease in household income and increase in health care expenditures, it is not atypical for families to face bankruptcy or challenges with subsisting on limited public assistance. In such situations, palliative care providers play a pivotal role in recognizing the day-to-day challenges faced by the household that may be concealed from other health care providers and prioritizing the basic needs before commencing with the customary aspects of palliative care.

> I have to remember the concrete things that are important. You can be providing wonderful support but if the family doesn't have enough money to put food on the table, pay rent and all those resources, that's an important thing to make sure to be aware of.
>
> Social Worker

Within a hierarchy of needs, once the life-sustaining basic needs and implications of poverty are addressed, care providers reveal the ability to shift their focus to traditional elements of whole person care, including the physical or medical needs of the child. Physical or medical care includes health care services that can be provided to children as an extension of the medical care offered in other care settings. The provision of pediatric palliative care establishes a routine frequency for the total number of times a child is seen by a health care professional, which can contribute to proactive identification of potential problems and the increased ability to maintain a child's health for a longer period of time without needing to seek care outside the home. In some instances, palliative care providers may begin partnering with a family who is expecting a child with a life-limiting condition so early preparations can be taken to address the health care needs in the perinatal period before, during and after the child is born. Once a child is home from the hospital, the conventional physical or medical care offered by palliative care providers includes physical assessments during each home visit,

---

[13] Based on the lived experiences of pediatric palliative care providers, unmet basic needs are prevalent in many households where families are caring for children with life-limiting conditions. For example, a family may face hunger or the inability to provide sufficient food for their household, leading care providers to focus, first and foremost, on urgent needs to ensure the child and family is fed. Other families encounter issues with ensuring safety and security in their household, such as providing a home that is free of violence. The challenges generated by caring for a child can serve as a catalyst to escalate conflicts between family members, siblings and others who are present, with some situations threatening the safety of the home. Moreover, care providers find shelter is a concern for families, both in terms of finding an appropriate place to live and being able to pay for their rent or mortgage. The housing requirements can be complicated by the child's needs, such as having sufficient space for a hospital bed, medical equipment or other items needed to care for the child at home. Finally, the ability to maintain utilities in their household, including electricity, water, sewer and garbage service, also is found at the crux of problems for some families. The experiences of palliative care team members demonstrate electricity is most critical utility, given the medical devices needed to care for the child in the home.

which may be called nursing assessments, head-to-toe assessments or a similar term. The assessments reflect an organized, systematic approach to evaluating the child's health, informing the family of the findings and discussing implications for the plan of care.

> In my role as nurse, very frequently, they look forward to me looking at them and saying, "Everything sounds fine." As soon as I take the stethoscope out of my ears, they look at me and I say, "Everything sounds fine. I don't hear any changes." "Whew …". You can see them relax because so often, remember, they're getting seen by a physician every single day in the hospital who comes and listens to their chest. They've come to recognize that brief assessment as sort of the harbinger of doom, so if you say to them, "Everything sounds fine", they need that from you.
>
> Nurse

Within the home, clinical members of the palliative care team also provide routine medical care, such as skin and wound care assessments, dressing changes and other basic medical care that may be beyond the ability of the family to address on their own and that would otherwise need to be provided in a health care setting outside the home. While health care professionals define this type of care as "routine", families who find themselves caring for a child with a life-limiting condition are commonly overwhelmed in the initial stages by the level of care necessitated by their child's condition. When enough time passes, the high degree of physical and medical care in the home becomes their new normal or baseline. In many instances, routine medical care is closely intertwined with other physical and medical priorities voiced by families to keep their child as comfortable as possible, which may encompass requests for assistance with pain and symptom management, medication changes and overall comfort care.

Children who are receiving pediatric palliative care are commonly prescribed multiple medications for their medical diagnosis, pain management or symptom control. Within the hierarchy of addressing whole person needs, pain and symptom management are commonly viewed as prerequisites before other facets of caring for the child and family can be addressed in an effective manner, such as their emotional or spiritual needs. Therefore, palliative care providers serve in a critical capacity to identify, prescribe and monitor the use of medications or other treatments, which build on the preferences of the child and family for medication usage (see Major Theme 2). Due to ongoing changes in the child's health that often necessitate medication changes, providers also lend expertise by monitoring the medications a child is taking, tracking compliance issues, addressing dosage changes, watching for medication interactions or other factors.

Even with a steadfast focus on the regular medications needed by the child, families and palliative care providers encounter some days when those medications and routine medical care are not enough. Because a child's illness can progress or change with insufficient warning, emerging needs may surface for comfort care, which includes providing a "comfort kit" in the family home that contains additional medications and tools that can be used to make a child comfortable. Often times, utilization of the comfort kit is connected to the need for crisis management, which is commonplace for children with life-limiting conditions. Crisis management can encompass unscheduled visits to a family home to address out-of-control symptoms or a change in the child's condition, such as when the child transitions to become actively dying. With effective crisis management from a pediatric palliative care team, families can care for their child at home or receive expert guidance as to when care should be sought from a higher acuity facility.

> From the nursing aspect, the other thing is attempting to reduce emergency visits and last-minute visits by being able to have nursing assessments in the home and coordinating with the physicians in order to prevent children having to go in for emergency treatment.
>
> Nurse

Apart from basic needs and physical or medical care, the third facet of caring for the child and family as a whole person includes emotional and psychosocial care. This comprises a comprehensive array of services, therapy and support to address the feelings, stressors and emotional factors that arise in the life of the child, family and siblings, as applicable. As a starting point, families require support to address the emotions they are experiencing due to having a child with a life-limiting condition. Feelings of grief, anger, sadness, anxiety, guilt and depression are commonplace among parents. Emotional support also spans the unique needs of siblings, which may necessitate different forms of help than that which is rendered to parents or the child who is ill. Typically, siblings feel a range of emotions surrounding what is taking place in the life of their brother or sister or the changes in the family home, yet siblings can become overlooked in the fervor to address other emergent issues. While not the case in every situation, the emotional response of siblings can manifest in detrimental ways, such as depression, behavior problems or physical aggression. Therefore, the ability to offer emotional support to siblings or connect families with resources focused on sibling support is a crucial but sometimes underestimated need within palliative care. Finally, children who have life-limiting conditions also require emotional support in order to be cared for as a whole person. The emotional response of a child depends on age, developmental and cognitive ability, with teenagers often requiring the greatest emotional support due to their ability to verbalize the milestones they will miss because of their illness and shortened life, including graduating from high school, getting married, having children and other facets of adulthood that will not be realized. In these situations, children may need care providers to normalize the feelings, explore the emotional issues and provide unconditional support.

> She had some angry feelings. She said, "Gosh, I just have so much anger, you know." She said, "My mom brought in some food today, and it wasn't warm enough, and I flipped the whole tray, just flipped it. I was so mad. I just have these feelings, these angry feelings," so we talked for an hour about her feelings and her emotions. She said, "I feel like I'm not strong enough. Sometimes I feel like I'm strong, and sometimes I feel like I'm not strong enough." I said, "Well, who says you have to be strong?" Just talking about emotions is such a crucial part of what we do; it's essential.
>
> Nurse

From a standpoint of practical application, the emotional support offered to the child, family and siblings may include professional counseling and therapy to address the emotional issues, conflicts or challenges that can become exacerbated by their present situation. Depending on the needs of the family, the palliative care team may lead the counseling or partner with external resources. Furthermore, emotional and psychosocial care may include grief and bereavement support, including proactive support when families are facing the shortened life and anticipated death of a child. Addressing anticipatory grief before the loss of the child can be as equally important as providing bereavement support after the child has died. Due to the age of children who are receiving palliative care, grief and bereavement support is most often directed to the family or siblings. Nonetheless, care should be taken not to overlook or take for granted the anticipatory grief felt by the child in recognition of their own mortality.

The lived experiences of care providers also demonstrate the extent to which families yearn for psychosocial support, which includes non-therapeutic interventions to help a child and family cope with stressors or become connected with additional services that can help them address needs that are related to psychological and social factors. At a more granular level, families experience feelings of isolation that can drive the need for additional emotional and psychosocial care. Caring for a child with a severe health care condition can limit the ability of a family to leave home, travel with ease or participate in routine social activities. In turn, isolation can prompt parents to feel like they are walking the journey by themselves or living in seclusion. Addressing isolation comes in the form of support designed to help children and families feel like they are not alone or to concentrate on challenges that arise from feeling separated from others. Apart from isolation, families also struggle with the ability to cope with caring for their child through the end-of-life. However, developing coping skills from the perspective of caring for the whole person underscores the benefits of looking for the extent to which families can increase their ability to cope by finding holistic solutions that draw from physical, emotional and spiritual perspectives.

> I think probably the hardest thing is still struggling with the fact that they will be losing their child. They may understand, but we always want it not to be. The fact is that no matter what, it’s going to be hard, which is a different kind of hard than working with the adult population because it isn’t supposed to be happening.
>
> Social Worker

Next, spiritual care represents the fourth aspect of providing whole person care, which comprises comprehensive support to help the child and family address spiritual issues, draw assurances from their faith-based views or partake in traditions of spiritual importance, such as prayers, blessings, anointings and baptisms. The spiritual care that is offered builds upon the individuality of the family in terms of the spiritual diversity and customs of the household (see Major Theme 2). Of note, children and families express the level of support should remain flexible as their spiritual needs evolve. For example, key turning points in the child’s condition may prompt families to place a greater focus on their spiritual needs. The spiritual care sought by children and families also may build connections to their spiritual or religious traditions in order to help them draw answers from faith-based or spiritual beliefs that bring them comfort. In some situations, families may turn to prayer or express a desire to maintain hope for the child's recovery, as these actions are aligned with their spiritual beliefs and allow them to find solace. Care providers also find through their lived experiences that families and children need spiritual care that helps them contemplate and address their faith-based or deity-directed questions. For example, in seeking to justify and understand the current tribulations, a family may question why the deity in whom they have placed their faith is allowing them to suffer or whether they have done something to anger the deity in which they believe. The faith-based or deity-directed questions may contribute to an array of emotional responses, ranging from comfort to anger, as the questions raised may have no answer.

> I would say the biggest thing I do as a chaplain across the board is people want to make meanings. They struggle with the "why". "Why is this happening? Why is this happening to me? What have I done? If I can make meaning, if I can find reason, then I can deal with it." In chaplaincy terms, we call that the odyssey, especially when somebody's theology is that God is supposed to be good, God is supposed to be all-powerful and yet this shit is happening in my life. It's the odyssey of how do I rectify that with this idea because most people have this idea of God or this being that is having them suffer like this.
>
> Chaplain

Finally, the last aspect of answering the call of children and families to care for them as a whole person pertains to care offered through the end-of-life, which will reflect a complement of physical, emotional and spiritual needs. End-of-life care includes comprehensive services and support for both children and families preceding and following the child's death, ranging from the need for information to facilitate decision-making to constant support at each stage through the end-of-life journey. Based on the needs of families, pediatric palliative care providers may increase home visitations as a child's condition deteriorates, remain present in the home as the child is actively dying and stay with the family until the child's body is removed from the home. At times, families voice that they do not need care providers to do anything specifically, but they desire to have a team member present through the end-of-life journey for their child. Care providers reflect through their lived experiences that end-of-life care often begins early in the palliative care journey, as they will start working with families on acceptance issues pertaining to the child's life-limiting condition and impending death. While the recognition of a child's imminent death remains difficult for families, the acceptance of the end-of-life can provide a conduit for proactive preparations, such as speaking with families about how they wish to spend the final days with their child or decisions about end-of-life care or extraordinary measures the family wants to pursue. It also often includes families turning to the palliative care providers to validate their observations or personal feelings that the child is nearing the end-of-life.

> Rather than wait for them to say anything, I will say to them, “When I start to sense that we’re approaching that period, we need to sit down and have a discussion about changes I’m seeing in your child.” That is how I start out. I’ll say, “But more importantly, what changes do you see in your child?” and see if we’re on the same page. They’ll say, “She’s sleeping more. She hasn’t wanted anything to eat. I noticed that she only peed one time yesterday.” They’ll notice all this stuff, and I’ll say, “You’re really a good mom. You really know your daughter, and you’re right – these are changes that indicate that things have moved right along here. I think you need to know that these are the beginning signs that there might not be very much time left.” They’ll cry and say, “I was afraid that’s what was happening, but I was afraid to ask.” Then you give them sort of the little speech about what is likely to happen going forward, make sure that they understand that we can control symptoms, that if they have any questions about what’s happening that they can call us, and if they feel like they can’t manage the symptoms by themselves, the additional resources that we have available, too.
>
> Nurse

While families will seek validation of the end-of-life, children also may seek recognition from others that they are dying. Those who provide pediatric palliative care share from their experiences that children often recognize they are dying even before the family understands it to be true. Therefore, care providers will seek to create a supportive environment in which children feel comfortable talking about their personal recognition and emotional response that the end-of-life is approaching. While emotional support is a critical facet of pediatric palliative care and the ability to care for the child and family as a whole person, emotional support is particularly necessary through the end-of-life period.

> It starts here, and the children will lead them. I tell them, “They will take you along this path where you can see that it’s coming. You may not want it, but you’ll be more accepting of it.” I think what they are looking for is support along the path and recognizing those symptoms and helping them get through, understanding that it’s normal – these are normal changes, and that they’re being the best parents that they can be. You’re doing everything possible.
>
> Community Liaison

Beyond emotional support, families also seek guidance for end-of-life decision-making. While families must make the ultimate decisions about how to care for their child or when to discontinue treatments, they may seek input from the palliative care team or other providers who have been delivering care to their child and whom they view as a well-respected voice. As the final days or hours in the child’s life grow imminent, palliative care providers observe that families need a sacred space in which they can say goodbye to their child. Often times, the care providers will work to create and preserve a home environment that is free of disruption or intrusion so families feel as though they have the space and capacity to spend time in their final farewell to their child before and after the child dies. Following the death of a child, palliative care providers may make death visits, which are home visits designed to assist with necessary arrangements or provide multifaceted support to the family; these often occur before the mortuary has retrieved the child’s body. The death visits can serve as a transition in which a family moves from receiving palliative care to bereavement support. Of interest, an aspect of end-of-life care that often surprises palliative care providers is the number of families who express feelings of abandonment by the team following the death of their child. Families feel abandoned that they no longer have regular support in their home, as they have grown accustomed to the routine presence of the care providers as an extension of their family. In this regard, the care providers may seek to transition the family to new forms of support so the feelings of abandonment are minimized.

> I never expected families to feel hurt or abandoned by not hearing from us as much. When you're in someone's family and home, you become part of that dynamic a little bit, sort of because it's a personal home and personal space. I have heard so many families say or I've seen on surveys that families say, "I just felt so abandoned because I didn't get to see my team every week like I used to." I would have never thought that.
>
> Nurse

Ultimately, caring for children and families from the perspective of a "whole person" requires an intentional mind-body-soul approach in pediatric palliative care to knit together their physical, emotional, psychosocial and spiritual care needs, as well as the basic needs that are a prerequisite to effective holistic care. Overall, these elements should not be separated or addressed in isolation, meaning it is critical to recognize the interrelationship between the elements and the extent to which they are intertwined in the life of the child and family.

4.4 Major Theme 4: Be My Guide

The fourth major theme found in the lived experiences of pediatric palliative care providers and their observations about caring for families who have children with life-limiting conditions is answering a call to "Be my guide" (See Table 4.4). Families can find themselves quickly enveloped in dimensions of the health care system with which they have no familiarity. The combination of caring for a medically complex child and traversing unknown aspects of the health care system can be a tipping point for families. In this context, families seek a trusted guide to navigate the path and identify resources they have had no prior reason to access. Symbolically, the guide bears the benefit of seeing the path ahead, including pitfalls and detours that may surface due to the child's health and family needs; a guide also can highlight key milestones and suggest resources to aid the journey.

TABLE 4.4 SUMMARY OF MAJOR THEME 4: BE MY GUIDE

Major Theme	Sub-theme	Core Elements
Be my guide	Guidance through health care system	• Navigation of health system • Care coordination • Transitions between levels of care
	General practical issues	• Insurance coverage • Financial assistance • Assistance for undocumented immigrants • In-home & community resources • Medication & durable medical equipment • Interpretive services & literacy solutions • Care of body • Burial & funeral arrangements

As a first step, families need a personal compass so they do not become lost, misplaced or disoriented during their personal journey through the U.S. health care system to care for their child. The role of a guide establishes a sense of control in a situation that families might otherwise perceive as chaotic and outside their ability to manage. Because no two children or families are identical in their journey and the turning point decisions that must be made along the path, the role of the guide is no simple feat but can ease the way of the family that would otherwise be left to traverse the health care system on their own. By adopting a role as a guide for the family, those who provide pediatric palliative care often focus their attention on navigating the health system, including helping families find their way through the complexity of receiving care in multiple locations from multiple providers, understanding where to go for assistance and obtaining answers to questions along the way.

The providers underscore that care coordination is a key time during which families benefit from a guide who understands the health care system, appropriate sequencing of care and how best to balance the appointments necessary to help the child and family. With children receiving care from multiple providers, families need care coordination to organize and align the child's care, appointments and next steps with providers. Similarly, families often seek guidance when transitioning between levels of care to ensure their child continues to receive care that is most suitable for the diagnosed condition, such as transitioning from palliative care to hospice. When appropriate guidance is provided, the transition between levels of care reflects well-coordinated, seamless handoffs between care providers. Overall, when families allow palliative care providers to be their guide, it removes certain stressors within the abnormal, unfamiliar situation and permits families to focus on issues of greater importance to them.

> What strikes me a lot of the time is the frequency of appointments and the things that they have to keep track of and how easy it would be to miss things that are important or forget to get a prescription refilled. To have that weekly or at least every other week support coming in and reviewing the whole thing … "What's your med situation? What appointments do you have? Oh, let's call that clinic." The care coordination help alone is huge; I guess because in my own mind for my own kids, it's huge. Even with very healthy kids, there's appointments to make, appointments to keep and things to juggle. Having a child whose medical condition can so rapidly deteriorate just intensifies the need to stay on top of things and how taxing that can be physically if you don't have someone who is with you in it and monitoring how the care is going.
>
> Social Worker

Moreover, the role of a guide for children and families also comprises assistance with practical issues that families may have had no reason to access prior to their child's diagnosis or the progression of the child's disease. By and large, the average age of parents who are caring for children with life-limiting conditions is relatively young,[14] meaning they often have had little to no prior experience in their lifetime with some of the commonplace needs that must be addressed, including ordering durable medical equipment (DME)[15] for their home or making burial and funeral arrangements. Therefore, families rely on the expertise of palliative care providers who have knowledge of available resources and the processes for addressing these practical issues.

For example, insurance coverage is a top-of-mind practical issue for families, including challenges related to finding and maintaining insurance coverage, interacting with insurance companies, completing insurance applications and paying for health care services. Beyond insurance coverage, families require guidance in being made aware of financial assistance that may be available to help them pay for care or other necessities in the home. This may include helping families determine their eligibility and access to local, state or federal financial assistance programs that can offset their rising health care expenditures. For care providers, the practical issues of families also may be best addressed by helping connect and make families aware of more in-home and community resources from which they may benefit. These are services separate from pediatric palliative care that may be offered by other organizations. In addition, the majority of families who are receiving pediatric palliative care also benefit from guidance about how medications and DME can be delivered directly to a family home, thus reducing the number of trips outside the home to obtain items required to care for the child.

Depending on the geographic location, the practical issues of families also may include assistance for undocumented immigrants who are not U.S. citizens, as the prevalence of undocumented immigrants is higher in some parts of the country

---

[14] According to the National Center for Healthcare Statistics (2009), the most current demographic data demonstrates the average age of first-time mothers in the U.S. is 25 years old. Using the age of first-time mothers as a proxy in combination with pediatrics defined as children age zero to 21, the average age of mothers caring for children with a life-limiting condition may range from approximately age 25-46.

[15] DME can include, but is not limited to, hospital beds, infusion pumps, patient lift devices and other equipment or supplies needed to care for children at home.

than others. Regardless of immigration status, care providers can guide families to obtain health care services and other resources to care for their child. For families who do not speak, read or write English as their primary language, interpretive services and literacy solutions are practical needs that can help families feel more confident in caring for their child, which builds upon the desire of families to receive care in their own language (see Major Theme 2). Aside from ensuring interpreters are available during in-home visits and external appointments, practical literacy solutions may be developed to help the family care for their child, such as implementing color-coded medication systems or pictorial diagrams to assist with daily care.

> We worked closely with that family to set up a labeling system with their medications where all of their medications are labeled and then we have arranged for a delivery pharmacy so all the medications are delivered to their home so that they don't have to try to go out to get them, then I come to their home immediately and I label them with these color-coded stickers and then that sticker's on a chart and they know which time of day to give the med because they don't read.
>
> Nurse

Following the death of their child, families often seek practical assistance and expert guidance in caring for their child's body in accordance with family wishes, such as preserving the body at home for a longer period of time or washing and clothing the child after death. On a related note, families also need assistance with burial and funeral arrangements for their child, preferably proactively. Based on parental age, the death of their child may represent the first time they have made burial and funeral arrangements since many have not yet had responsibility for the arrangements of older family members, such as their parents. The child's death represents a time for families when they may benefit from additional guidance from a third-party, often the pediatric palliative care team, in understanding the decisions they need to make so they can memorialize their child in a manner that brings closure and comfort in the years to come.

> They kept him in the home for three days after he died. We work with some funeral homes who can work with the families to provide dry ice so that the body can be kept in the home. So people came and said goodbye to him and then the family went with him to be cremated.
>
> Nurse

In summary, families who are receiving pediatric palliative care want an experienced guide who can escort them through the journey of caring for their child, navigate the complexities of the health care system and provide assistance with practical issues as they arise. Because palliative care providers work closely with families in their home on a routine basis, they can forge meaningful relationships with the families and comprehend the type of guidance and practical issues that are particularly meaningful to address. While the journey of each family is unique, commonalities are found when the needs of families are viewed in aggregate, which means care providers serve in a distinctive position to leverage their expertise of having helped multiple families through similar circumstances.

4.5 Major Theme 5: Educate & Prepare Me for What I Need to Know

Upon examination of the lived experiences of pediatric palliative care providers, the fifth major theme focuses on a request from families to “Educate and prepare me for what I need to know” (see Table 4.5). The precise proactive preparations will vary based on individual and family preferences, as well as the amount of information that is imperative to convey in order to care effectively for the child in the home. The educational needs of families increase when they have a child with a life-limiting condition, with the underlying requisite to understand how to care for the child and how best to prepare for the steps in the journey yet to come. However, a balancing act exists in telling families what they *need* to know versus the potential to overwhelm them with too much information at any point in time. While proactive education and communication is optimal in comparison to details being shared reactively when the condition of the child changes, care providers caution that the abundance of information that must be shared with families cannot be offered at one time.

TABLE 4.5 SUMMARY OF MAJOR THEME 5: EDUCATE & PREPARE ME FOR WHAT I NEED TO KNOW

Major Theme	Sub-theme	Core Elements
Educate & prepare me for what I need to know	**Proactive preparation of the family**	• **Anticipating & addressing needs proactively** • **Proactive identification of disease progression** • **Ability to look at big picture** • **Preparing families for end-of-life** • **Proactive bereavement support** • **Proactive planning for future scenarios**
	Educational needs	• **Multifaceted education** • **Education about child’s condition** • **Education about treatment options** • **Education about equipment** • **Education about medication & pain management** • **Education about DNR / POLST** • **Sibling education**
	Communication with family from beginning through end-of-life	• **Diagnosis & prognosis communication** • **Care conference** • **Communication of medical treatment options** • **End-of-life communication** • **Repetition of communication**

In the face of uncertainty, families desire future-oriented insights from pediatric palliative care providers about the preparations they should make or the knowledge they need to acquire. The proactive education and preparations help reduce the fear of the unknown and allow families to become more comfortable with decisions they will need to make or the type of care they must be adept in administering to their child. As a starting point, families desire education from care providers to help them identify emerging issues proactively, rather than responding reactively as the child's condition or factors in the home change. For example, based on close relationships forged in their home, families often ask the care providers to inform them about how their child's illness may progress, including estimates of the time remaining in the child's life. The proactive identification of disease progression offers a means by which families can understand the status of their child's health and contemplate the upcoming decisions for the child. Similarly, families value the ability of the care providers to look across the health care disciplines that are caring for the child to explain the full story of the child's condition and steps being taken to address the problems that have surfaced, as opposed to a narrowed focus on one aspect of the child's health.

Through the efforts to offer proactive education and prepare families for the next chapters in the journey with their child, care providers reflect that families may experience a continual state of grief as more information is shared, heard and processed. Therefore, another area of preparation pertains to proactive bereavement support, as the grief felt by families often begins well in advance of the child dying, such as at the point of diagnosis, during a change of condition or at times when a family is contemplating the next decision that must be made for the child. The proactive bereavement support works in tandem with the emotional and psychosocial care that is administered to the family as an element of whole person care (see Major Theme 3) but also is meaningful to note within the context of the breadth of proactive preparations that providers often pursue with each family. Families benefit from care providers who understand that grieving for the child and the loss of milestones they will not experience in life may necessitate ongoing bereavement support. In thinking about events that may occur in a child's future, care providers may work with families to explore "what if" scenarios and steps that should be taken if the scenarios come to bear. The proactive dialogue allows families to contemplate scenarios in a calm state of mind and more fully process the actions that can be taken. If the hypothetical scenarios come to fruition, families are better prepared to respond, as opposed to being caught off-guard by a crisis.

> I think the child's quality of life and end-of-life would be shortened without the palliative portion of our program. So that's a big statement to throw out there, but I think it sustains families in a way that nothing else really can because you're there with them in the home and you're conscious and aware of what their needs are from week-to-week. You can anticipate what's coming next week with them, what's likely to be coming down the road in terms of a procedure or benefits that have lapsed or a reapplication that needs to be done.
>
> Social Worker

Moreover, families must become experts in the care of their child. The educational needs tend to be multifaceted in terms of families needing to know more about their child's condition, available treatment options, equipment that will be used at home, medication and pain management techniques, and DNR / POLST information. The need for extensive education is multifaceted, starting first with palliative care providers being able to develop the skills and competencies of families to provide high quality, safe care for their child. In addition, addressing the education and training needs of families is critical in terms of bolstering their personal confidence in the ability to care for their child and make daily decisions about the steps to maintain the child's health. While educating the family is often the greatest priority, sibling education that is individualized to their age and developmental level is an important nuance, as well. Depending on age, siblings may play a role in the care provided in the home, or they may need to have an awareness of the medical equipment that is being used so that they do not inadvertently cause harm to their brother or sister (e.g. playing with or unplugging the equipment). Likewise, just as adults in the home need information about the child's condition in order to begin to cope and understand the journey that lies ahead, siblings also benefit from age-appropriate explanations that allow them to process the things they are seeing in the home, which can be scary or concerning.

> How can we teach better? How can we educate better? How can I make this mom and dad feel more comfortable helping their child? It's hard enough being the parent of a normal child who doesn't have special needs, but when special needs come into effect, it can be very scary. Parents can feel very inadequate. They need a lot of support.
>
> Nurse

When reflecting upon the desire of families to have pediatric palliative care providers or other stakeholders educate and prepare them for what they need to know, families yearn for frequent communication from the point of diagnosis through end-of-life. A need exists for families to be able to talk openly about the child's diagnosis and prognosis, which also can help care providers confirm the family's understanding or the need for further discussion. To aid in communication with the family, palliative care providers may convene care conferences, which can be used to address topics requested by the care team, child or family. Common care conference topics include dialogue about medical treatment decisions, end-of-life care, the child's prognosis and family dynamics in the household. One of the final facets of communicating with families from the beginning through end-of-life reflects the need for frequent, repetitive communication so the information is heard and understood. As noted by the lived experiences of the care providers, telling a family and having them hear the information are two different things. Therefore, repetition in communication is needed since this may be the first time they have truly heard the information being presented to them.

> If they want to know how long I think the child has to live, I'll tell them that. If they want to know what to expect in the future, I'll do that. I do ask them. I think part of our job is to prepare parents for the future, so I do ask them, "Are you worried about the future?" If they say, "Nope, we're just living day-to-day, and we don't want to talk about that," then I let that go. If they do want to talk about that, then I address it.
>
> Physician

In general, families who are receiving pediatric palliative care have a hunger for education and information they believe they need to know through the journey with their child from the beginning through end-of-life. While proactive preparation and frequent education are crucial, the lived experience of care providers reveals a subtlety of not merely *educating* families about what they need to know, which could be perceived as one-directional, but truly *communicating* with families in two-way dialogue that elicits greater understanding.

4.6 Major Theme 6: Come Alongside Me

For families who have children with life-limiting conditions, an often unspoken need exists to form close relationships with others who can wrap around them, join their journey through life and offer formal and informal systems of support. Therefore, the sixth major theme demonstrates a calling from children and families for pediatric palliative care providers to “Come alongside me” (see Table 4.6). Through the peaks and valleys of caring for their child, families may elect to open their lives to forming a deeper connection with care providers and signal they have a desire for providers to walk at their side. In these circumstances, palliative care becomes a relationship, not merely a care delivery model, because the deeply personal union that is forged demonstrates a level of intimacy necessary for this type of health care service to aid a family in their time of greatest need.

TABLE 4.6 SUMMARY OF MAJOR THEME 6: COME ALONGSIDE ME

Major Theme	Sub-theme	Core Elements
Come alongside me	Being part of a family’s journey	• Development of relationship • Support on journey • Presence with family • Witness to experience • Preservation of hope versus acceptance of reality • Celebrating successes • Support at end-of-life
	Relationship-based care	• Proactive relationship-building • Trusted partner in care • Personal connection to child and/or family • Seeing the child through the family’s eyes • Family storytelling
	Support system	• Social media support • Support groups & events • Inter-family connections

By coming alongside families, a notion exists of becoming part of their unexpected journey, which is representative of the experiences families and care providers describe in traveling from the beginning through end-of-life with a child. Instead of palliative care providers being set apart as an isolated third-party, families often desire providers to become folded into their experience and interwoven within the fabric of the family, recognizing the development of the relationship may take considerable time to cultivate and will vary by family. Once a relationship has been formed, families seek support that allows them to remain the experts about their child but permit care providers to accompany their journey and ease their way when possible. Moreover, coming alongside families requires the art of being present, as opposed to feeling the need to take action or do something tangible. From the perspective of one social worker, “there is a lot of isolation, especially for the primary caregivers who are at home with the child all day, 24 hours a day.” Consequently, families look to care providers to be present with them, either in the home or by phone, during their time of need to help care for the child, resolve issues as they surface and support the socialization of the child and family. Families also need others to serve as witnesses to their experience and see first-hand the issues they are facing, including the daily reality and routine of that which is occurring in the home.

> The ability and intensity to be in the home with them was so clear to me. They needed somebody to witness this and be with them in it in order to really know how to help them. Having visits in doctors’ offices and therapists’ offices didn’t quite grasp the intensity of it if you were talking to them outside of the home … It just feels like a privilege in some ways to be called on to provide that for a family. I don’t think this particular family would have fared nearly as well had they not had that – real people in their homes connecting with them and witnessing all the losses that they were experiencing.
>
> Social Worker

Beyond witnessing the experience of families in their home, care providers frequently find attention must be paid to balancing the preservation of hope versus acceptance of reality, which is closely connected to the spiritual traditions and deity-related beliefs of the family (see Major Theme 3). Palliative care providers articulate the balance they maintain of hoping with the families but also thinking ahead about the realities that will likely be forthcoming. The need exists to identify the feelings of hope families have for their child but also help them move toward acceptance of the child’s condition, likelihood of mortality and the need to contemplate significant decisions that must be made. The contemplative balance between hope versus reality will vary by situation and family, with the balance undulating throughout the journey as the child’s condition changes. As part of the journey, families look to palliative care providers to join them in recognizing and celebrating small wins in the child’s life. For example, this may include reaching an age milestone, achieving remission of the illness or seeing improvements in symptom management. While the journey may be filled with challenges and setbacks, the recognition of small wins along the way can promulgate feelings of hope and encourage families. By celebrating successes together, families and palliative care providers also deepen their relationship so that they can traverse the setbacks in partnership with each other. For example, the need to support families through the ups-and-downs of the journey with their child is especially poignant during the end-of-life. The support may include a physical presence in the home when the child is actively dying so families do not go through the experience alone or partnering with families so they can find comfort in the final moments with their child. While crisis management and support during the phase in which the child is actively dying is a component of the physical and medical care that is offered (see Major Theme 3), it is worth noting that it also serves as an aspect of the manner in which palliative care providers come alongside families through every phase of their journey.

> Mom is holding her; the grandparents took [the sister] out, and this little baby's heart beat – because that's all she has left – starts to slow, slow … And I'm thinking, [the dad's] got 20 minutes on the I-405 to get here; I don't know if he's going to make it here. So momma is talking to her daughter. She is holding her. She has nothing in the way. She is in her space. She's telling her, "I wish you could have gone to college. I do wish I could have seen your boyfriend. But look at your life, you've had a lifetime. You've had two months. You've had this lifetime." Profound for this young mother, right? So dad arrives, and he hears the last two heartbeats. [The child] saved him two heartbeats.
>
> Community Liaison

With palliative care representing a vulnerable time, families seek a relationship-based approach to care, as they are inviting others into this moment with them. In many regards, palliative care providers become an extension of the family through the relationships that are forged. Due to the serious nature of the child's condition, families desire to work with care providers who are trustworthy, reliable and in whom they can place confidence in caring for their family as a unit. When possible, the relationship-building between families and care providers begins as early as possible so providers can serve as trusted partners from the onset of a child's diagnosis, rather than waiting until a crisis or the end-of-life when greater support and a heightened level of trust is required. Through the process of forming trust, children and families yearn to make personal connections with pediatric palliative care providers before allowing them to enter their experience. Relationship-based care is bolstered when care providers build personal connections to the child and family in order to deepen the bond that will serve as the basis for holistic care.

Furthermore, families long for palliative care providers to see their child through the family's eyes with a quality of unconditional acceptance that mirrors how the family views the child. The ability of care providers to look beyond the child's diagnosis or visible anomalies to see the internal and external beauty, personality and unique characteristics of the child makes a difference in families perceiving that they are receiving relationship-based care. From a practical standpoint, care providers emphasize the importance of storytelling as a conduit to see the child through the family's eyes. Storytelling is regarded as one of the most natural and deeply-rooted forms of communication for people in the world, thus serving as a customary path for people to describe, process and draw meaning from their experiences (Agency for Healthcare Research and Quality, 2014). Rather than providing limited medical facts to care providers, families are encouraged to engage in storytelling to explain their personal journey to-date, including their feelings, emotions and the overall story of their child and family. Storytelling serves to build a relationship with care providers and can help identify ways in which to come alongside the family's story.

> Typically, what I will do if I am doing an admission or consulting, going in and giving them a good open-ended overview of our services to them and having that lead into them telling us about their child's story and the story of them as a family, and getting a better personal history of how they have walked to this palliative point for them, both the positives and the negatives. Admission visits are really important because if we take more time to hear that story, then it's a little easier to build on it when you're going in for shorter periods of time. It allows us to do a better job of building a plan of care that meets that family's needs or fits into that patient's walk and where they are headed.
>
> Nurse

Beyond the relationships forged with palliative care providers, families may seek support from a broader network of families who share the common experience of caring for a child with a life-limiting condition or community organizations that can offer beneficial resources. The support ranges from practical to emotional, with families adjusting their need for support over time. Even families surrounded by a strong support system of extended family or friends may find themselves in need of new forms of support. The support system may include utilizing social media (e.g. Facebook, Twitter), routine support group meetings and special events to build connections with other families who are receiving pediatric palliative care or those who have lost a child. Of note, the care providers have found that developing inter-family connections are particularly effective in terms of strengthening the support system that surrounds families and can contribute to families feeling as though others have come alongside their journey. Palliative care providers can play an instrumental role in building relationships between families who may be experiencing similar circumstances. Immeasurable value occurs when families are able to share their stories with one another, find common ground, pinpoint value-added ideas or obtain encouragement from one another as peers.

> We decided let's have the other party [contact the new palliative care family], "Is it okay if we give your number to this person?" So like Michelle,[16] she's a mom with a kid in the NICU. "Could I give Michelle your phone number? She would love to call you and just chat because she's been in your shoes. Would that be okay?"
>
> Nurse Practitioner

In summary, when children and families ask others to come alongside them, they are looking for those who can walk next to them, not to be too far in front in trying to lead the journey or too many steps behind in reacting to it. The imperative of accompanying a family reinforces the value of relationships and support systems that are needed to envelop a family and move along where the journey may take them.

4.7 Major Theme 7: Cultivate the Plan & Purpose for My Life

Next, the aggregation of lived experiences from pediatric palliative care providers reveals a seventh major theme for children and families to "Cultivate the plan and purpose for my life" (See Table 4.7). While the presence of a child's life-limiting condition may influence how aspects of life must be lived, the strong desire

---

[16] Pseudonym.

remains to have life reflect the aspirations and goals for the family and child. In large measure, these plans for life do not differ fundamentally in comparison to families who do not have children with these diagnoses, including the common aim to function as a regular family, build lasting memories and find a purpose in a child's life. However, while all families uniformly desire to maintain the health of their children, the ability to optimize the health of a child is a particularly fervent endeavor for families who have children with life-limiting conditions since the ability to bolster and maintain the child's health can influence the capacity to achieve other family aims.

TABLE 4.7 SUMMARY OF MAJOR THEME 7: CULTIVATE THE PLAN & PURPOSE FOR MY LIFE

Major Theme	Sub-theme	Core Elements
Cultivate the plan & purpose for my life	**Being a regular family**	• Parental bonding with child • Inclusion of child in family • Normalcy in home • Predictable routine • Traditional family activities • Quality family time
	Optimizing life of child	• Quality of life • Preservation of child's health • Relief of pain & suffering • Comfort of child • "Good death"
	Building memories for a lifetime	• Living in the moment • Memory-making activities • Memorializing the child • Remembrance activities
	Purpose of child's life	• Learning from child's life • Spreading best practices • Caring for others

When faced with circumstances that would be described as far from normal, families place significant value on functioning as a regular family, rather than having life defined solely by atypical experiences, illness and the potential death of their child. The families do not seek to ignore or minimize the fact they have a child with a life-limiting condition. On the contrary, prompted by their child's condition, families consider the aspects of life that are most important and recognize the magnitude of cultivating plans that support being a regular family and finding ways to normalize an abnormal situation during the limited time they have been granted. When confronted by the abnormality of caring for a child with a life-limiting condition, families seek normalcy in the midst of chaos and regard caring for their child at home as a measure of success. Overall, the desire to have the child present at home and integrated in daily life in as many ways as possible demonstrates the normalcy families seek, rather than seeing their child isolated or set apart as different. In some situations, the plans of a family for their child's life may include attending school or participating in activities outside the home, as opposed to the life of the child being defined exclusively by health care interventions. Not only do families long for their children to have aspects of a "normal" life, but they also yearn to forge time-honored memories with their child. These plans begin with helping parents bond with their child, which can be impeded in a hospital due to the presence of medical equipment and other life-saving measures that may prevent parents from being able to hold, feed or remain present with their child.

> Where infants are concerned, I think being in the hospital interferes with the bonding process. Consequently, I think it interferes with grieving to never have had your child in your home in the space that you prepared for them during your pregnancy. In a lot of ways, I've talked to these parents afterwards and they'll say things like, "It's almost like she was never born" because they never have a memory of that baby in their home. It's hard for them to grieve because they look around their home and there's not any sort of reminders; they don't have any memories of being with that baby in that home. Even if you only get them home for a few days, they have that time together so they can say, "She was home. She was a real person, and now she's gone." It's all about that piece for infants.
>
> Nurse

Because caring for a child with a life-limiting condition can generate significant uncertainty on a day-to-day basis, families also desire to maintain a consistent routine in the home to the extent that is possible in order to promote stability. A predictable routine has a settling effect on the child and family members, including siblings, as it reduces the stress of not knowing what is coming next and provides greater control over daily activities. With a more predicable routine in place, families have the opportunity to turn their attention toward traditional family activities and enjoying quality time as a family. Based on the lived experiences of the care providers, families want to partake in regular family activities, as opposed to having these milestones eclipsed by the child's condition. From photos with Santa Claus at Christmas to summer picnics at the park, families long for their child to experience traditional activities so they can feel what it is like to be a regular child who is not defined by a medical condition. The quality of this family time – as opposed to quantity of time – is a hallmark of being a regular family, as families seek to optimize the time they have together with their child, however long or short that time may be. In a situation in which quantity of life may be limited, families may elect to uphold and preserve family quality time as an utmost priority.

> I think the families that we touch, I think that they're able to feel much better and have peace of mind and they're able to grieve appropriately … I see a lot of our families at peace. They realize that they've done everything that they can, and they're able to spend those last hours or days or months doing quality things with their child.
>
> Nurse

Moreover, as families seek to optimize their child's life so they can enjoy as many moments as a regular family as possible, their key priorities often include seeking to preserve the child's health, relieve their pain and suffering, and ensure the overall comfort of the child. Preservation of the child's health places emphasis on proactively finding ways to maintain the child's current state of health for as long as possible, as opposed to being reactive to symptoms and problems that arise. The provision of palliative care is regarded as an integral factor in the ability of families to optimize the child's life. Beyond preservation of health, families concentrate on the relief of pain and suffering, which are common measures by which families assess quality of life and contemplate the provision of additional medical treatments. When a child's condition is incurable, quality of life and relief of pain and suffering often are given greater credence as families set short-term goals and redefine the plans for their child's life. In this regard, the original plan and purpose a family envisioned for the child's life may be recast with assistance from the palliative care team to cultivate a plan that focuses on the family's personal definition of quality.

> I often think of this as my role to walk with these patients and help them to live as they're dying. Then you see that the families get a greater awareness and insight into what's going on and the importance of maybe quality over quantity. When they come to us, they're not thinking about time. They're wanting their person to be at home and to get better or stronger in some way, then over time, they begin to see and understand that this may not be quality for this child or, in their way, they may say, "We don't want to see her suffer anymore or go through pain."
>
> Chaplain

Interwoven within the relief of pain and suffering and overall quality of life is the focus on the child's comfort, which may be defined holistically in terms of physical, emotional and spiritual comfort. The holistic view is consistent with the concept of caring for the child as a whole person (see Major Theme 3). While *physical* comfort is often top-of-mind, emotional and spiritual issues also may have implications for a child's comfort. Pediatric palliative care providers reveal through their experiences that families often seek guidance about assessing their child's comfort from a holistic standpoint and prioritizing comfort as one of the critical issues for optimizing the child's life. One palliative care chaplain summarized the importance of families addressing their child's comfort as "giv[ing] families a great sense of achievement and satisfaction when they've been able to keep the person and home and keep them comfortable." Finally, when families face the prospect of losing their child, they desire for comfort to be carried through their child's death, with death being as peaceful and gentle as possible. While a "good death" may seem counterintuitive when speaking of children, families will define the factors they wish to see or experience in order to find peace in the way the child dies, which will be driven by their perceptions of the child's passing.

> There's not a good way to say that the child had a "good death", but really that's the communication that we get from [families]. I think they feel as though their child has had a good death … Our goal is to support the family, make sure the child has a good life for as long as possible and then a gentle death when it's over. That's our job. Whatever we need to do to support that is what our job is … it's not our child who is dying and we have to support a family so that in the years ahead, they are not impaired by whatever we

> do but that all the things we've done have helped them in their grieving process.
>
> Nurse

Both during and following the child's life, families place attention on building memories together, as well as maintaining these memories after the child's death. To this end, families may strive to live in the moment with their child, rather than dwelling on the uncertainty of the future. For some, living in the moment is driven by spontaneity, such as pursuing family activities if the child is feeling well on a particular day. While tensions can emerge in celebrating life on a day-to-day basis versus preparing for the future, palliative care providers can help families attain balance and cultivate the plans they desire in life. For example, recognizing time together may be limited, families may be encouraged to pursue memory-making activities that can be treasured in the present, as well as after the child's death. The focus is not only on creating memories as a family but also developing the child's memories of the good times celebrated together so that the memories of life are not focused exclusively on illness. Reflecting on their lived experiences, care providers demonstrate the steps taken to memorialize the child also are value-added to families in building memories. Memorials to children after they have passed away may include mementos, tributes or items for families to celebrate the child's memory. One-time or ongoing remembrance activities to commemorate a child's life also are commonplace for families, with activities aligning with cultural, spiritual and family traditions. These may include observing the child's birthday, celebrating the child through an annual tribute activity or finding meaningful ways to keep the child's memory alive.

> Two years ago after I had worked with a couple whose baby died, they returned to deliver their second child. They were excited to have me meet their healthy newborn and to share with me that the Build-A-Bear® I had made with their first baby's heartbeat in it was in their new baby's crib at home, waiting to welcome their new baby. When we know a baby is unlikely to survive, we record the baby's heartbeat in a Build-A-Bear® for the family. Their first baby's memory is kept alive through this Build-A-Bear®.
>
> Nurse / Social Worker

Finally, faced with making peace with the shortened life of their child, families may turn toward finding purpose in the child's life, building a legacy or making the life of the child "count". The ability of families to define a purpose may begin by taking steps to learn from the child's life and allowing it to make a difference for others, such as studying the child's illness in order to save others or helping improve the lived experience of those facing similar situations. Influenced by the experience of caring for a child with a life-limiting condition, it also is commonplace for family members to dedicate their lives to caring for others, such as pursuing health care careers, leading support groups or finding ways to help those who face similar circumstances. In this regard, the purpose of the child's life can prompt a journey of self-discovery and personal calling for family members that redefines their plan and purpose for life. Moreover, families, palliative care providers or other community providers may pinpoint best practices from their efforts to care for a child that can be disseminated to others. Spreading best practices is another way in which families can draw comfort in feeling like their child's life has had a purpose or even that their own life has a purpose in being a resource for others.

> I asked one mom if she'd be willing to meet these parents who are going to start [having in-home nursing], so the couple went to the other room and the mom who has had two years of nursing was absolutely thrilled to share her experiences about what it's like to have home nursing. This new couple was very timid and looked like deer in the headlights. They had no idea about what they were getting into. After hearing another parent's experience, they were totally empowered. Now when they get on the phone to interview agencies, they're going to know questions to ask because they were able to connect with this other family. Families that are out there doing this care are experts. They are amazing experts in what they do because they have a little hospital in their home.
>
> Nurse / Social Worker

Ultimately, as evidenced through the experiences of pediatric palliative care providers, the desires voiced by families for being a regular family, optimizing the life of their child, building memories for a lifetime and finding purpose in the child's life are crucial. However, families also can benefit from the support of a palliative care team in helping them cultivate the plan and purpose they envision for their life, including care providers working alongside families as they reevaluate, redefine and embrace their new calling in life.

4.8 Major Theme 8: Be My Voice & Help Me Find My Own

When a child is diagnosed with a life-limiting condition, the voices of the child and family can become minimized amidst new competing voices, including those of health care professionals, extended family members, insurance companies, community agencies or a myriad of seemingly well-intentioned individuals who may overpower the ability of the child and family to feel heard. The competing voices can contribute to feelings of vulnerability and a lack of control during a time in which multiple facets of life seem unmanageable. Therefore, the eighth major theme speaks to the need expressed by children and families to "Be my voice and help me find my own" (See Table 4.8).

TABLE 4.8 SUMMARY OF MAJOR THEME 8: BE MY VOICE & HELP ME FIND MY OWN

Major Theme	Sub-theme	Core Elements
Be my voice & help me find my own	Giving children & families a voice	• Advocating for the child / family • Helping families feel heard • Empowering families
	Thought partner for families	• Active listening • Sounding board • Transparent communication • Honest communication • Listening to family goals • Supporting family decision-making
	Multifaceted communication & conflict resolution	• Parent-child communication • Parent-to-parent communication • Sibling communication • Extended family communication • Parent-team communication • Team-to-child communication

When children and families feel as though their voice has been silenced, the aim of pediatric palliative care providers becomes to advocate for their needs, preferences and desires by bringing the voice of children and families to the forefront. At times, the gravity of child's diagnosis and magnitude of the unfolding situation may lead a family to feel as though they do not have the strength to voice their concerns, or they may remain uncertain how they truly feel or what they need from a short-term and long-term perspective. In other moments, a family may feel uncomfortable questioning the highly-trained health care professionals who are caring for their child, instead of recognizing the benefit their voice and perspective can bring to identifying the optimal decisions and next steps. Therefore, while advocating for children and families, palliative care providers not only find a need to speak on their behalf but also help children and families regain their voice so they can communicate their thoughts and desires. This may include helping children and families feel heard by other care settings and health care providers, or it may encompass feeling heard by extended family and others who are involved in the child's life. Palliative care providers also empower families to feel in control of their situation and encouraged to take charge, as opposed to allowing events surrounding the child's condition to overpower them. Through restoration of empowerment, families can begin to feel as though they can articulate their needs to others and find their own voice.

> I think whenever you have a family that has a life-threatening illness, the minute you find out about it, a lot of your empowerment is taken away, especially if you don't have the medical knowledge, so I think you go into "whatever I need to do for my child" mode and automatically think that whatever they are telling you right then is exactly what you need to be doing. You don't know what you don't know. You just are doing what you think needs to be done; you're living in survival mode. I think the empowerment comes from being able to sit down and be able to talk with someone who's very clinically knowledgeable but who is also knowledgeable and

> open to something else to what that particular specialist is saying to you. It's about being able to say that you know you do have options and have a right to say "yes" or "no".
>
> Nurse

Families also long for pediatric palliative care providers to become their dedicated thought partner, create a forum for processing information and support the goals they have for their child. Because caring for children with life-limiting conditions represents a unique situation, the role of an effective thought partner often falls to palliative care providers who have years of experience and professional expertise to lend to the situation, starting first with the ability to actively listen to the family. Families often will utilize the providers as a sounding board to whom they can speak openly to test or evaluate ideas that will be held in confidence. By using the providers as a sounding board, a family can gain confidence in presenting their ideas, expressing concerns and articulating needs in a manner that will help them find their voice. As a trusted thought partner, palliative care providers also recognize the intrinsic value of speaking openly without withholding or restricting information from the family. While health care providers may have the best intentions in trying to protect families from the realities of their child's health care condition, a lack of transparency can contribute to families feeling misled or taken aback when the child's condition changes or a poor prognosis is presented.

Similarly, palliative care providers aim to speak in a truthful, sincere and straightforward manner with families. By demonstrating honesty as a thought partner, families often turn to the care providers as a voice of reason and truth upon which they can rely. Moreover, families will look to the care providers to listen to their goals and find ways to realize them, with providers being careful not to impose their own goals but rather actively listen to determine how to support the family. As appropriate, providers may gently offer suggestions for families to consider if they are receptive to alternatives. The last facet of serving as a thought partner is the need to support family decision-making, as they desire someone to stand behind their decisions rather than dismissing the conclusion they have reached. Careful attention must be paid to support families in the choices they have made, recognizing their decisions may evolve as the child's condition changes.

> All I could do at that point in the visit was to say when you're making these kinds of decisions, it's a fork in the road and you can decide to go forward this way or not, but at each step in the road, there are choices. So, right now your choice is to call 911, and we would support you in the way that you need to be supported and that would be okay but along the way, there will just be things to talk about at decision points. She wasn't ready to hear any more than that. So, that's where you go with it this time and then next time, she can talk about it a little bit more.
>
> Nurse Practitioner

Beyond the family need for a thought partner, multifaceted communication and conflict resolution between stakeholders can grow complex in situations involving children with life-limiting conditions. Having rarely had to discuss or reach consensus about such difficult topics, parents, children, siblings, extended family members and others may find themselves embroiled in complex dialogue with one another. Nonetheless, having been party to crucial conversations with other families, palliative care providers serve in an unparalleled position to open the communication channels between stakeholders so everyone is given a voice and opportunity to be heard. While stakeholders may not reach agreement, the greater value is found in having had the time to communicate with one another and understand the perspective of the other party. For example, parent-to-parent communication remains vital, as parents will encounter times during the palliative care journey with their child in which they need to reach consensus about the plan of care, how to manage issues in their household or interact with others outside the home. At times, palliative care providers will serve as mediators to bring parents together so they are able to hear one another and form the basis of open communication. The need for open communication and conflict resolution also extends beyond the immediate family to the extended family who may voice strong views about the decisions or actions being pursued. For instance, grandparents or extended family may stand in opposition to the parents signing a DNR order or foregoing invasive procedures. In such instances, the care providers can help families find their voice in responding to extended family or can facilitate dialogue between family members. Finally, one of the most important communication channels that the care providers will seek to bolster is that between the parents and child, as their time together is limited and each person often has important messages that need to be conveyed to one another during the remaining time.

> About a week before [the child] died, which was about four days before he stopped speaking to his mother, one day out of the blue he said to his mom, “I’m dying.” She was like, “Oh my goodness!” Helping her to reframe that “How wonderful that he felt comfortable talking to you about that.” The mother was feeling immense guilt, “He wants to talk about it, but I haven’t talked to him about it yet.” I said, “You know, he felt comfortable bringing it up with you.” The next time, he told his mom, “I’m sorry.” She said, “You have nothing to be sorry about.” He said, “No, I didn’t fight hard enough.” Then the next day, he said to his mom, “I love you.” He had always been the kind that that’s private, “Don’t say that to me in public,” you know. He gave his mom these wonderful gifts before he stopped speaking and then died peacefully.
>
> Nurse

Ultimately, in response to a calling by children and families, the aim of pediatric palliative care providers becomes to restore and embolden their voices so they feel heard and engaged in taking charge of decisions that must be made in their life. Via care provider efforts to serve as a thought partner, bolster communications and facilitate conflict resolution, families can regain the voice they feel has been quieted as a side effect of caring for their child and the complexities that arise from the situation.

4.9 Major Theme 9: Help Me Thrive

Finally, the ninth major theme echoes a calling from families to “Help me thrive” (See Table 4.9). Amidst the uncertainty of caring for a child with a life-limiting condition, individuals desire not merely to survive but thrive under these circumstances. The combination of caring for one's self and maintaining self-worth contribute to perceptions of being able to overcome current obstacles and come away as a person who is stronger because of the experience. From the perspective of families, a quality exists of not allowing the present tribulations to erase who they are or take away their spirit.

TABLE 4.9 SUMMARY OF MAJOR THEME 9: HELP ME THRIVE

Major Theme	Sub-theme	Core Elements
Help me thrive	Personal self-care	• Stress management • Self-preservation & caregiver fatigue • Preservation of self-identity
	Self-worth	• Autonomy • Positive affirmation • Confidence-building • Reassurance & validation • Family appreciation

For the majority of families, a sacrificial and all-consuming focus is placed on the child's health, which subtracts from personal self-care. In order to continue caring for their child to the best of their abilities, families need to direct attention to maintaining or restoring self-care to a healthy balance. For example, when reflecting on the overarching need for stress management, one chaplain emphasized the imperative to "acknowledge with [the family] that this is a very stressful situation for them, and it's very normal to feel overwhelmed at times." In these circumstances, learning healthy ways to manage stress are important to the ability to thrive. In addition to heightened stress levels, families may experience a loss of self-identity when they become so engrossed in the life and care of their child that they no longer preserve their independence and individuality. In order to thrive, families must take steps to maintain their self-identity so they do not become defined exclusively by the life of the child. Families also must learn to care for themselves and manage caregiver fatigue. When families are providing continuous care for their child, it often comes at the cost of no longer caring for themselves or taking time to become rejuvenated, thus contributing to a never-ending cycle in which the primary caregivers in the home become increasingly exhausted.

> We help support the potential for all of them to have caregiver fatigue. For me as a mom of a big family, I look at these poor families that are behind before they even get started. By the time they know what they are dealing with, they're already pretty exhausted, so being intentional about finding ways to support themselves in the midst of caring for their child is always challenging.
>
> Nurse

Equally important to personal self-care is the feeling expressed by families to maintain self-worth. In the face of abnormal circumstances, families yearn to view themselves in a positive light and recognize their personal value, as opposed to perceiving life as a series of shortfalls. Autonomy is especially meaningful to families who want to maintain independence and self-sufficiency in being able to care for their child to the extent that is possible at home, as opposed to being solely reliant on others. Moreover, for families to feel like they are able to thrive and maintain self-worth, palliative care providers frequently make statements of positive affirmation to uphold, support and encourage families. As an example, families need to hear they are doing a good job in caring for their child and household, supporting their spouse or managing the present circumstances to the best degree possible. The positive affirmation can inspire courage and build confidence, which are crucial in bolstering self-worth and learning to thrive under the circumstances. When families have higher self-confidence, it can contribute to feelings of being able to take charge and provide excellent care, rather than allowing the present situation to control them. Similarly, families often seek reassurance or validation about decisions they are making for their child and the care they are providing. The reassurance can boost the self-esteem of the family and their ability to feel like they are thriving amidst the complexity of the present situation.

> I think education about what to do and pointing out what they are doing well. "Look how intuitive you were to know that he was uncomfortable and that you turned him." Just really pointing out ways that they are being a good parent and a good caregiver of their child and trying to encourage them and letting them know that they are the expert on their child and that they are doing a good job at it.
>
> Nurse

As a final note, families find the ability to thrive is amplified by the opportunity to show gratitude to the palliative care providers who have aided the child and family in their journey. One of the hallmarks of palliative care is its holistic focus on the needs of the child and family, yet expressions of gratitude about the unconditional support that has been offered also commonly span the body-mind-soul continuum to reveal a physical, emotional and spiritual response from the family to those whom they most appreciate. Faced with numerous challenges during the course of receiving palliative care, family appreciation extends beyond the etiquette of a simple "thank you" to often encompass more meaningful, heartfelt responses. Being able to show appreciation is correlated with families feeling as though they are giving back and not merely taking, which feeds their perceptions of self-worth, personal happiness and fulfillment in being able to touch the life of someone who has touched them.

> One of my first patients that I was attached to and had a deep connection to was a little boy who had a brain tumor. That's where I got connected to all the pediatrics. My heart's for them. Right after he passed away, his mother has wrote me. She is Mexican. She wrote me in Japanese. She said, "Because you touch my son's heart, I decided to go to Japanese school, and I am writing a letter to tell you 'thank you' for the care" and then she wrote me a letter [in Japanese].
>
> Nurse

Ultimately, for families who need pediatric palliative care, the ability to thrive seems almost unfathomable, yet it is precisely what the lived experiences of care providers demonstrate that families desire. Despite so much attention being deservedly directed toward the child, families also walk a careful balance in needing to care for themselves and maintain their self-worth so that they will not merely survive but truly thrive through the experience.

4.10 Summary of the Research Findings

In closing, the pediatric palliative care providers who shared their lived experiences during the research study afforded critical details about what it is like to care for children with life-limiting conditions and their families. The research findings have been encapsulated in nine major themes and supported by illustrative quotations in order to allow scholars and practitioners to step into the experience and see it through the eyes of those who work in partnership with families every day. At every juncture, the research findings have placed the focus on the children and families by building upon themes that frame the experience from their perspective, while simultaneously leveraging the voice of care providers in a manner that provides key insights. Ultimately, the research findings have proffered a foundation on which to articulate the overall essence of the experience and assess the degree to which the research objectives have been fulfilled. The findings also serve to identify implications for future practice and contributions that address deficits in the extant literature, while remaining mindful of the limitations of the study and avenues for future research.

CHAPTER 5

Discussion

"These children … if you can get away from 'I'm going to save them … I'm going to save them … I'm going to save them', one of the things I learned as a new graduate was you can't always save them, but death is not always a failure. It doesn't mean you have failed. Sometimes it's not in our hands; it's in God's hands, and a child is going to die, so what are you going to do? You can't run away. You have to sit and help the child through that; you have to help the family through that."

~ Pediatric Palliative Care Nurse

The Pediatric Palliative Care Study served to address two core research objectives, which were to understand the lived experience of caring for a child with a life-limiting condition and their family, as well as comprehend how the totality of these experiences can be utilized to reveal the needs associated with pediatric palliative care. Taken as a whole, phenomenology affords a conduit for stepping into the lived experience and, by doing so, creates a manner in which the insights about the experience can serve as a springboard to identify needs and help inform the optimal plan and justification for care (Jasper, 1994, p. 313). According to Pringle et al (2011a, p. 23), reflecting on Munhall (1994), "unless we understand meanings, we cannot alter health behaviour and lifestyles. It is surely only by maintaining an open, adaptable approach that we can truly reach, hear, and understand and access our participants' experiences, particularly of those who may be in greatest need of our support." Therefore, the following discussion aims to uncover the overall essence of the experience and examine how the experience proffers implications for future practice and contributions to extant literature. The limitations of the study and implications for future research also are outlined in order to aid those seeking to build upon the current research who want to offer additional contributions to the extant literature and advance the emerging field of pediatric palliative care.

5.1 Statement of Essence

In Chapter 4: Research Findings, the analysis of the lived experiences of care providers generated core elements, sub-themes and major themes that extend textural and structural descriptions of what and how the providers experienced the phenomenon of caring for children and their families (Creswell, 2007, p. 60). While the individual experiences of providers are subjective, the commonalities observed across the lived experiences can reduce individual experiences to major themes that contribute to a "universal essence" (Creswell, 2007, p. 58) and "grasp of the very nature of the thing" (van Manen, 1990, p. 163). The major themes are sometimes called "essential themes" by researchers in order to reinforce that these points garner a more abstract view across the lived experiences of all research participants and are intended to reflect the essence of the phenomenon (Van Alst, 2012). As a point of reference, the nine major themes – or "essential themes" – within the study include (1) Develop an innovative approach to caring for me, (2) Place me at the center of care, (3) Care for me as a whole person, (4) Be my guide, (5) Educate and prepare me for what I need to know, (6) Come alongside me, (7) Cultivate the plan and purpose for my life, (8) Be my voice and help me find my own, and (9) Help me thrive.

Overall, interconnectedness exists between the major themes, which suggests they should not be viewed in isolation of one another (see Figure 5.1). On the contrary, the themes flow from one another in a manner that tells the story of the experience and typifies the benefits of placing the themes into words that could be expressed by children and families. The common threads across the textural and structural descriptions and a discernment of the major themes contribute to the following statement of essence about the phenomenon of caring for a child with a life-limiting condition:

> From the beginning through end-of-life, the journey of caring for a child with a life-limiting condition is anomalous, yet it does not dissuade families faced with atypical circumstances from seeking to function as a conventional family. Indeed, families confer greater importance on living a lifetime with their child, regardless of how long or short the time may be. They value being able to make decisions to care for and raise their child, create lasting memories as a family, help their child thrive and find purpose in their child's life in a manner that is reflective of the family's heritage, beliefs and norms, which are actions consistent with the aspirations of other families.
>
> Nonetheless, a child's life-limiting condition does promulgate inherent complexity and unanticipated challenges for families being able to realize the plan and purpose for their child's life, as well as the life they desire as a family. Often times, caring for a child with a life-limiting condition immerses a family into an abyss of vulnerability, critical decision-making and feelings of traversing the journey alone. In such situations, families need support from those who can work in partnership alongside them to place the child and family at the center of care, as opposed to the family becoming an extension of the complex health care system in which they find themselves. Families seek a guide, trusted resource and confidant on whom they can lean for expertise in helping them learn how to care confidently and holistically for their child, address their newfound needs and make informed decisions that reflect the qualities of life they desire for their child and family. Through the eyes of the family, they desire the child not be reduced to a medical diagnosis or set of symptoms but rather the child should be cared for as a whole person who has a mind, body and soul that needs support from the beginning through end-of-life.
>
> Overall, families who are caring for a child with a life-limiting condition endeavor not to be overcome by the unpredictable

difficulties that arise on any given day but to thrive to the extent that is possible as the family they yearn to be.

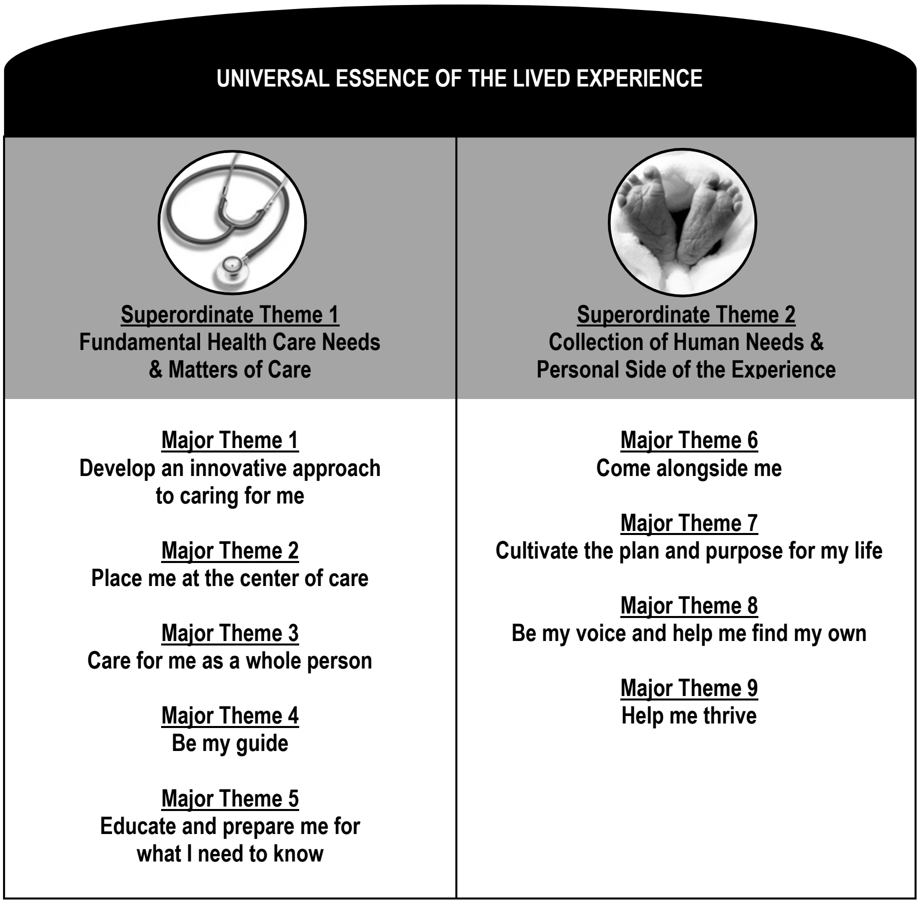


Figure 5.1. Conceptual Diagram of the Statement of Essence.

5.2 Implications for Future Practice

According to Rose et al (1995, p. 1128), a distinct advantage of using phenomenology is the “potential to generate knowledge for practice from practice”. The research findings and insights obtained from the lived experiences of care providers present information that can be utilized by those working in the health care industry to drive changes in daily operations and engender improvements in the provision of care for children and their families. As a result, the implications for future practice include, but are not limited to, the following examples:

Superordinate Themes: Balancing Matters of Care With the Human Experience

In many ways, the research findings and statement of essence reveal two overarching themes in which all major elements can be nested to summarize the needs relating to the phenomenon (see Figure 5.1). The first superordinate theme pertains to fundamental health care needs and matters of care; it speaks to the practical provision of services and how care is organized and delivered to children and their families. For direct patient care providers or industry leaders, the practical matters of care include the overall design of palliative care, including the location of care and construct of utilizing an interdisciplinary care team and partner organizations (Major Theme 1); efforts to place the child and family at the center of care, such as developing individualized care plans or providing care that is aligned with the traits of the family (Major Theme 2); caring for them as a whole person by addressing their basic needs, physical and medical care, emotional and psychosocial care, spiritual care and end-of-life care (Major Theme 3); guiding them through the health care system and addressing practical issues, such as insurance coverage or burial arrangements (Major Theme 4); and educating and preparing families for that which they need to know to care for their child, including providing hands-on education about an array of important topics (Major Theme 5).

The second superordinate theme encompasses the more personal side of the experience about how life will be lived, which signifies the phenomenon sparks more than needs for health care services. A collection of human needs also arise to which practitioners and leaders must be mindful. These include coming alongside the family to be part of their journey through the provision of relationship-based care and support systems (Major Theme 6); helping families cultivate the plan and purpose for life by supporting efforts to live as a regular family, optimizing the life of the child and building lasting memories (Major Theme 7); serving as the voice of the child and family and, likewise, helping them find their voice (Major Theme 8); and helping them thrive amidst the circumstances in which they find themselves (Major Theme 9).

The two superordinate themes offer guidance that addressing an unmet health care need in a community should encompass more than solutions for the matters of care but also must be attentive to the human dynamic of how people are experiencing the phenomenon and the manner in which they are seeking to live their life. At times, a tension can arise between balancing the fundamental matters of health care design with the personal side of the experience. It raises a question as to whether health care providers are designing models of care from their own perspective with regard to the greatest efficiencies and effectiveness or whether the voice of patients is maintained as the central focus. The Pediatric Palliative Care Study offers a statement of essence and details about the lived experience that afford helpful insights that should be leveraged when designing health care delivery models to ensure the proposed solutions align with the needs of children and families. Rather than regarding the superordinate themes as being in potential conflict with one another, the greater opportunity is to use them in tandem to generate innovative health care solutions that meet the dual imperatives of health care providers and recipients of care. Overall, the aim to balance matters of care with the human experience is applicable not only to pediatric palliative care but rather to multiple aspects of the U.S. health care industry, as seeking to understand the lived experiences of others and infuse this knowledge into the design of future care models is a novel approach that can help industry leaders pinpoint optimal solutions to meet the needs of multiple stakeholders.

Addressing the Aims of Health Care Reform Legislation

In March 2010, the U.S. passed comprehensive health care reform legislation known as the Patient Protection and Affordable Care Act (PPACA) that seeks to increase access to health care services, enhance quality and coordination of care, and improve affordability (White House, 2014). Across the country, health care organizations are seeking solutions that will help them reinvent U.S. health care to align with the PPACA objectives. While pediatric palliative care is not specifically mandated within the 2010 legislation, it represents a solution that reflects the reform-based principles, as extensive care coordination, communication between providers and partner organizations, and a focus on patient-centered care are fundamental elements of the model that will improve quality and reduce fragmentation of care (Meier, 2011, p. 349). Other common facets of palliative care, including care planning and goal-setting with children and families, pain and symptom management, and the opportunity to offer care within a home-based setting, serve to reduce the cost of care, limit hospitalizations and prevent unnecessary emergency room utilization (Meier, 2011, p. 349-350). The Pediatric Palliative Care Study provides timely insights into the lived experiences of those who have benefitted from a unique health care delivery model that aligns with the aims of health care reform. In this manner, the study provides direct patient care practitioners and health care leaders with a tangible way to see how they can bend the cost curve and better meet the needs of children and families in the communities they seek to serve. In addition, the constructs of the pediatric palliative care model and dedicated focus on whole person care may be applicable to a broader complement of health care conditions, as it seeks to shift the focus from the current biomedical model of diagnosing and treating a disease to caring for the body, mind and soul of the person as a whole (Thornton, 2005, p. 111).

Developing Care Models for Home-based Settings

In a related manner, the research findings offer confirmation that the health care industry needs to design health care solutions that optimize the provision of care in the home. The traditional hub-and-spoke model that has placed hospitals as the central point for care is segueing to an integrated care delivery model designed to shift a greater percentage of care to ambulatory and home-based settings (Taylor, 2014, p. 2). By transitioning the focus away from hospitals, health care providers have the opportunity to increase patient satisfaction, decrease the overall cost of care and serve patients in a more timely and convenient manner by offering direct access to care providers (Taylor, 2014, p. 3). The study demonstrates the value of providing palliative care in a home-based setting, as this aligns with the desires of the child and family to remain at home to the degree that is possible (see Major Theme 1); it also provides them with the greatest opportunities to function as a regular family and optimize the life of the child (see Major Theme 7). With advances in modern medicine supporting the provision of care in the home, health care providers should increasingly look for ways in which to transition services into a home-based setting, as opposed to requiring families to seek care for their children from acute care hospitals, ambulatory clinics or other settings outside the home that may be less convenient, less cost effective and more disruptive to their daily routine.

Customizing Care & Developing Solutions from the Family Perspective

Moreover, to expand the number of pediatric palliative care programs, researchers contend that sharing information about best practices and conducting ongoing research are critical to addressing the unmet needs for services (Downing et al, 2014, p. 109). While quantitative studies and scientific inquiry are prevalent in health care, knowledge that informs future practice is most effective when the data includes a reflection of the lived experience and phenomena (Rose et al, 1995, p. 1128). Indeed, phenomenology "could become the basic instrument in the reform of nursing research as it moves from the positivist to the humanist paradigm" (Rose et al, 1995, p. 1123). In the midst of the health care industry seeking to standardize health care practices and leverage evidence-based medicine, the study proffers a concrete example that pediatric palliative care is not one size fits all but rather is most effective when the lived experience of the child and family is understood so that care can be customized to meet their needs. Simultaneously, health care providers must recognize the customization of care will necessitate identifying the optimal ways to increase the intensity and sophistication of care that can be offered in a home-based setting in a manner that still ensures high-quality, safe and effective care for the child and family. To scale up the level of care, the study demonstrates the importance of addressing the educational needs and preparedness of families to care for their child (see Major Theme 5), while also developing an innovative approach to care that includes constant support and the ability to deploy resources to the home at any time (see Major Theme 1).

Due to advances in modern medicine, children with life-limiting conditions are surviving for longer periods of time than previously possible, which raises new challenges in terms of designing suitable health care delivery systems and determining where to make investments that will address the escalating community demand. With pediatric palliative care considered an emerging specialty, the study findings offer the first comprehensive overview of the lived experience and create the foundation on which tangible solutions may be developed to address the needs that transpire from the experience. Without an understanding of the lived experience, direct patient care providers and health care industry leaders will remain ill-informed about the problem to be solved or how the services they provide can make a difference. The study serves to generate awareness among direct patient care providers and non-clinical health care leaders about what it is like to experience the phenomenon, which will be informative in helping to ensure the provision of care is aligned with and responsive to the needs of children and their families. By bringing the voice of the child and family to the forefront, the health care industry has the opportunity to shift its focus to developing care delivery solutions from the viewpoint of the family, as opposed to designing care from the provider perspective alone.

Educating About Pediatric Palliative Care

One of the limitations encountered in seeking to increase the availability of pediatric palliative care services is the overall lack of knowledge about the specialty and the manner in which the services can assist families. In a systematic review of the literature to ascertain the interventions that are most likely to garner greater hospice and palliative care referrals, Kirolos et al (2014, p. 962) concluded health care employees need training to increase their awareness of the specialty and how to initiate dialogue with patients and families about their personal wishes for care. In addition, greater attention must be given to educating referring physicians about the specialty and building stronger collaboration with palliative care providers (Kirolos et al, 2014, p. 962). For those seeking to increase referrals, the Pediatric Palliative Care Study provides a conduit for not only creating awareness of the lived experience but also the means by which palliative care can serve as a viable solution. It demonstrates the importance of increased communication and education for health care stakeholders, including direct patient care providers, health care business leaders, insurance companies and external community agencies. To increase referrals and improve alignment between providers, the lived experience and knowledge of palliative care need to be more widely disseminated to stakeholders who are in positions to educate families and connect them to services in their community.

Likewise, the study also can be leveraged by insurance companies (commonly referred to as payers) to understand the lived experience and manner in which palliative care can address the needs of children and families. Today, pediatric palliative care faces reimbursement challenges, which may be one of the principle detractors for health care organizations that might otherwise initiate or expand their program offerings. In simple terms, insurance companies and payers establish fee schedules to identify the amount of reimbursement they are willing to provide for certain types of procedures or health care services. The fee schedules and payer contracts may not cover the cost of providing care, nor is value necessarily assigned to preventing hospitalizations or invasive procedures. Therefore, despite health care providers offering alternatives that would maintain the health of patients and reduce long-term expenses, payers do not necessarily reward providers and incentivize the adoption of these innovative models of care (Luft, 2006). In order to rally payers to amend their payment models and contracts with health care providers, they require an understanding of the service, value proposition and degree to which it offers a cost-effective alternative to current care models.

Understanding the Skills Needed for Palliative Care Providers

Moreover, the study brings clarity to the multifaceted role and responsibilities of pediatric palliative care providers and the combination of skills necessary to assist families during their time of need. Overall, only a small percentage of health care providers and nurses have the skills and expertise necessary to offer palliative care to children, as the availability of specialized education and training is limited (Meier, 2011, p. 356; Reid, 2013, p. 541). The inadequate workforce and lack of palliative medicine training is considered one of the most significant barriers to expanding access (Meier, 2011, p. 356). For those organizations seeking to expand their existing pediatric palliative care programs or initiate new services, the study provides insights into the technical and interpersonal skills that are most valued. Based on the complexity of care, providers do not merely address the physical, emotional, psychosocial and spiritual needs as health care experts, but they also adopt roles as guides, companions, educators, trusted partners, witnesses, active listeners, thought partners and vocal advocates. These insights can be utilized to shape provider education and training, as well as the recruitment priorities for hard and soft skills.

Improving Data Reporting for Palliative Care

Finally, the study serves to raise awareness of an overlooked and under-reported health care need in the U.S. At present, neither adult nor pediatric palliative care programs are required to track quality data, volume statistics or other operational details for external reporting purposes or accreditation bodies (Meier, 2011, p. 353). On an annual basis, the Center to Advance Palliative Care (CAPC) and the National Palliative Care Registry gather operational statistics from existing programs for a data repository to assess the current offerings, staffing, patient population and other key details from providers across the county (CAPC, 2014). However, the annual survey is optional and does not collect data specific to pediatrics; it also does not assess epidemiological data to quantify the number of people who are eligible for palliative care in comparison to the availability of services. By generating an awareness of children with life-limiting conditions and palliative care, the study has the ability to be leveraged to rally for improved epidemiological reporting and tracking of pediatric palliative care programs in the country. Without accurate data about the number of children affected by life-limiting conditions, the number of palliative care programs in the country and the patient volumes within those programs, it will remain impossible to know the improvements that are being made in the provision of care or the access shortfalls that exist across the country. In order to measure the rate of change over time, the study supports a call to action for improved reporting.

Ultimately, the Pediatric Palliative Care Study can be used by practitioners in numerous ways within their areas of expertise, ranging from initial forays to step into the lived experience to concrete actions that may expand the provision of services. Because the study tells the comprehensive story of the phenomenon, it creates a foundation for practical applications by care providers, operational leaders, insurance companies, government entities and other stakeholders who can discern how best to utilize comprehension of the experience to drive change and innovation at a local market, state and national level.

5.3 Contributions to Extant Literature

Apart from the study affording implications for future practice, the Pediatric Palliative Care Study offers three contributions to extant literature by building upon the published research of other scholars to address deficits in the literature. The contributions include validation and suggested refinements to the WHO definition of pediatric palliative care, a systematic review of the literature from 2011-2014 to ascertain the ongoing lack of pediatric-focused research in the leading palliative care journals and, most importantly, a comprehensive study of the lived experience that begins to address a known gap and build upon the body of extant literature.

Validation & Refinement of WHO Palliative Care Definition

First, the study validates the most widely recognized definition of pediatric palliative care, which was originally developed by WHO as a subset of its Cancer Control Programme but has been recognized as applicable to other diagnoses beyond oncology (WHO, 2014). Because WHO does not describe how it developed its definition, it is value-added to evaluate the definition in the context of the lived experience to ascertain its comprehensiveness or potential limitations. Overall, the lived experiences shared during the study align with the key components of the WHO definition, although the research findings suggest areas in which the definition could be augmented to highlight additional points of distinction in comparison to adult palliative care. The following assessment offers a comparison of the WHO definition to the lived experience (see Table 5.1):

TABLE 5.1 COMPARISON OF WHO DEFINITION TO LIVED EXPERIENCES

Excerpt from the WHO Pediatric Palliative Care Definition (WHO, 2013)	Key Observations from the Research Findings
Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders.	WHO has noted accurately that the provision of palliative care is most appropriately directed to both children and families, as opposed to the child alone. The research findings demonstrate the interconnectedness of the child and family, with care providers noting the "patient" in these circumstances and overall scope of care extends beyond the child (see Chapter 4). However, the findings reveal others beyond the child and family also are within the purview of palliative care, including the extended family and community members who may maintain a connection to the family, be affected by the illness and death of the child, and have a need for support in varying ways (see Major Theme 1). This is an area in which the WHO definition does not extend far enough in calling out others who may be included in the scope of services.
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.	The research findings validate the multifaceted approach of caring for the child and family as whole person by paying particular attention to their physical / medical care needs, emotional and psychosocial needs, and spiritual care needs (see Major Theme 3). In addition, the lived experience demonstrates a priority to address basic needs that are life-sustaining and physiological in nature, which, if left unaddressed, could inhibit the ability to address the total care of the body, mind and spirit.
It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.	WHO is astute in noting care begins at the point of diagnosis, regardless of whether the child is receiving curative treatment (WHO, 2013). While the definition is accurate, the research findings reveal palliative care and support for families may begin *prior* to the birth of the child if a life-limiting condition is diagnosed during the perinatal period (see Major Theme 3). Acknowledging the diagnosis of illness may occur prior to birth is a subtle nuance, but it warrants further study and recognition within the health care industry. It may serve to evolve the definition of pediatric palliative care to consider the holistic needs of the family from the moment they learn about the prognosis of the child and encourage consideration of how best to provide services to meet their needs.
Health providers must evaluate and alleviate a child's physical, psychological, and social distress.	Similar to acknowledging the "total care of the child's body, mind and spirit" (WHO, 2013), WHO focuses on concrete aspects of care that providers must aim to address during times of distress. These are validated through the lived experiences of care providers who confirm their responsibility to place the child at the center of care (see Major Theme 2) to care for them as a whole person (see Major Theme 3) and allow the child's voice to be heard (see Major Theme 8). However, it is worth noting that providers do not focus on caring for the child during times of distress alone but rather are present throughout the trajectory of the child's illness during times of both suffering and greater well-being.
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.	A hallmark of pediatric palliative care is the interdisciplinary care team and partnership with referring providers, acute care and primary care providers and other community resources (see Major Theme 1). The lived experiences also demonstrate the value of connecting families with resources to address practical issues (see Major Theme 4), as well as external support systems (see Major Theme 6). While resources vary by community, the team approach plays a pivotal role in making families aware of the resources that may be beneficial in their situation.
It can be provided in tertiary care facilities, in community health centres and even in children's homes.	The WHO definition reflects accurately the diverse locations in which care can be provided. The experiences suggest children and families have a preference for home-based care (see Major Theme 1), but the diversity of research settings included in the study demonstrate that effective options also exist in acute and ambulatory locations, as well.

Assessment of Adult Versus Pediatric Palliative Care Literature

Second, the literature review for the study (see Chapter 2: Background) evaluated a systematic analysis of the top twelve palliative care journals from 2006-2010, which revealed less than three percent of the articles were related to the pediatric population (Kumar, 2011). The principal researcher built upon the research by Kumar (2011) by examining the extant literature from 2011-2014 and determined the comparative trend has not changed significantly during that time period (see Chapter 2, Figure 2.1). The percentage of pediatric articles increased by less than 2.5 percent from 2.66 percent in 2006-2010 to 5.10 percent in 2014, meaning the disproportion between adult versus pediatric contributions to scientific knowledge remains largely unchanged. In 2012, the twelve palliative care journals reached their highest percentage of pediatric articles at 5.30 percent, but this volume declined by one percent in 2013 before rebounding in 2014. Because adult palliative care research is not germane or transferable to pediatric care, the ongoing deficits in the literature remain a noteworthy concern. With the availability of literature continuing to be limited, it means the emerging field of pediatric palliative care remains poorly researched and understood by those who could affect change, including practitioners and researchers (Stayer, 2012, p. 350). The trend in the literature will remain critical to monitor, as the percentage of pediatric articles in the leading journals may signal the extent to which the health care specialty is taking hold as an interest for researchers and practitioners.

Addressing Gap in Literature Through Comprehensive Study of Lived Experience

Finally, the third major contribution to scientific knowledge pertains to the gap in the extant literature that has been addressed by the study, specifically as it relates to understanding the lived experience of caring for a child with a life-limiting condition and their family, as well as the needs that emerge from the phenomenon. According to the International Children’s Palliative Care Network (ICPCN), research is one of the top five strategic priorities that must be pursued in order to increase the provision of care to children (Downing et al, 2014, p. 109). Deficits exist within the literature in terms of understanding family experiences and designing palliative care in a manner that meets the needs of the child and family (Steele and Davies, 2006; Ullrich and Morrison, 2013, p. 335).

During the literature review and ongoing evaluation of the most recently published literature, the principal researcher did not uncover prior studies that sought to articulate the lived experience from a comprehensive standpoint (see Chapter 2: Background). The systematic review by Kumar (2011) and further analysis of the leading palliative care journals by the principal researcher through 2014 has revealed nominal research about palliative care in a home-based setting with no published articles examining the comprehensive lived experience and associated needs. Therefore, the Pediatric Palliative Care Study has begun to fulfill a known gap in the extant literature and provides a foundation on which future studies can be built. Undertaking a phenomenological study was the optimal approach for addressing the considerable shortfalls in the literature, as it has afforded an opportunity to introduce a comprehensive picture of the lived experience of children and families, as opposed to a narrowed research topic that would have bypassed the crucial step of establishing the context of the overall experience. By using the study as a foundational element, any number of more narrow subsets of the experience now can be evaluated, as it will be possible to ground them in the context of the areas in which the subsets nest within the broader lived experience.

Therefore, by validating the most commonly utilized definition of pediatric palliative care in the world against the authentic experience of the phenomenon, assessing and quantifying the shortage of literature about the topic, and offering novel research that addresses a known shortfall, the principal researcher has proffered a study that is meaningful and value-added to scholars and practitioners alike. While the study has its limitations and cannot address the totality of deficits in the literature, it has promulgated findings that offer the basis for future research.

5.4 Limitations of the Research

Despite fulfillment of the research objectives, implications for future practice and contributions that build upon the extant literature, the Pediatric Palliative Care Study has six limitations, which may serve as laudable avenues for future research. In each instance, the limitations pertain to decisions associated with the methodology or research design of the study and thus were acknowledged by the principal researcher as acceptable limitations at the outset of the study. Unforeseen limitations did not arise during the course of the study, which speaks to the due diligence that was undertaken by the researcher in designing the study and contemplating potential pitfalls. The six limitations include that (1) no interviews were conducted with children or families, (2) the interviews relied on recall from pediatric palliative care providers and a willingness to share their lived experiences, (3) the study featured limited representation from some roles on the palliative care team, (4) the study was limited to palliative care programs within Providence Health & Services, (5) the geographic scope of the study was limited to the states of Washington and California and (6) the study was conducted by a single researcher, including all interviews and data analysis.

First, the study seeks to understand the pediatric palliative care needs of children and families and explore the phenomenon of caring for a child with a life-limiting condition, yet the study was designed to rely on the lived experiences of pediatric palliative care providers, rather than the children and families themselves. This scope of research was advantageous for several reasons, including that care providers were able to draw from experiences spanning many families and years of professional experience, thus making the sample size of family experiences appreciably greater than the 27 individuals who were interviewed. In addition, the providers work closely with families in their homes, often for an extended period of time (e.g. months or years), thus becoming an extension of the family and making them a suitable proxy for the voice of the family. Nonetheless, the lack of a direct voice from families and children could be a source of criticism.

Next, the interviews relied on providers to recall and be willing to share their lived experiences. The research findings may have differed if providers had been asked to keep a journal for a period of time, as opposed to relying on their memory to recount critical details, such as the questions posed to them by children and families during home visits. Nonetheless, the interviews proffered rich examples and detailed stories of working with specific children and families. While the providers offered broad statements about their experiences, they also supported the statements with detailed examples. If interview participants had been asked to keep a journal, it is plausible that fewer care providers would have agreed to participate in the voluntary study, as securing up to 90 minutes for an interview represented a substantial time commitment. While more detail may have been attained if care providers wrote about their experiences closer to the time in which the events took place, it is unknown whether the additional details would have generated considerably different findings or whether the greater time commitment would have been a detractor to the study.

Of the 27 care providers who consented to participate in the study, almost half (48.1 percent) were nurses and 18.5 percent were social workers, followed by more limited involvement from other roles on the care team (see Chapter 3: Methodology, Section 3.6 and Section 3.7). While the participation generally aligns with the composition of the team and the proportion of time participants spend in family homes, the voice of some roles was more limited. The variation in representation and, in some cases, the inclusion of a single voice for a unique role may be a limitation of the study since additional participation from identical or similar roles was not present to validate the views of the lived experience. Nonetheless, during the data analysis, the principal researcher found the number of participants by employment role may not have been a critical factor due to the repetition in themes that spanned the roles. For example, a core element was frequently referenced by several roles on the team, as opposed to being isolated to one function.

Moreover, the setting for the study was limited to four research sites within Providence Health & Services, as these represent the only pediatric palliative care programs in the health system where the principal researcher is employed (see Section 3.5). The four Providence programs share the same organizational mission, vision and core values. The scope of research was not expanded to include other locations across the country, including health care providers who are not associated with a non-profit or religiously-affiliated organization. Based on the design of the research study, it is unknown whether organizational context is relevant and whether perceptions about the lived experience or the needs of the family may be perceived in a different manner by employees who work for other types of health care organizations. For example, it is unknown whether the religious affiliation of Providence as a Catholic health care entity influences the cognition and approach to the spiritual needs of children and families. Also, due to the research setting being limited to the pediatric palliative care programs within Providence, the geographic scope of the study was restricted to the states of

Washington and California. Some interviewees had experience working in other states and were able to draw from a broader frame of reference for their career. However, it is unknown whether geographic diversity may be a factor in the needs of patients and families, which may be informed by the ethnic diversity of the communities served or the availability of support services or resources for children and their families.

Finally, the principal researcher conducted and maintained ownership for all aspects of the study, including the research interviews and data analysis. Therefore, the potential exists for the research findings to reflect the bias of the researcher. Throughout the study, steps were taken to guard against researcher bias, such as completing a bracketing paper, limiting the literature review to an appropriate scope and asking research participants to review and validate the thesis before it was finalized. In addition, primary and secondary thesis supervisors also reviewed the work of the researcher in a manner consistent with traditional peer review processes. Nonetheless, the potential for bias may be higher in a study that has been predominantly undertaken by a single researcher, as opposed to research that is executed by a team of researchers for the duration of the study.

5.5 Implications for Future Research

As has been noted, the Pediatric Palliative Care Study makes noteworthy contributions by addressing a substantial gap in the extant body of literature and leveraging phenomenology to offer a comprehensive overview of the lived experience of caring for a child with a life-limiting condition and the holistic needs of the family. Nonetheless, the research findings and limitations of the study demonstrate opportunities for ongoing research that would advance the field of pediatric palliative care and offer meaningful contributions for scholars and practitioners. While not meant to serve as an exhaustive list, the following recommendations are intended to tender a suggested starting point for a future research agenda for the current principal researcher and those seeking to build upon the research findings from the study.

First and foremost, the current study has helped construct an overarching understanding of the lived experiences of caring for a child and their family, as well as the needs that should be addressed through the provision of palliative care. The research findings proffer both granular details with direct practical applications and more conceptual depictions that illuminate the lived experience at a higher level. As such, the study has represented an appropriate starting point in addressing the lack of research about the comprehensive palliative care needs of children and their families. Before delving into a specific niche in pediatric palliative care, it was consequential to research and build a holistic portrayal of the lived experience. However, due to the intentional breadth of the study, only limited details can be provided about the themes. In general, the study has provided a foundation on which future studies can be grounded, as any one of the 151 core elements, 28 sub-themes or nine major themes would benefit from dedicated focus and in-depth study by future researchers.

Future studies that incorporate the voice of the child and family also would be beneficial in advancing the understanding of the lived experience and needs that arise in relation to palliative care, as it would be advantageous to hear directly from families and children, depending on their age and cognitive development. A 2014 study concluded institutional review boards (IRBs) may limit approval of studies designed to gather information from families due to concerns that the studies may be “onerous” or “troubling”; however, families have been found to value involvement in research and even find it empowering to make a difference for others (Steele et al, 2014). The voice of pediatric palliative care providers and their experiences have been instructive in understanding the phenomenon of caring for children and their families, as well as the needs that emerge from these situations. Nonetheless, an opportunity exists to replicate the current study and interview families or children in order to validate the research findings and determine if new themes emerge that were not discerned within the provider interviews.

Moreover, future opportunities exist to conduct and delineate research on the basis of age group. The personal examples shared during the research interviews for the current study indicate the lived experience of the family and the needs of children vary by age and cognitive development. For example, teenage patients tend to be more vocal and have the ability to articulate their holistic needs, emotions and preferences. By comparison, newborns or children with severe cognitive and developmental delays may be less vocal or less engaged in their care. The age of the child also can influence the role of the family, preferred communication style and other factors in providing palliative care in a home-based setting. Therefore, research that explores the lived experience and comprehensive needs based on the age of the child could be advantageous.

As reflected in Section 5.4, the study was conducted with a limited geographic scope, as the research interviews were held with providers in Washington and California. Replicating the current research study in other locations across the U.S. or international sites would provide opportunities to assess whether the community, state or country where the child and family is located influences their lived experience and needs. Conducting research in multifarious locations would serve to confirm whether the major themes noted in the current study are universally acceptable or if themes vary by geography, which would be of interest to scholars and pivotal to practitioners seeking to utilize the findings to address the palliative care needs in their community.

Furthermore, the literature review for the current study (see Chapter 2: Background) demonstrated the dearth of published research about pediatric palliative care; it also is worth noting the scarcity of research in the body of literature that is specific to pediatric palliative care teams and providers. While outside the scope of the study, additional topics that are specific to the needs and lived experiences of providers surfaced during the research interviews that warrant further exploration. For example, compassion fatigue, professional burnout, resilience and coping skills were issues raised by providers as they reflected on their lived experiences. Future phenomenological research that explores how the lives of providers are affected by their professional experiences and the situations to which they are exposed on a regular basis would be beneficial to scholars and practitioners since these topics may influence the extent to which providers are prepared to care for children and their families.

Finally, the literature review also revealed information gaps that would be optimal to address in order to provide context for the current and future studies. For example, quantitative research about the number of pediatric palliative care programs in the U.S. and more accurate data about the number of children with life-limiting conditions would be beneficial so that progress toward addressing the unmet needs can be measured and evaluated in a longitudinal manner. In addition, a lack of quantitative research exists about the definitive amount of time pediatric palliative care providers spend with children and families. This type of future research would bolster the rationale for care providers serving as a suitable proxy in speaking to the phenomenon of caring for children with life-limiting conditions and the related palliative care needs.

In summary, the Pediatric Palliative Care Study has opened avenues for innumerable future research opportunities by articulating the lived experience of caring for a child with a life-limiting condition and exploring the comprehensive needs of the child and family. In the words of a pediatric palliative care social worker who was interviewed for the study, “It would be just wonderful if there were way more efforts. I know there’s a way of being able to put the real stories of these families and these kids into the hands of hospitals, doctors and new students … that just speaks volumes to how important this work is.” Indeed, the current study has begun to address the gaps in the body of literature, but one isolated study is not sufficient to overcome the knowledge deficits about pediatric palliative care.

5.6 Validation by the Research Participants

As noted in Chapter 3, Section 3.14, research participants were provided an opportunity to review the draft Pediatric Palliative Care Study and provide input prior to its completion and publication by the University of Liverpool. Participants were invited to review any or all chapters of the study. However, recognizing the overall length of the document and wanting to be respectful of their time, the principal researcher recommended participants pay particular attention to Chapter 4: Research Findings and Chapter 5: Discussion. These chapters include the greatest information from the interviews; they are most closely connected to the work performed by the palliative care providers each day and the recommendations for how the study can be utilized in the future. Although reviewing and providing feedback was not required, more than one-third of participants elected to respond with written feedback to the principal researcher. Of those who responded, all indicated they had read the thesis in totality. The written feedback served to validate the research findings and overall essence of the lived experience, with many expressing appreciation for the manner in which the findings from the study shed light on an inadequately understood issue. They also noted the respectful balance proffered by the study for not only bringing awareness to pediatric palliative care but also the manner in which the study acknowledges the progress that has been made in developing an innovative approach to caring for children with life-limiting conditions. The participants responded affirmatively about the high degree to which the findings resonated with them, including the importance of the decision to compose the nine major themes that emerged from the study with the voice of the child and family in mind (see Chapter 4: Research Findings).

> The nine major themes that presented themselves would have only been impersonal "Themes" had you not given them the most important emphasis. "Place ME at the center of care", Care for ME as a whole person", Be MY guide" … Just listing them is inspiration!! If your work can compel us to serve in this way, you have accomplished a great deal.
>
> Community Liaison

Moreover, as it relates to the methodology, the research participants validated in their own words the importance of selecting IPA because of the richness of details about the lived experience that are included in the study. The use of quotations to tell the comprehensive story of the lived experience and provide tangible examples for the major themes drew the research participants into the study, with one participant calling the thesis "thoughtful, in-depth and balanced work." More importantly, the participants affirmed that they felt their voice was heard and represented within the findings.

> As I have read and re-read certain chapters in your work, I am left with a deep sense of gratitude. Not often is scholarly knowledge and research so filled with compassion … Having given my life for the furtherance of this important work with these many children and their families, it has been of utmost importance that we capture this 'labor of love' and substantiate its progress and challenges. Something I think you have accomplished so well here … Your choice of language is so accurate in describing the unbelievable journey into and out of the "abyss of vulnerability." Perhaps that lies in part because it is indeed the voices and stories of the children and their families that serve as your foundation. Also, using the interviews from those 'in the trenches' adds the dimension that makes it all authentic!
>
> Community Liaison

In terms of the implications for future practice and future research, the participants not only validated that the implications listed in Section 5.2 resonated with them, but several participants also expressed a desire to continue collaborating and partnering on future research endeavors. Multiple participants asked permission or expressed a desire to share the study with others, including coworkers, health care providers in the community and other stakeholders. They viewed the study as a conduit for helping palliative care providers and other stakeholders develop a better understanding of palliative care for children.

> I really enjoyed reading this and intend to have my intern read this. Thank you for bringing life to something that so many pediatric practitioners have little understanding of and hopefully this will help as it gives a clear and accurate picture of pediatric palliative care needs.
>
> Social Worker

Ultimately, while asking research participants to validate the data interpretation of an IPA study prior to its publication is consistent with phenomenological analysis (Hammill and Sinclair, 2010, p. 20), it is not a compulsory requirement. Nonetheless, the inclusion of the pediatric palliative care providers in the review process has served to bring the study full circle. Having initiated the study by listening to the voice of the providers during the research interviews, it was appropriate for the participants to be given an opportunity to review and reflect upon the thesis, especially the research findings and implications for future practice and future research. The validation of the major themes and positive response to the manner in which the quotations were utilized serve to substantiate the accuracy of how the comprehensive lived experience has been portrayed. Furthermore, the review process also serves as a catalyst for ongoing research, as the pediatric palliative care providers who participated in the study desire to continue working with the principal researcher to address additional avenues for future research (see Section 5.5) and work in partnership to utilize the study to bring greater awareness to pediatric palliative care.

CHAPTER 6

Conclusion

"But [the families], I think, want to know that someone is there for support in case they need us. They want to be supported. They want to have that safety net that in case something drops out that they're not going to fall into the abyss. We're there to catch them. It's not just that someone's there, but it's someone's there who cares. Someone's there who cares about their child, who loves their child, that cares about them, that knows them, that has a relationship with them."

~ Pediatric Palliative Care Nurse

Upon final reflection, advances in modern medicine have served to curb the high incidence rate of infant and pediatric mortality within industrialized nations around the world. However, these same advances also have led to longer-term survival of children who are facing serious conditions that, even now, may preclude them from reaching adulthood. Based on the most conservative estimates from currently available epidemiological data, the regrettable reality remains that approximately one of every 160 children in the U.S. *will* face a life-limiting condition -- whether it is a condition present at birth, a medical diagnosis that arises during childhood or an accident that causes irreversible damage that will be fatal.[17] Nonetheless, faced with the difficult truth that not all children can be saved, the opportunity exists for understanding the lived experiences of families who are caring for these children and offering care that is responsive to their needs, especially pediatric palliative care that can be provided from the point of diagnosis through the end-of-life. Despite the known advantages of the holistic approach embodied within pediatric palliative care, less than one percent of children and families who could benefit from these services are receiving them today (Stayer, 2012, p. 350).

As previously noted in Chapter 2: Background, the slow adoption rate and limited growth of pediatric palliative care across the U.S. may be attributed to several factors, most notably the dearth of research in the existing literature about the emerging specialty (Kumar, 2011). Due to the recognized deficits in the extant literature, the Pediatric Palliative Care Study was designed to fulfill two research objectives: (1) understand and articulate the comprehensive lived experience of caring for children with life-limiting conditions and their families and (2) delineate how the collective experiences provide insights into needs that can be addressed through the provision of pediatric palliative care. The research objectives were aptly sequenced to recognize that understanding the lived experience should be regarded as a prerequisite to designing innovative health care delivery models and solutions for children and their families.

6.1 Fulfillment of the Research Objectives

Building upon current literature, the Pediatric Palliative Care Study serves as the first IPA study to examine the comprehensive lived experience of caring for children with life-limiting conditions and their families, and it offers a statement of

---

[17] Per the U.S. Census Bureau (2014a), there were 73,585,872 children under age 18 in 2013. While epidemiological data is limited, the annual incidence rate of U.S. children with a life-limiting condition is estimated to include 400,000 children, plus an additional 53,000 children who succumb to their condition per year (Friebert and Huff, 2009, p. 1). More aggressive estimates suggest more than a million children have a life-limiting condition (Rushton and Catlin, 2002, p. 57), which would equate to one of every 75 U.S. children.

essence that connects the major themes from the research findings to tell the overarching story of the phenomenon. The lived experiences of 27 pediatric palliative care providers within Providence Health & Services and analysis of their spoken word have fulfilled the aims of the first research objective by using the IPA methodology to bring the phenomenon to light. It has provided a conduit for scholars and practitioners to step into the experience in a manner that cannot be proffered in a parallel manner by quantitative research. The explanatory study has provided the necessary depth to understand the holistic experience, which has been augmented appropriately by illustrative quotations from the research interviews. The quotations serve to bring awareness to the first-hand accounts of care providers who have worked extensively with families and are intimately familiar with the day-to-day experiences and the needs that surface when caring for a child with a life-limiting condition. The voice of participants and their personal perspectives have been positioned as the central focal point of the research findings in a manner that is a trademark characteristic of IPA studies (Reid et al, 2005, p. 22). In relation to the second research objective, the Pediatric Palliative Care Study also has used the collective experiences to offer insights into needs that can be addressed through the provision of palliative care services. Scholars contend that phenomenology is a means by which to examine the experiences of patients in order to identify care delivery solutions that will meet their needs (Jasper, 1994, p. 313), which has been validated by the current study. The amalgamation of the 151 core elements, 28 sub-themes, nine major themes and the overarching statement of essence tender key insights into the needs encountered by children and families, as well as practical implications for the way in which pediatric palliative care can address these factors (see Chapter 4: Research Findings and Chapter 5: Discussion).

6.2 Benefits of the Study for Future Practice & Extant Literature

Through the fulfillment of the research objectives, the study has garnered implications for future practice, contributions to address deficits in the extant literature and recommendations for future research that are relevant to researchers and practitioners both now and in the future, as the findings are timely, applicable and transferable to decision-making (Tuckett, 2005, p. 31). In terms of timeliness, the Pediatric Palliative Care Study has been introduced at the appropriate juncture to respond to emerging concerns within the U.S. health care industry, both in terms of addressing the unmet need for palliative care services in the vast majority of communities across the country and acting in response to the three-prong aim of the PPACA health care reform legislation to increase access to care, improve affordability and enhance quality. In both situations, an underlying need exists first to understand the comprehensive lived experience of the children and families that the industry must seek to serve, which has been introduced by the study as a starting point for future application and ongoing research.

Moreover, the study has generated seven examples of implications for future practice and actionable knowledge that are applicable and transferable to decision-making, although the findings have the potential to be leveraged by practitioners in numerous ways based on their organizational or community needs. The key implications for future practice include (1) balancing matters of health care design with the human experience, (2) addressing the aims of health care reform legislation, (3) developing care models for home-based settings, (4) customizing care and developing solutions from the perspective of families, (5) educating about palliative care, (6) understanding the skills needed for palliative care providers and (7) improving data reporting for palliative care. Furthermore, whereas the aim of research studies is to pinpoint and address a single known gap in the extant literature, the Pediatric Palliative Care Study has offered three contributions, including: (1) validating and refining the WHO definition of palliative care in comparison to the lived experience, (2) completing an assessment of the adult versus pediatric palliative care literature from 2011-2014 and (3) addressing a known deficit in the literature by offering the first IPA study to articulate the comprehensive lived experience (see Chapter 5: Discussion).

6.3 Closing Remarks About the Pediatric Palliative Care Study

Ultimately, pediatric palliative care is a health care service that modern society and families across the U.S. would likely concur that they would prefer need not exist. The necessity of the emerging specialty indicates young lives will fall short of reaching adulthood, with at least one child with a life-limiting condition dying every 10 minutes in the U.S.[18] While there may not be hope for a medical cure to save every child, there should remain hope for innovative care that makes a tangible difference in the lives of children, families and care providers. The Pediatric Palliative Care Study has offered the foundation for scholars and practitioners to understand the experience of the children and families and make decisions to drive change in the development and provision of services at a local, state and national level. In addition, the study has contributed to the development of a future research agenda for those seeking to address the dearth of applicable literature. In the closing sentiments of a pediatric palliative care nurse:

> I think we're put on this earth to be here for each other. It's easy to be here in the good times – the celebrations, the births, the anniversaries, the promotions, the things like that. But sickness and dying? Those are the tough ones, but we're still called to be here for each other. It's a privilege to be on this team to help a fellow human who is going through suffering and to be there for them.

---

[18] Approximately 53,000 children die from a life-limiting condition in the U.S. each year (Friebert and Huff, 2009, p. 1), which equates to 145 children per day, six per hour or one every 10 minutes.

Postscript

Reflections from the Principal Researcher

“The King will reply, ‘Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.’”

Matthew 25:40 NIV

As I contemplate the journey to complete the Pediatric Palliative Care Study, the single question I have been asked most frequently is “What led you to select this topic?” From a business and academic perspective, the answer is straightforward (see Chapter 1, Section 1.4). In summary, children with life-limiting conditions are living longer due to medical advances in the health care industry, yet a nominal amount of families are benefiting from pediatric palliative care that can aid the journey with their child. The study also is timed appropriately to offer key insights to those seeking to develop innovative health care delivery models that reflect the aims of the PPACA legislation and may prompt health care providers to pursue this emerging growth opportunity in the U.S. health care system. Finally, the deficits in the extant literature have created a conduit for scholars to offer novel contributions. However, despite the abundance of practical and scholarly reasons for the study, those who posed the question were seeking deeper insights into why I, personally, would seek to adopt this particular research topic. Indeed, this represents a pivotal question that all researchers should seek to answer before selecting a problem to solve and commencing with a study. After completing one of the first modules in the Doctor of Business Administration (DBA) program, I wrote a brief note to myself that read, “I want to write to make a difference. This informs the topics that I select (e.g. underserved and vulnerable populations).” The now tattered and faded note remains taped to my office computer as a reminder of the underlying principle of how I select research topics. When the time came to select a thesis topic, I reflected on the insightful note and determined my study needed to comprise an area in which I could provide value to others and seek to make a tangible difference through the completion of the thesis. The following excerpt has been extracted from the reflections I penned in November 2013 to provide insight into my rationale for selecting pediatric palliative care as the focus of my thesis:

> In the beginning, pediatric palliative care wasn’t a topic that I planned to adopt as a researcher. After all, the subject matter is difficult to fathom and can be uncomfortable to acknowledge. From my perspective, so few are willing to contemplate that there are children around the world who are battling life-limiting conditions that will lead to their early death, nor do people necessarily want to acknowledge the challenges faced by families and what it must be like to care for these children each day. Overall, the difficult nature of the subject matter as an almost “taboo” subject may help explain why so little has been written about pediatric palliative care within the literature. Nonetheless, this is a topic that I have felt a true calling to address … [H]aving worked in the health care industry since 2000, I have been inspired by the care providers who devote themselves to caring for the most vulnerable patients and their families. Their dedication to serving people in the most difficult times of life is awe-inspiring and courageous. While hands-on care

> hasn't been my personal calling, I admire those who can give so fully of themselves to help those in need.

Therefore, before concluding the Pediatric Palliative Care Study, I would like to offer a handful of closing observations and excerpts from my reflection notes to those seeking to utilize the research findings in daily practice or build upon the study in future research.

7.1 Autobiographical Nature of Research

According to Primeau (2003), researchers must complete an honest assessment and inventory of personal values and interests that may influence their research work. By becoming more reflexive and deliberate about taking inventory of my personal values, attributes and interests through a bracketing process (Ahern, 1999), I have been able to more fully explain the decisions made in selecting and scoping the Pediatric Palliative Care Study. The design of the study also was informed by a unique component of the DBA program called a Doctoral Development Plan (DDP), which each student is required to complete prior to commencing with the thesis in order to consider the ways in which the doctoral coursework has informed their development as a scholar practitioner and researcher. In turn, the DDP reflections provide a foundation that students can utilize to inform the selection and design of a research study that is appropriate to them. For example, in my DDP reflections about knowledge creation, I explained (Crockett, 2013):

> Simply put, I yearn to make a difference in the U.S. health care industry and global community by introducing scholarly knowledge and management research that impacts others. One of my goals has been to find a subject niche to own as a scholar practitioner in offering contributions for the body of knowledge.

While I have not wavered from the earlier reflections in my DBA journey, I have gained clarity about the type of topics I want to embrace in my career as a researcher and, in particular, for my DBA thesis. When selecting a deficit in the extant literature to address or choosing a subject as the basis for a study, an autobiographical quality exists between the nature of the study and the principal researcher. The research becomes a part of you, and you become a part of the research. In this regard, the Pediatric Palliative Care Study is now an element of my personal identity because it reflects the charge I have adopted to make a difference for vulnerable populations through the research contributions that I offer.

7.2 Selection of the Research Methodology

The selection of the topic was an important starting point for the Pediatric Pallative Care Study, but so, too, was the identification of a suitable research methodology. As previously noted, limited information is available in the published literature for pediatric palliative care, so selecting the IPA methodology was an appropriate starting point for describing the lived experience from a comprehensive perspective (see Chapter 3, Section 3.1). When conducting research, a methodology should be selected on the basis of that which will answer the problem that is central to the research and offer contributions that can affect change. As the principal researcher for the study, I needed to consider my strengths as a researcher, areas in which I would seek to grow and the methodology that was best matched to the research problem. If the methodology that is best matched to a research topic is not a strength of the researcher, then a researcher should consider whether the topic is one which he or she should seek to address, as it may involve the development of new skills and competencies. In my DDP paper, I reflected on the following ideas in my profile as a researcher (Crockett, 2013):

> The fruits of my research solidified that I selected the right methodology for pediatric palliative care to generate research that could inform other scholars and practitioners, allow people to enter a world they might not otherwise explore and become moved to action by the findings in a manner that would not have been possible via a quantitative study. Now that I have used a qualitative research methodology successfully and overcome personal concerns about my ability to use more than quantitative methods, I have expanded my scope as a scholar practitioner and no longer am allowing a research methodology to define who I am. Quite the opposite, I am defining my success as a scholar practitioner in being adept in pairing workplace problems with the most appropriate research methodologies. My DBA journey has revealed I can engage confidently in quantitative, qualitative or mixed-methods research and can allow the problem to inform my methodological selections.

Before choosing a methodology and initiating the data collection, I also considered the type of results I envisioned at the end of the study that would be most value-added in order to address the deficit in the extant literature. I reviewed published theses and journal articles, critically analyzing the diverse array of research methodologies that were utilized and the type of results generated by each methodology before selecting IPA. In turn, it became apparent that the use of a research methodology is not precisely the same in each instance. A great deal of flexibility exists in how researchers employ a research methodology, make decisions about the design of the study and articulate the research findings. Therefore, understanding the aspects of prior studies that I wished to emulate became as equally important as identifying methodological choices that I did not find to be appropriate for the Pediatric Palliative Care Study. For example, I placed value on approaches used by researchers to make their studies thorough and rich in detail, yet comprehensible and straightforward to follow. This included studies that leveraged the spoken word of research participants as a central feature in order to generate greater understanding of the lived experience. I also lauded studies that promoted transparency and offered insights into the methodological decisions made by the researcher and how the data analysis that was undertaken resulted in the identification of the particular themes from the research interviews.

7.3 Reminder of Those Represented by the Research

One of the distinct advantages of the IPA methodology is the manner in which others can be drawn into the lived experience by reading the spoken words of others and seeking to understand the overall essence of the experience. Nonetheless, an imperative remains to remember that each personal story and a glimpse into the lived experience is about a real child, a real family and a real palliative care provider who has worked alongside them. The specific stories shared by the care team members about children and families for whom they have cared have left a distinct impression upon me. A deep richness exists in these stories, as they illustrate the type of needs more than could be fathomed through a quantitative survey. It has cemented for me the importance of conducting qualitative research and examining the lived experiences. During the first week of research interviews for the study, I wrote the following reflection note about the importance of remembering those who are represented by the research:

> As I walked down the hall to the office I would be using for the week, I was struck by the artwork that lined the hallways. No, these weren't the typical landscape photos or generic paintings that hang in many office buildings. On the contrary, they were beautiful photos of palliative care patients in their homes — often with their care providers or family members. At the end of one hallway hung two large bulletin boards with collages of hundreds and hundreds of faces of pediatric patients, most of whom I am told have passed away. As I begin my qualitative research, the photos are a critical reminder that the stories I am about to hear are about real people – young children whose precious faces show the wear-and-tear of illness and a wisdom past their years that only comes from fighting for a little extra time on this earth.

As I reflect on my role as a scholar practitioner, the photos serve as a poignant reminder of the importance of the research I have undertaken for my thesis. I am in a position that is forever indebted to the care team members who entrusted me with their personal stories. They have provided a glimpse into their world and the realities of what it is like to care for children with life-limiting conditions and their families. To me, the research I have pursued is greater than merely completing a thesis; it is about being the conduit to allow these stories to transform what others understand about the palliative care needs of children and their families. In the end, I hope the contributions offered to the body of knowledge are meaningful and make a difference for this vulnerable population. However, in reality, I know the stories and this research have had an even more profound impact on my life as a scholar practitioner and researcher. In research, we may hope to affect change around us, but it is we who are forever changed by the journey of grappling with a difficult problem and offering contributions to address it.

7.4 Personal Lens Through Which a Phenomenon is Examined

Following the completion of the research interviews and data analysis, I prepared the written synopsis of the research findings within the thesis. The review process for the Pediatric Palliative Care Study provided an opportunity for all research participants to review the study and offer feedback, as well as the primary and secondary thesis supervisors for the University of Liverpool and other selected professional colleagues. Interestingly, each time the study findings have been reviewed, the reader has commented on a quotation or passage in the explanation of the lived experience that has a resonating quality. However, the quotation to which each person is drawn has been invariably different than the next person. In this manner, the feedback from the study demonstrates the personal lens through which people examine the phenomenon as they step into the lived experience. It also demonstrates the importance of capturing the comprehensive lived experience so that scholars and practioners can understand not only the aspects of the experience to which they are drawn but also the broader experience. A reviewer of the thesis offered the following comment about an excerpt in Chapter 4: Research Findings:

> In my opinion, this is the strongest quote in the study. It resonates with me and touches me on a personal level. However, it also has given me an entry point to understand the experience on a broader level. Because I was drawn in by this example that really touched me, I can't help but continue to be drawn into the rest of the research. The findings matter to me because I can grasp the meaning of it all on a personal level.

7.5 A Call to Action & Implications for the Scholar Practitioner

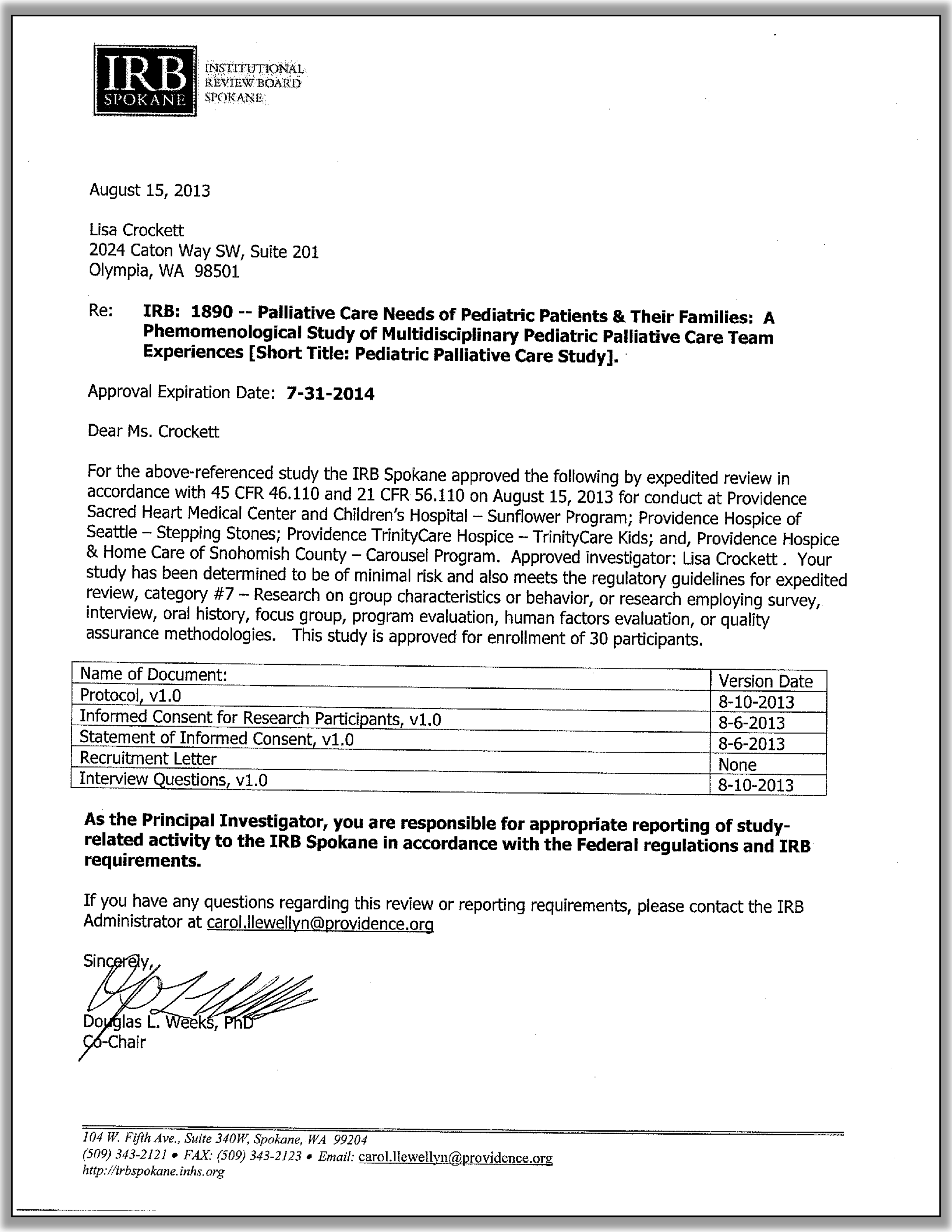
From an individual perspective, the completion of the Pediatric Palliative Care Study has begun to present new avenues for me to utilize the research presented within the thesis, both within Providence Health & Services and external settings. Through speaking engagements, conference presentations, internal workgroups and opportunities to publish elements of the research in academic journals, I will continue to devote attention to advancing the field of pediatric palliative care and bringing attention to a population that would otherwise have a limited voice in the literature. Along the way, I remain mindful that deep-rooted change can be slow to occur and requires a long-term commitment, not the completion of an isolated study. The following excerpt from my bracketing paper expresses an important consideration:

> The gift of time has allowed me to see the importance of planting seeds that may cultivate at a much later point in life. It was a humbling lesson in my life that making a difference may not be immediate and may not work at all, but it doesn't mean I should shy away from difficult issues or topics that others aren't willing to address. I need to listen to where I am being called and be willing to accept the successes and failures, ups and downs, and overall challenges that will be encountered on any journey in my personal, professional or academic pursuits.

In closing, I would like to delineate a call to action to those seeking to learn from the study, utilize the results in daily practice or build on the study via future research. In Chapter 5: Discussion, I have offered suggestions for the manner in which the research can be used in future practice to drive change in daily operations, redesign the health care delivery system and offer care to children and families in a way that is cognizant of their lived experiences, as expressed by the pediatric palliative care providers. The research is only as significant as the extent to which it serves as inspiration to drive change and is applied by others. Moreover, the chapter also proposes avenues for future research that can use the current study as a viable platform for further contributions to the literature. As reflected within this chapter, I encourage future researchers – including myself – to consider five questions: (1) Why are you seeking to research this topic?, (2) How are *you* reflected in the research?, (3) How will you select the optimal research methodology and design a study that answers the question at the center of your research?, (4) How will you maintain a focus on those represented by the research? and (5) What is the personal lens through which you and others are examining the lived experience?

APPENDIX A

Ethical Approval of Research Study



IRB
SPOKANE
INSTITUTIONAL
REVIEW BOARD
SPOKANE

August 15, 2013

Lisa Crockett
2024 Caton Way SW, Suite 201
Olympia, WA 98501

Re: **IRB: 1890 -- Palliative Care Needs of Pediatric Patients & Their Families: A Phemomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences [Short Title: Pediatric Palliative Care Study].**

Approval Expiration Date: **7-31-2014**

Dear Ms. Crockett

For the above-referenced study the IRB Spokane approved the following by expedited review in accordance with 45 CFR 46.110 and 21 CFR 56.110 on August 15, 2013 for conduct at Providence Sacred Heart Medical Center and Children's Hospital – Sunflower Program; Providence Hospice of Seattle – Stepping Stones; Providence TrinityCare Hospice – TrinityCare Kids; and, Providence Hospice & Home Care of Snohomish County – Carousel Program. Approved investigator: Lisa Crockett . Your study has been determined to be of minimal risk and also meets the regulatory guidelines for expedited review, category #7 – Research on group characteristics or behavior, or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. This study is approved for enrollment of 30 participants.

Name of Document:	Version Date
Protocol, v1.0	8-10-2013
Informed Consent for Research Participants, v1.0	8-6-2013
Statement of Informed Consent, v1.0	8-6-2013
Recruitment Letter	None
Interview Questions, v1.0	8-10-2013

As the Principal Investigator, you are responsible for appropriate reporting of study-related activity to the IRB Spokane in accordance with the Federal regulations and IRB requirements.

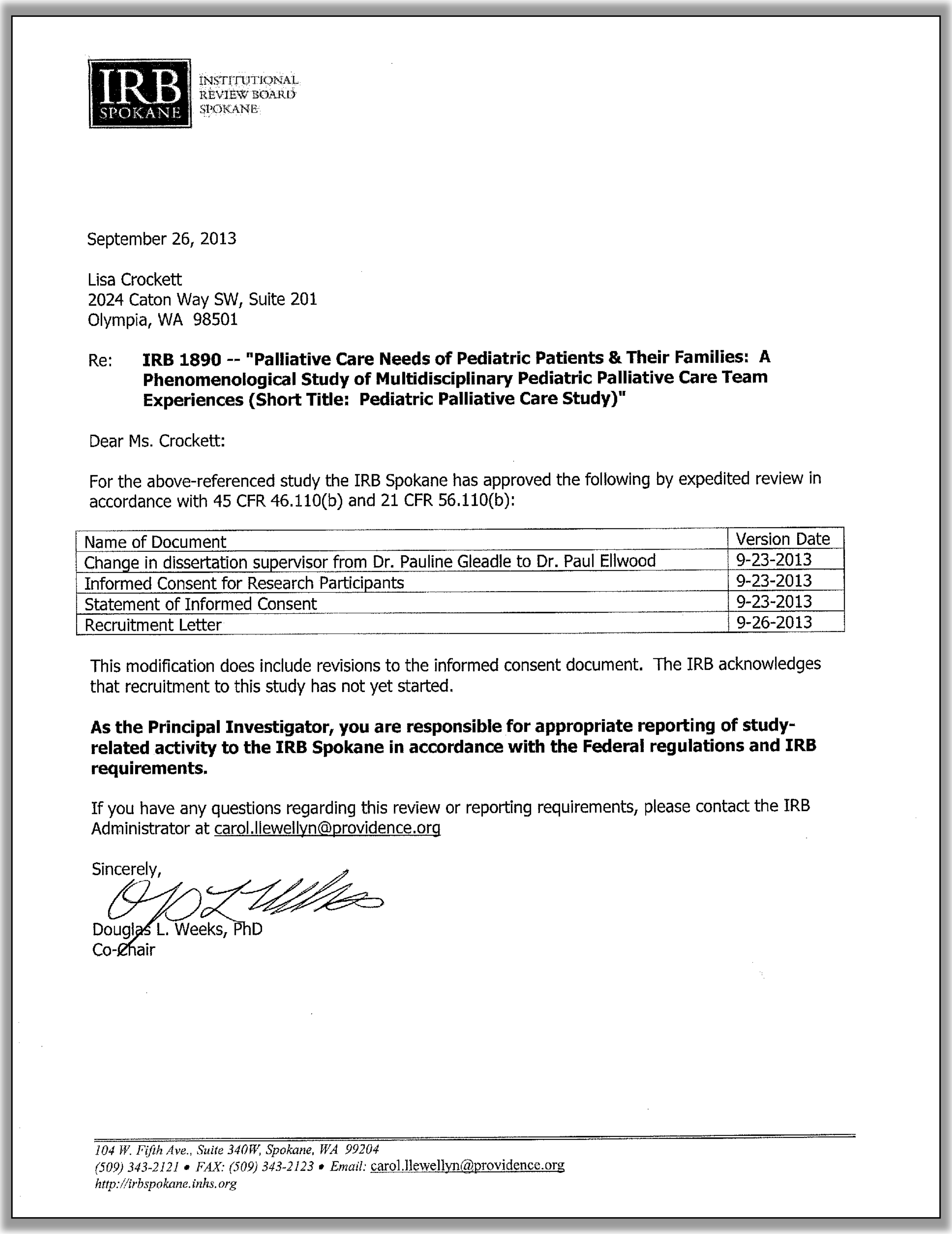
If you have any questions regarding this review or reporting requirements, please contact the IRB Administrator at carol.llewellyn@providence.org

Sincerely,

Douglas L. Weeks, PhD
Co-Chair

104 W. Fifth Ave., Suite 340W, Spokane, WA 99204
(509) 343-2121 • FAX: (509) 343-2123 • Email: carol.llewellyn@providence.org
http://irbspokane.inhs.org

Figure A.1. Ethical Approval Letter from the Institutional Review Board Spokane for the Pediatric Palliative Care Study (IRB 1890), August 15, 2013.



IRB
SPOKANE
INSTITUTIONAL
REVIEW BOARD
SPOKANE

September 26, 2013

Lisa Crockett
2024 Caton Way SW, Suite 201
Olympia, WA 98501

Re: **IRB 1890 -- "Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences (Short Title: Pediatric Palliative Care Study)"**

Dear Ms. Crockett:

For the above-referenced study the IRB Spokane has approved the following by expedited review in accordance with 45 CFR 46.110(b) and 21 CFR 56.110(b):

Name of Document	Version Date
Change in dissertation supervisor from Dr. Pauline Gleadle to Dr. Paul Ellwood	9-23-2013
Informed Consent for Research Participants	9-23-2013
Statement of Informed Consent	9-23-2013
Recruitment Letter	9-26-2013

This modification does include revisions to the informed consent document. The IRB acknowledges that recruitment to this study has not yet started.

As the Principal Investigator, you are responsible for appropriate reporting of study-related activity to the IRB Spokane in accordance with the Federal regulations and IRB requirements.

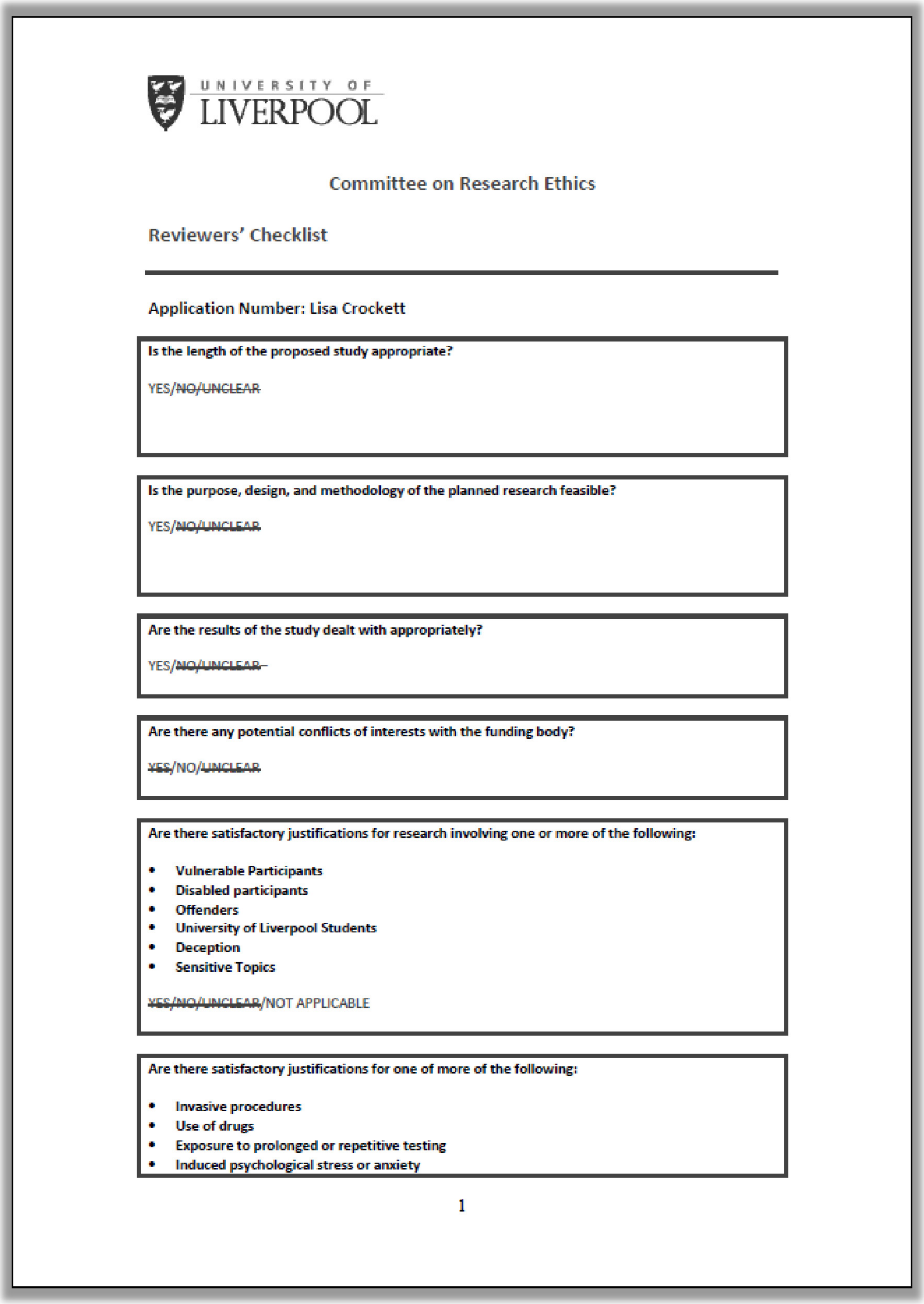
If you have any questions regarding this review or reporting requirements, please contact the IRB Administrator at carol.llewellyn@providence.org

Sincerely,

Douglas L. Weeks, PhD
Co-Chair

104 W. Fifth Ave., Suite 340W, Spokane, WA 99204
(509) 343-2121 • FAX: (509) 343-2123 • Email: carol.llewellyn@providence.org
http://irbspokane.inhs.org

Figure A.2. Amendment Letter for Ethical Approval from the Institutional Review Board Spokane for the Pediatric Palliative Care Study (IRB 1890), Noting the Change of Supervisor, September 26, 2013.



UNIVERSITY OF LIVERPOOL

Committee on Research Ethics

Reviewers' Checklist

Application Number: Lisa Crockett

Is the length of the proposed study appropriate?

YES/~~NO/UNCLEAR~~

Is the purpose, design, and methodology of the planned research feasible?

YES/~~NO/UNCLEAR~~

Are the results of the study dealt with appropriately?

YES/~~NO/UNCLEAR~~

Are there any potential conflicts of interests with the funding body?

~~YES~~/NO/~~UNCLEAR~~

Are there satisfactory justifications for research involving one or more of the following:

- **Vulnerable Participants**
- **Disabled participants**
- **Offenders**
- **University of Liverpool Students**
- **Deception**
- **Sensitive Topics**

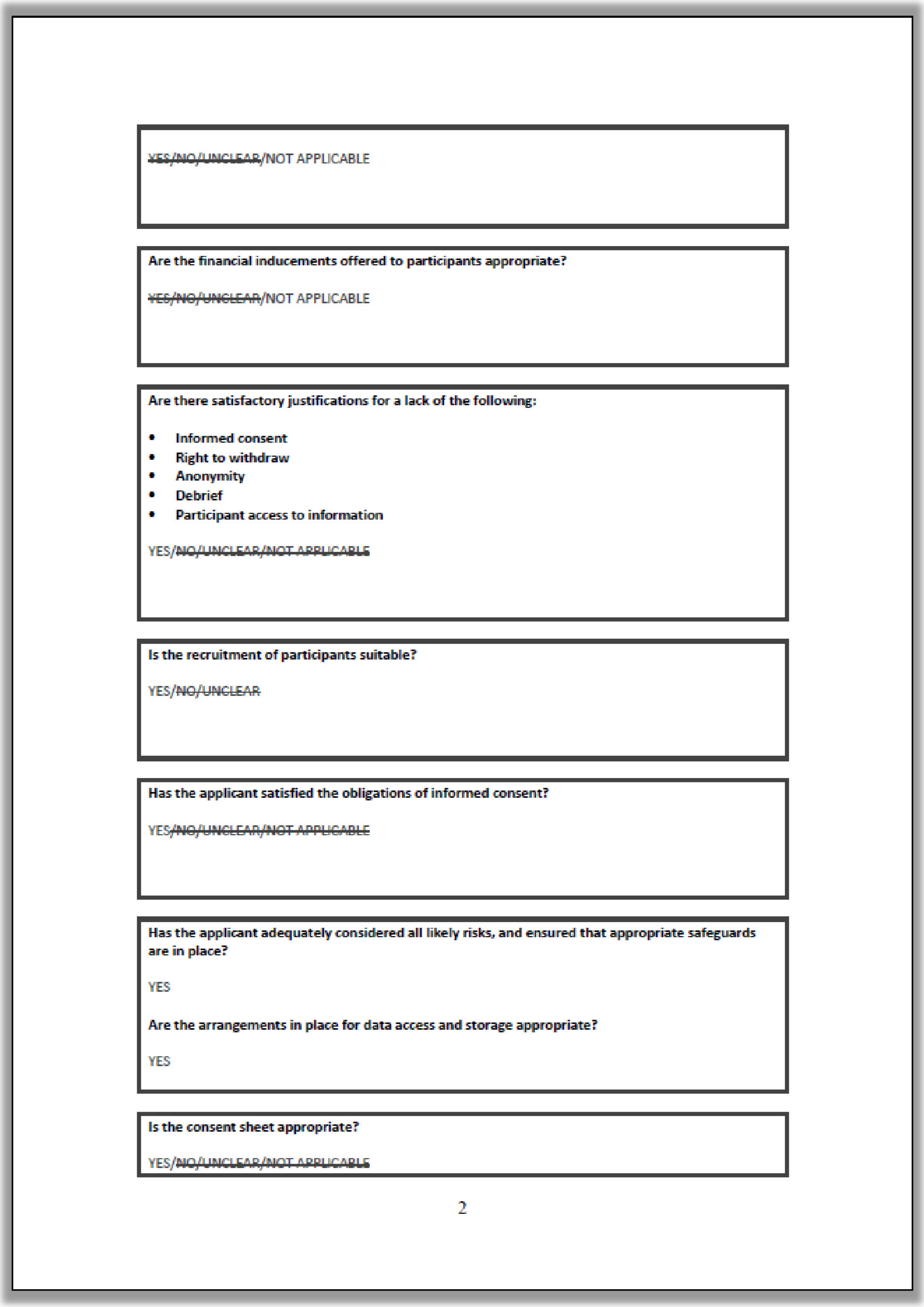
~~YES/NO/UNCLEAR~~/NOT APPLICABLE

Are there satisfactory justifications for one of more of the following:

- **Invasive procedures**
- **Use of drugs**
- **Exposure to prolonged or repetitive testing**
- **Induced psychological stress or anxiety**

1

Figure A.3a. Ethical Approval from University of Liverpool – Committee on Research Ethics for Pediatric Palliative Care Study, Page 1 of 3, October 9, 2013.



~~YES/NO/UNCLEAR~~/NOT APPLICABLE

Are the financial inducements offered to participants appropriate?

~~YES/NO/UNCLEAR~~/NOT APPLICABLE

Are there satisfactory justifications for a lack of the following:

- **Informed consent**
- **Right to withdraw**
- **Anonymity**
- **Debrief**
- **Participant access to information**

YES/~~NO/UNCLEAR/NOT APPLICABLE~~

Is the recruitment of participants suitable?

YES/~~NO/UNCLEAR~~

Has the applicant satisfied the obligations of informed consent?

YES/~~NO/UNCLEAR/NOT APPLICABLE~~

Has the applicant adequately considered all likely risks, and ensured that appropriate safeguards are in place?

YES

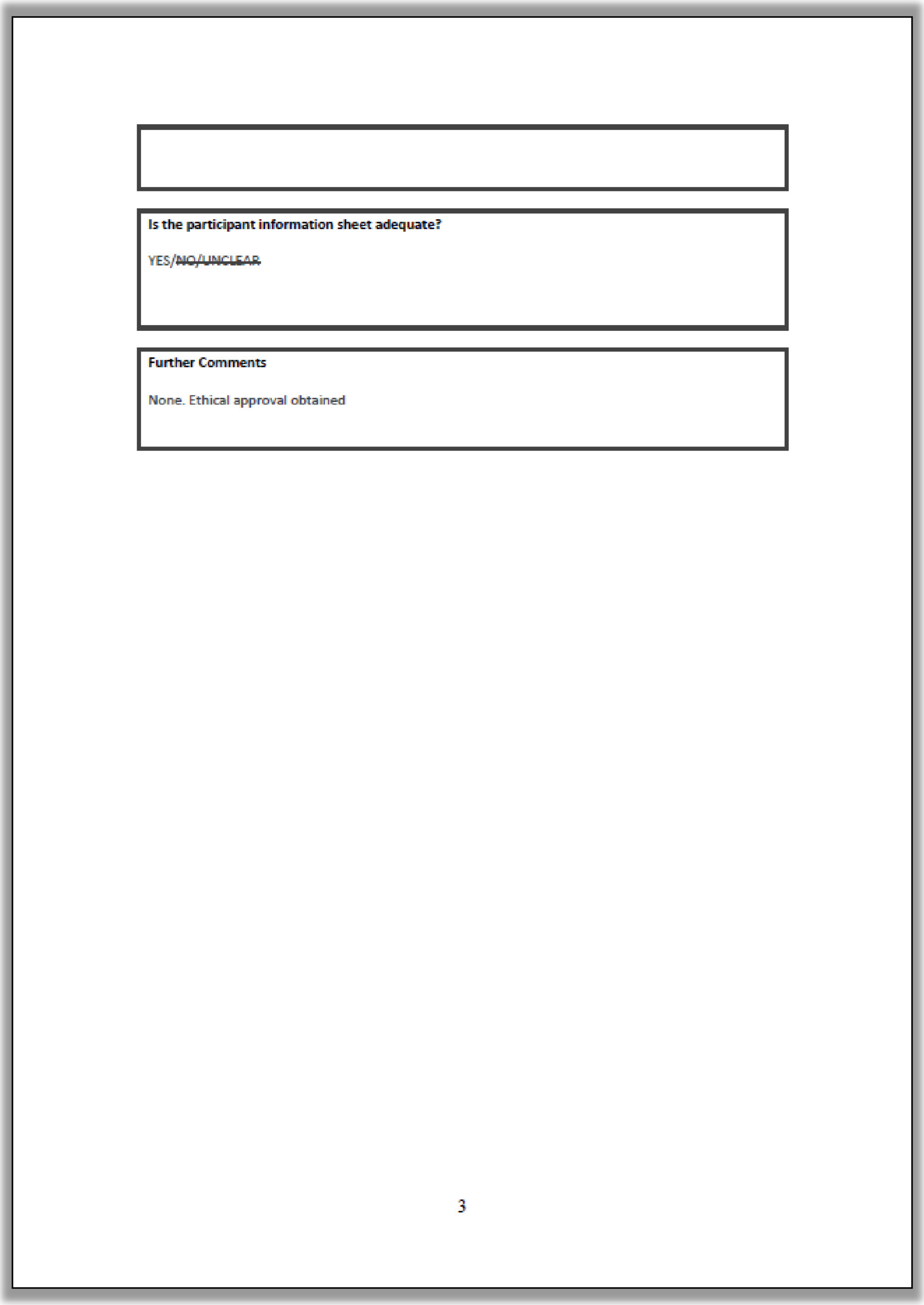
Are the arrangements in place for data access and storage appropriate?

YES

Is the consent sheet appropriate?

YES/~~NO/UNCLEAR/NOT APPLICABLE~~

Figure A.3b. Ethical Approval from University of Liverpool – Committee on Research Ethics for Pediatric Palliative Care Study, Page 2 of 3, October 9, 2013.



Is the participant information sheet adequate?

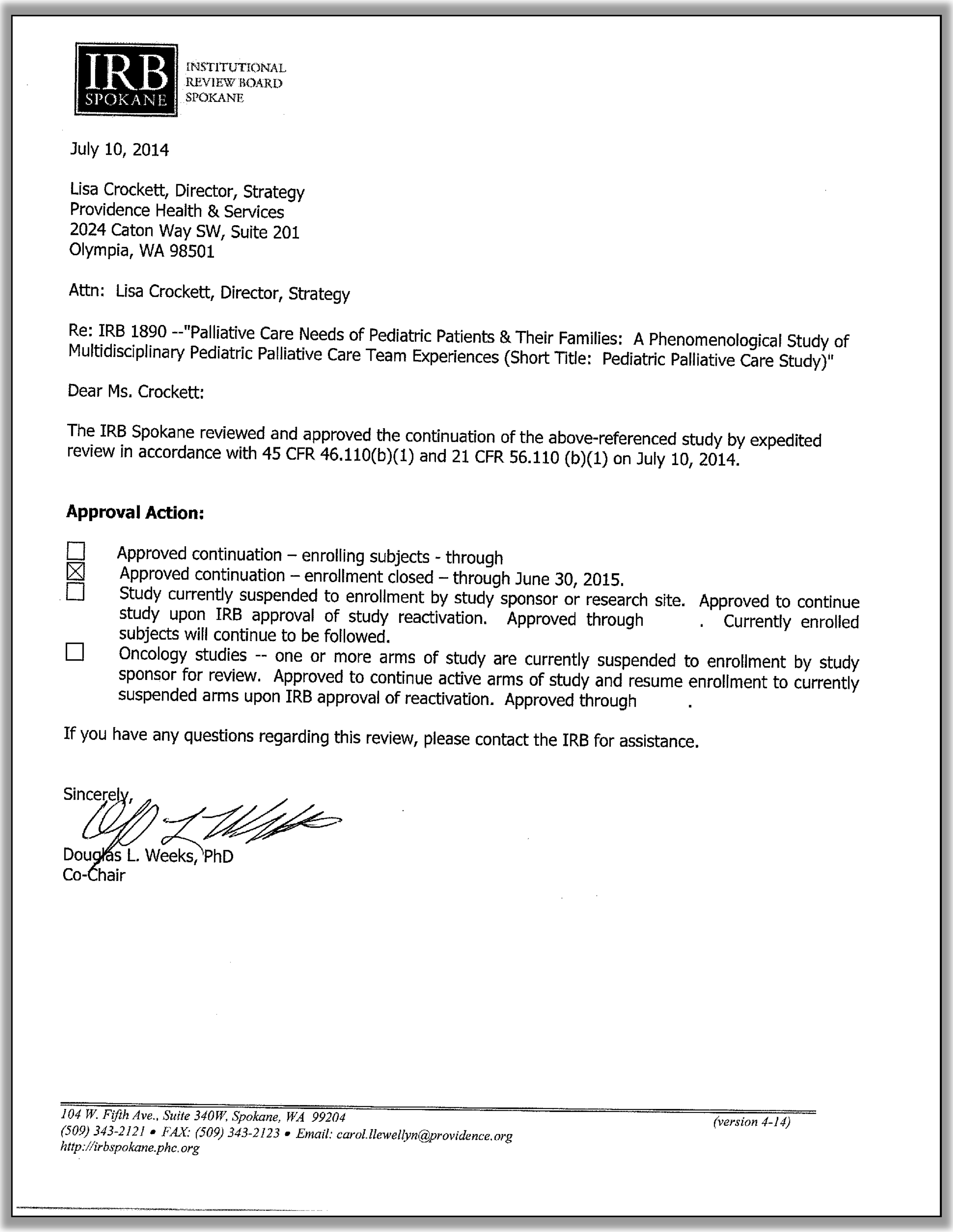
YES/~~NO/UNCLEAR~~

Further Comments

None. Ethical approval obtained

3

Figure A.3c. Ethical Approval from University of Liverpool – Committee on Research Ethics for Pediatric Palliative Care Study, Page 3 of 3, October 9, 2013.



IRB
SPOKANE
INSTITUTIONAL
REVIEW BOARD
SPOKANE

July 10, 2014

Lisa Crockett, Director, Strategy
Providence Health & Services
2024 Caton Way SW, Suite 201
Olympia, WA 98501

Attn: Lisa Crockett, Director, Strategy

Re: IRB 1890 --"Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences (Short Title: Pediatric Palliative Care Study)"

Dear Ms. Crockett:

The IRB Spokane reviewed and approved the continuation of the above-referenced study by expedited review in accordance with 45 CFR 46.110(b)(1) and 21 CFR 56.110 (b)(1) on July 10, 2014.

Approval Action:

☐ Approved continuation – enrolling subjects - through
☒ Approved continuation – enrollment closed – through June 30, 2015.
☐ Study currently suspended to enrollment by study sponsor or research site. Approved to continue study upon IRB approval of study reactivation. Approved through . Currently enrolled subjects will continue to be followed.
☐ Oncology studies -- one or more arms of study are currently suspended to enrollment by study sponsor for review. Approved to continue active arms of study and resume enrollment to currently suspended arms upon IRB approval of reactivation. Approved through .

If you have any questions regarding this review, please contact the IRB for assistance.

Sincerely,

Douglas L. Weeks, PhD
Co-Chair

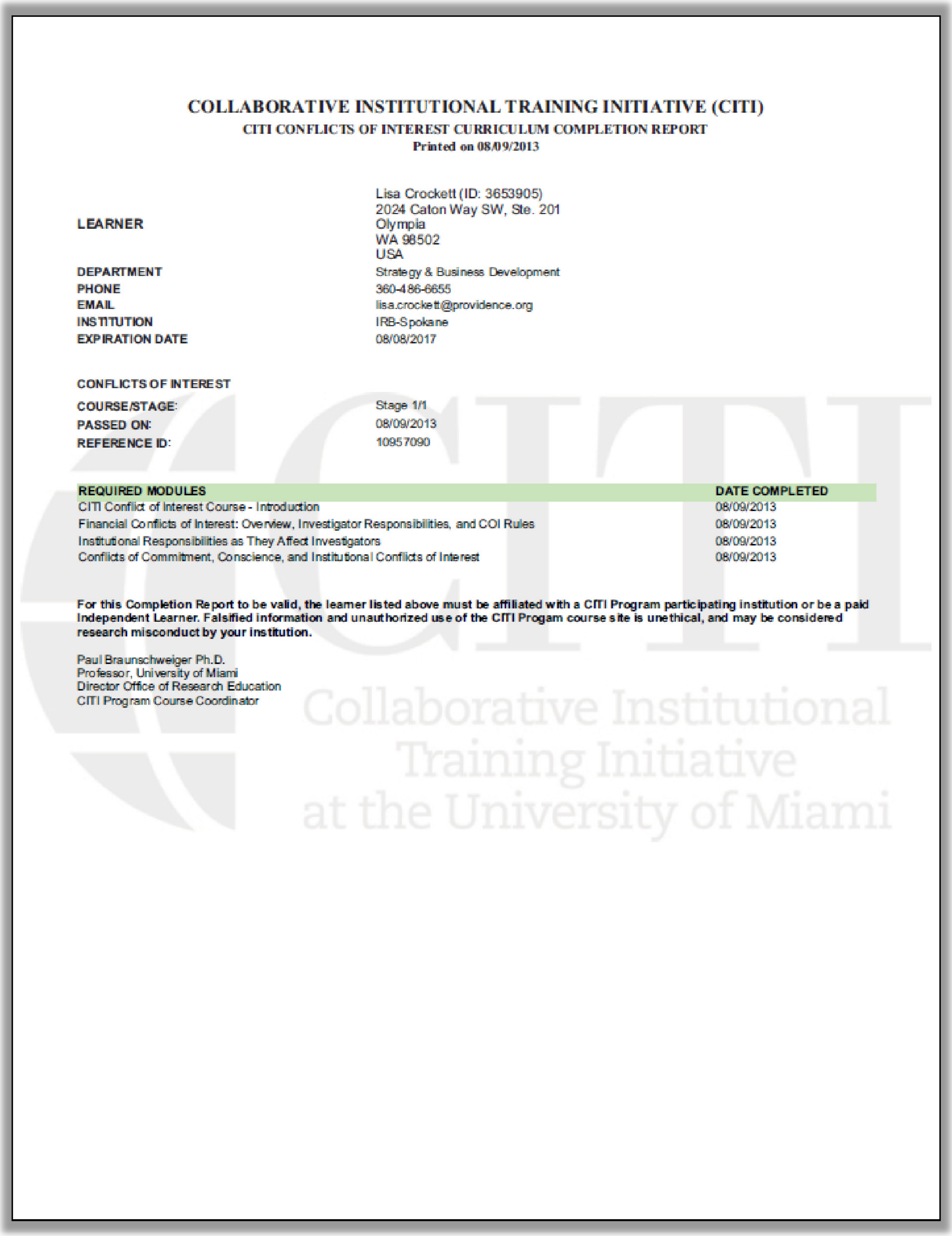
104 W. Fifth Ave., Suite 340W, Spokane, WA 99204
(509) 343-2121 • FAX: (509) 343-2123 • Email: carol.llewellyn@providence.org
http://irbspokane.phc.org

(version 4-14)

Figure A.4. Continuation Letter from the Institutional Review Board Spokane for the Pediatric Palliative Care Study (IRB 1890), July 10, 2014.

APPENDIX B

Ethical Research Training Requirements



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)
CITI CONFLICTS OF INTEREST CURRICULUM COMPLETION REPORT
Printed on 08/09/2013

LEARNER	Lisa Crockett (ID: 3653905) 2024 Caton Way SW, Ste. 201 Olympia WA 98502 USA
DEPARTMENT	Strategy & Business Development
PHONE	360-486-6655
EMAIL	lisa.crockett@providence.org
INSTITUTION	IRB-Spokane
EXPIRATION DATE	08/08/2017

CONFLICTS OF INTEREST

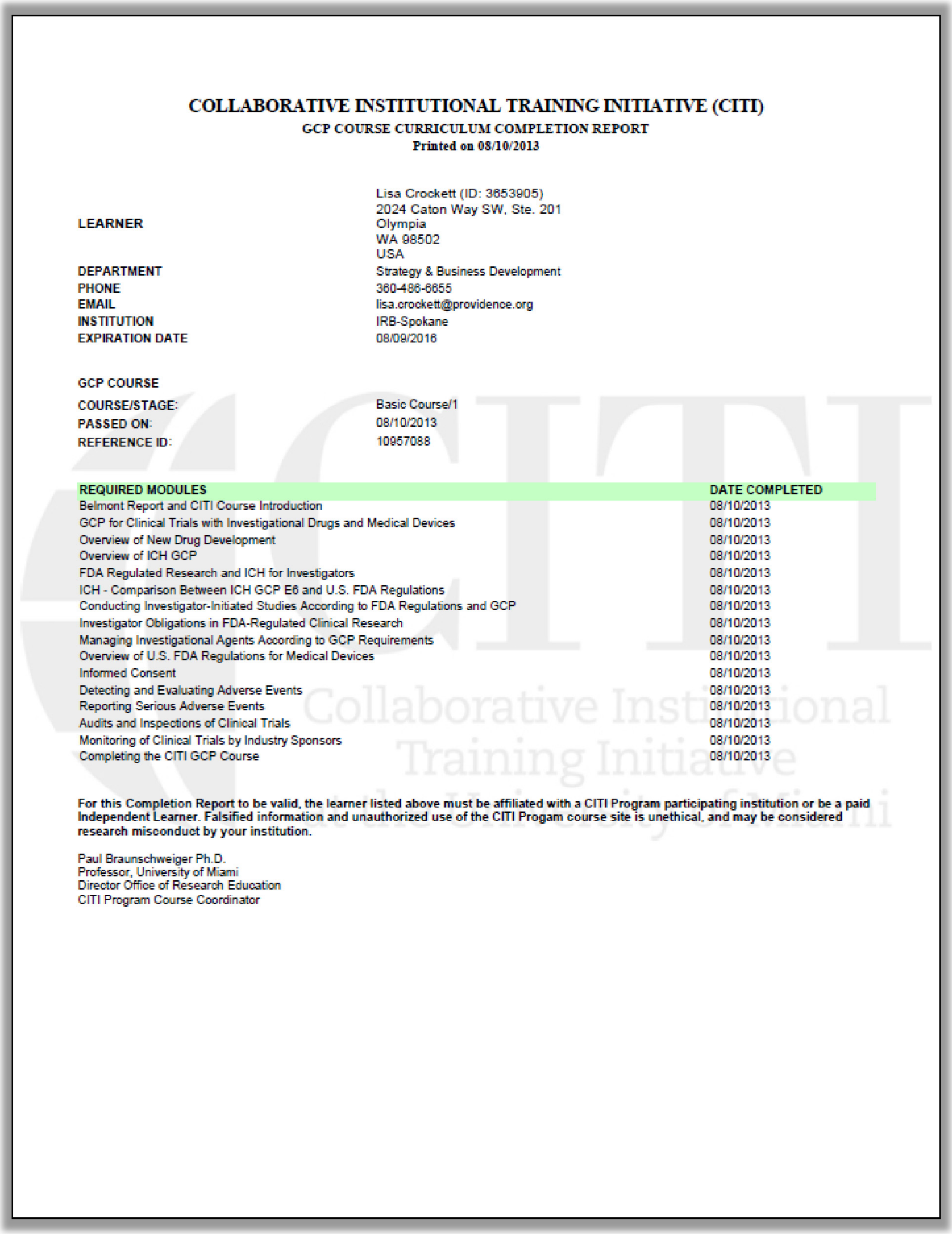
COURSE/STAGE:	Stage 1/1
PASSED ON:	08/09/2013
REFERENCE ID:	10957090

REQUIRED MODULES	DATE COMPLETED
CITI Conflict of Interest Course - Introduction	08/09/2013
Financial Conflicts of Interest: Overview, Investigator Responsibilities, and COI Rules	08/09/2013
Institutional Responsibilities as They Affect Investigators	08/09/2013
Conflicts of Commitment, Conscience, and Institutional Conflicts of Interest	08/09/2013

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Figure B.1. Collaborative Institutional Training Initiative (CITI) Conflicts of Interest Curriculum Completion Report, August 9, 2013.



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

GCP COURSE CURRICULUM COMPLETION REPORT
Printed on 08/10/2013

LEARNER	Lisa Crockett (ID: 3653905) 2024 Caton Way SW, Ste. 201 Olympia WA 98502 USA
DEPARTMENT	Strategy & Business Development
PHONE	360-486-6655
EMAIL	lisa.crockett@providence.org
INSTITUTION	IRB-Spokane
EXPIRATION DATE	08/09/2016

GCP COURSE

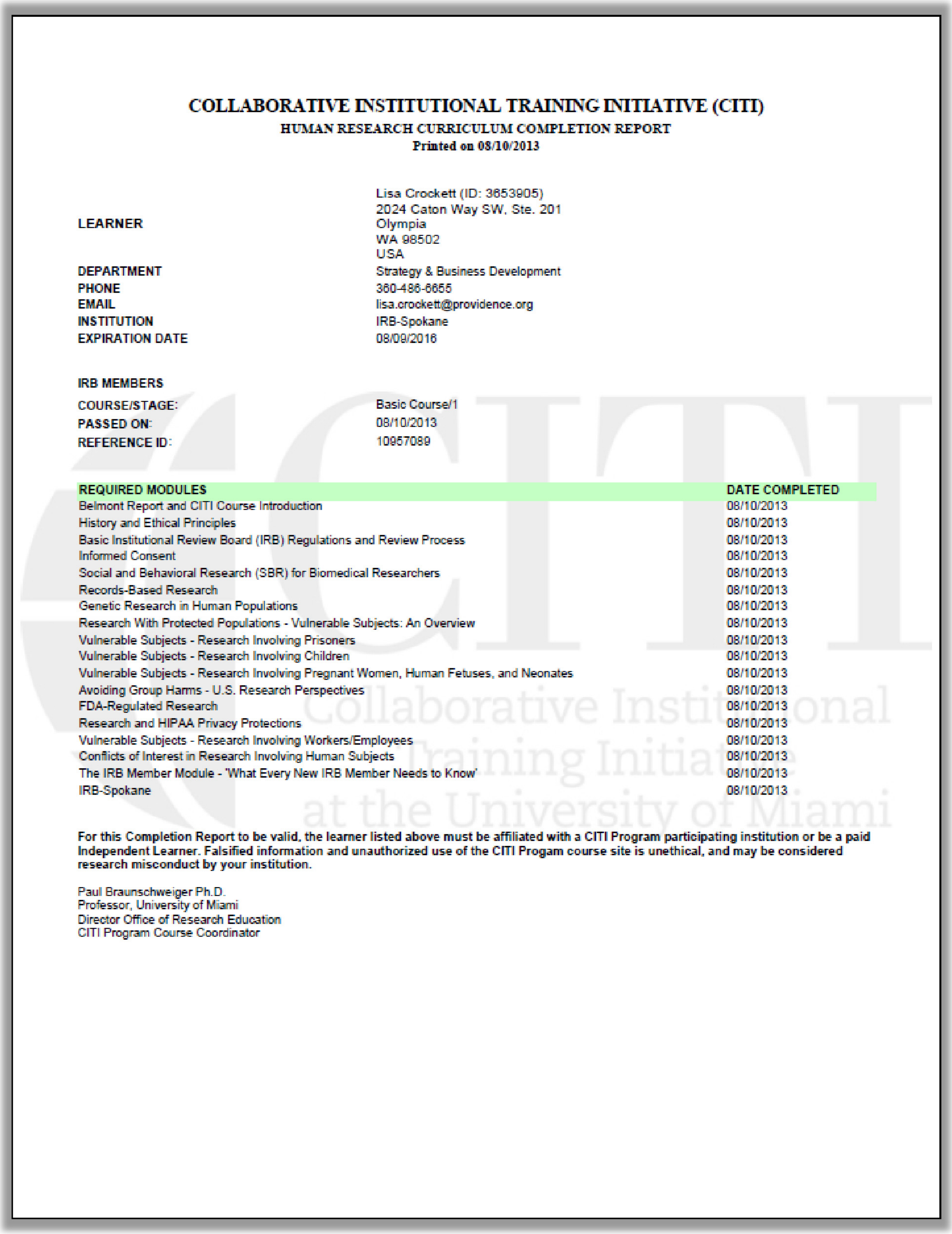
COURSE/STAGE:	Basic Course/1
PASSED ON:	08/10/2013
REFERENCE ID:	10957088

REQUIRED MODULES	DATE COMPLETED
Belmont Report and CITI Course Introduction	08/10/2013
GCP for Clinical Trials with Investigational Drugs and Medical Devices	08/10/2013
Overview of New Drug Development	08/10/2013
Overview of ICH GCP	08/10/2013
FDA Regulated Research and ICH for Investigators	08/10/2013
ICH - Comparison Between ICH GCP E6 and U.S. FDA Regulations	08/10/2013
Conducting Investigator-Initiated Studies According to FDA Regulations and GCP	08/10/2013
Investigator Obligations in FDA-Regulated Clinical Research	08/10/2013
Managing Investigational Agents According to GCP Requirements	08/10/2013
Overview of U.S. FDA Regulations for Medical Devices	08/10/2013
Informed Consent	08/10/2013
Detecting and Evaluating Adverse Events	08/10/2013
Reporting Serious Adverse Events	08/10/2013
Audits and Inspections of Clinical Trials	08/10/2013
Monitoring of Clinical Trials by Industry Sponsors	08/10/2013
Completing the CITI GCP Course	08/10/2013

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Figure B.2. Collaborative Institutional Training Initiative (CITI) Good Clinical Practice (GCP) Course Curriculum Completion Report, August 10, 2013.



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

HUMAN RESEARCH CURRICULUM COMPLETION REPORT

Printed on 08/10/2013

LEARNER	Lisa Crockett (ID: 3653905) 2024 Caton Way SW, Ste. 201 Olympia WA 98502 USA
DEPARTMENT	Strategy & Business Development
PHONE	360-486-6655
EMAIL	lisa.crockett@providence.org
INSTITUTION	IRB-Spokane
EXPIRATION DATE	08/09/2016

IRB MEMBERS

COURSE/STAGE:	Basic Course/1
PASSED ON:	08/10/2013
REFERENCE ID:	10957089

REQUIRED MODULES	**DATE COMPLETED**
Belmont Report and CITI Course Introduction	08/10/2013
History and Ethical Principles	08/10/2013
Basic Institutional Review Board (IRB) Regulations and Review Process	08/10/2013
Informed Consent	08/10/2013
Social and Behavioral Research (SBR) for Biomedical Researchers	08/10/2013
Records-Based Research	08/10/2013
Genetic Research in Human Populations	08/10/2013
Research With Protected Populations - Vulnerable Subjects: An Overview	08/10/2013
Vulnerable Subjects - Research Involving Prisoners	08/10/2013
Vulnerable Subjects - Research Involving Children	08/10/2013
Vulnerable Subjects - Research Involving Pregnant Women, Human Fetuses, and Neonates	08/10/2013
Avoiding Group Harms - U.S. Research Perspectives	08/10/2013
FDA-Regulated Research	08/10/2013
Research and HIPAA Privacy Protections	08/10/2013
Vulnerable Subjects - Research Involving Workers/Employees	08/10/2013
Conflicts of Interest in Research Involving Human Subjects	08/10/2013
The IRB Member Module - 'What Every New IRB Member Needs to Know'	08/10/2013
IRB-Spokane	08/10/2013

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Progam course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Program Course Coordinator

Figure B.3. Collaborative Institutional Training Initiative (CITI) Human Research Curriculum Completion Report, August 10, 2013.

APPENDIX C

Background of Research Locations

Figure C.1. Providence Health & Services – Pediatric Palliative Care Program Locations.

Providence Health & Services was founded in 1856 by the Sisters of Providence, who traveled to the Pacific Northwest to address the unmet needs of the new pioneering community (Providence, 2014a). Today, Providence has steadily grown to become the third largest non-profit health care system in the United States, with ministries located in Alaska, Washington, Montana, Oregon and California (Providence, 2014b). In 2013, the organization achieved a total net operating revenue of $11.1 billion and provided more than $950 million in community benefit and charity care costs (Providence, 2014a). In total, Providence operates "34 hospitals, 475 physician clinics, 22 long-term care facilities, 19 hospice and home health programs, and 693 supportive housing units in 14 locations" (Providence, 2014b). Moreover, Providence owns its own health plan, which has more than 390,000 covered members (Providence, 2014b). Within its hospice and home health ministries, Providence provides palliative care services to adult and pediatric patients. The Pediatric Palliative Care Study was conducted at four locations in Washington and California, which represent the only pediatric palliative care programs within Providence at the time of this study.

1 Providence Hospice & Home Care of Snohomish County – Carousel Program
2731 Wetmore, Suite 500; Everett, Washington 98201

Providence Hospice & Home Care of Snohomish County was established in 1978 to serve the needs of Snohomish County and Camano Island (Providence, 2014g), with the Carousel Program beginning to provide home-based palliative care for children and their families around 1993. Snohomish County, which is the primary service area for the Carousel Program, is 2,087 square miles in size and has almost 746,000 residents, of which 9.8 percent are living below the federal poverty line (U.S. Census Bureau, 2014b).

2 Providence Hospice of Seattle – Stepping Stones
425 Pontius Avenue North, Suite 200; Seattle, Washington 98109

Providence Hospice of Seattle – Stepping Stones provides home-based pediatric palliative care and hospice services to children and families residing in King County, including Vashon Island (Providence, 2014d). King County is the most populous county in the State of Washington with more than two million residents in 2,115 square miles; an estimated 10.9 percent of residents are living below the federal poverty level (U.S. Census Bureau, 2014b). Providence Hospice of Seattle cared for its first child and family in February 1994, with the palliative care program gaining its official name – “Stepping Stones” – in 2005. In addition to its pediatric services, Stepping Stones also offers perinatal hospice and bereavement support (Providence, 2014d).

3 Providence Sacred Heart Medical Center & Children’s Hospital – Sunflower Program

101 West 8th Avenue; Spokane, Washington 99204

As part of Providence Sacred Heart Medical Center & Children’s Hospital, the Sunflower Program provides pediatric palliative care services within ambulatory and acute care settings, while also coordinating home care with external organizations that work in partnership with Providence after children are discharged from the hospital (Providence, 2014h). In addition, the Sunflower Program is complemented by the Forget-Me-Not Program, which focuses on perinatal palliative care for babies who are diagnosed with a life-limiting condition prior to birth. Launched in 2007, the Sunflower Program serves primarily Spokane and Stevens counties in Washington, which is a predominantly rural area spanning more than 4,200 square miles that has approximately 523,000 residents (U.S. Census Bureau, 2014b). In total, 14.8 percent of Spokane County residents and 16.6 percent of Stevens County residents are living below the federal poverty level (U.S. Census Bureau, 2014b). The program also serves children from parts of western Montana, northern Idaho and other surrounding areas who may be receiving care at the Children’s Hospital.

4 Providence TrinityCare Hospice and TrinityKids Care

5315 Torrance Boulevard; Torrance, California 90503

Providence TrinityKids Care serves as the only dedicated pediatric hospice and palliative care program in Los Angeles and Orange counties (Providence, 2014i). The service area for TrinityKids Care is a geographic region spanning almost 5,700 square miles that has more than 12.8 million residents (U.S. Census Bureau, 2014b). Approximately 17.1 percent of Los Angeles County and 11.7 percent of Orange County residents are living below the federal poverty level (U.S. Census Bureau, 2014b). TrinityKids Care is one of the only pediatric hospice programs in California and is known for providing home-based hospice and palliative care services to infants, children and adolescents (Providence, 2014g). The program was established in 2001 to address an unmet community need and has since grown to become the largest pediatric palliative care program on the West Coast of the United States.

APPENDIX D

Recruitment Advertisement

UNIVERSITY OF
LIVERPOOL

Pediatric Palliative Care Study

Seeking Physicians & Employees to Serve as Research Participants
Your Response is Requested by Friday, Oct. 25

Title of Study: Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences [Short Title: Pediatric Palliative Care Study]

Student Investigator: Lisa A. Crockett (#H00016240)
Supervisor: Dr. Paul Ellwood

I am currently pursuing a Doctor of Business Administration (DBA) degree through the University of Liverpool and am conducting a qualitative research study related to examining and discerning the palliative care needs of pediatric patients and their families, which is the focus of my doctoral dissertation. I would like to invite you to participate in this voluntary research study, as you are a member of a Providence pediatric palliative care team that provides care in a home-based setting. I am seeking to recruit 30 research participants, including physicians, nurses, social workers and chaplains for this research study.

Before you decide whether to participate, it is important for you to understand the purpose of the research and what it will involve. Therefore, I am attaching copies of the “Informed Consent for Research Participants” and the “Statement of Informed Consent,” which provide details about my proposed study and your role as a participant. Again, this is strictly a voluntary research study, and you should agree to participate only if you are interested in doing so.

As a participant, you will be asked to participate in an in-person or videoconference interview, lasting approximately 90 minutes per interview. There is no travel associated with this research study, as I will travel to your location or make videoconference arrangements at a date/time that works best for your schedule. During the interview, I will ask you a series of open-ended questions about your work experiences and personal insights as a pediatric palliative care team member in caring for pediatric patients and their families in a home-based setting. The information you share, combined with that of your peers, will be analyzed to detect key themes and details related to the palliative care needs of pediatric patients and their families, which will form the basis for my dissertation.

The Ask: Contact Me By Friday, Oct. 25 if You Will Participate
Once you have had an opportunity to review the attached documents, please contact me with any questions you have about the research study. You may reach me at 360/486-6655 or by e-mail at lisa.crockett@providence.org. By Oct. 25, please let me know if you are interested and willing to serve as a participant in the Pediatric Palliative Care Study. Thanks for your consideration and the work you do each day for Providence Health & Services.

IRB-Spokane – #1890
APPROVED: 9-26-13

APPENDIX E

Informed Consent for Research Participants & Statement of Informed Consent

INFORMED CONSENT FOR RESEARCH PARTICIPANTS

Invitation to Participate: You are being invited to participate in a voluntary research study. Before you decide whether to participate, it is important for you to understand the purpose of the research and what it will involve. Please take time to review the following "Informed Consent for Research Participants" in order to make an informed decision; you may contact the student investigator or supervisor if you have any questions or would like more information. Again, this is strictly a voluntary research study, and you should agree to serve as research participant only if you are interested in doing so. Thank you for your consideration.

Title of Study: Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences [Short Title: Pediatric Palliative Care Study]

Student Investigator: Lisa A. Crockett (#H00016240) **Supervisor:** Dr. Paul Ellwood

---

Introduction

As part of the academic degree requirements for the Doctor of Business Administration program at the University of Liverpool, Lisa A. Crockett (student investigator) is conducting a qualitative research study related to examining and discerning the palliative care needs of pediatric patients and their families. You have been invited to participate in the study based on your employment as a pediatric palliative care team member (i.e. physician, nurse, social worker, chaplain) who provides care in a home-based setting. Your participation will provide data that will contribute to the knowledge and understanding of the palliative care needs of pediatric patients and their families. The inclusion of different employment roles is anticipated to elicit insights from diverse perspectives in caring for pediatric patients and their families in unique capacities with in-depth understanding about their needs. Approximately 30 research participants from Providence Health & Services will take part in the study.

Purpose of the Study

Overall, few U.S. health care systems offer pediatric palliative care services, representing a significant unmet need for seriously ill children and their families in communities across the country. Within the U.S., the need for pediatric palliative care is projected to grow due to the increasing demand. While abundant research has been published about adult palliative care and the needs of the adult patient population, far fewer articles have been devoted to understanding the distinctive needs and considerations of pediatric patients and their families. The lack of information published about pediatric palliative care and the needs of this patient population may be contributing factors in its slow growth and adoption by U.S. health care providers. Therefore, significant opportunity exists to add to the literature by introducing qualitative research that provides a comprehensive overview of the palliative care needs of pediatric patients and their families by delving into the lived experiences of care team members who provide care in a home-based setting. As U.S. health care providers contemplate the addition and/or refinement of pediatric palliative care, the research study may provide critical insights into the patient and family needs that must be addressed through the optimal design of pediatric palliative care services.

Research Procedures

As a research participant, you will be asked to participate in an in-person or videoconference interview with the student investigator, lasting approximately 90 minutes. Participation in this study will require completion of the interview during non-work time. You will be asked a series of open-ended questions about your work experiences and personal insights as a pediatric palliative care team member in caring for pediatric patients and their families in a home-based setting. Additional questions or clarifications may be sought from you following the initial interview. During the interview, you are not required to answer the questions and may refuse to answer for any reason. You also have the right to retract your answers after they have been provided. With your permission, a digital audio recording of the interview will be made for subsequent analysis. The analysis will focus on identifying the common themes across the experiences shared by research participants during the interviews.

Information Statement v2.0
September 23, 2013
LAC

IRB-Spokane – #1890
APPROVED: 9-26-13

Length of Participation
You will be asked to participate in one interview with the student investigator, lasting approximately 90 minutes. Additional questions or clarifications may be sought from you following the initial interview during the 12 months following your interview while data collection and analysis are under way.

Risks
The Pediatric Palliative Care Study involves no more than minimal risk to you as a research participant, such as emotional or psychological distress from answering questions about professional work in pediatric palliative care. In the event of extreme emotional distress, you will be provided with contact information for Employee Assistance (or equivalent department) that is located in proximity to your facility. Data security and protection of identity also pose a risk, but safeguards will be taken to store all study-related data and files on an encrypted, password computer and a locked file cabinet that is accessible only by the student investigator. In the event of a data breach or disclosure of identity, the student investigator will notify you of the loss of security and also will report the event to the University of Liverpool Research Governance Officer and the IRB-Spokane.

Benefits
There are no direct benefits from your participation in the Pediatric Palliative Care Study. However, your professional expertise and lived experiences will provide knowledge that can help advance the pediatric palliative care field, in general.

Right of Refusal to Participate & Withdraw
Participation in the research study is voluntary, and there is no penalty for refusal of participation. You have the right to withdraw from the study at any time, including after you have agreed to participate. The choice you make to participate or withdraw from the research study will have no bearing on your job or any work-related evaluations. In the event you choose to withdraw from the research study, all information you provided will be destroyed and omitted from the research data.

Confidentiality
All information collected from you during the research study will be kept confidential. Your name and identifying information will not be associated with any part of published findings. Any direct quotations or excerpts from the interview that are utilized within the published findings will be made without attributing them to your name or disclosing your identity. All information collected from research participants during the Pediatric Palliative Care Study will be kept strictly confidential and stored in an anonymous manner. Code numbers will be assigned to interview recordings and transcripts in place of your name. Only the student investigator will have the “key” to identify your name and corresponding code. The key will be stored in a separate location than the coded data files in a locked file cabinet that is accessible only by the student investigator. The only person to know your identity will be the student investigator. In addition, your supervisor will not be informed of your participation in the Pediatric Palliative Care Study and will not be provided with any identifiable information about your responses to the interview questions.

Information Usage & Disposal Procedures
The information gathered from you and other research participants will be used by the student investigator to write a dissertation, which will be submitted to the University of Liverpool’s Doctor of Business Administration program. In addition, the student investigator may use the information gathered from research participants as the basis for future research, other publications (e.g. academic journal articles) or workplace presentations. The report(s) generated by the research will be shared with you before they are published. You will have the right to review your remarks and ask for the addition, modification or deletion of statements. The raw data and interview recordings will be kept confidential, de-identified and maintained in a secure location by the student investigator for the duration of the study, consistent with organizational data security policies and archival procedures. The data files will be retained for ten years after the completion of the research study and then will be destroyed.

Expenses or Reimbursement
There are no expenses or reimbursement associated with your participation in the research study.

Other Options
You may choose not to participate in the Pediatric Palliative Care Study.

Investigator Disclosure
The student investigator is a Providence employee but has no direct supervision of the sites where the Pediatric Palliative Care Study will take place.

IRB-Spokane – #1890
APPROVED: 9-26-13

For Additional Information

If you have any questions regarding this study or your participation, please contact the student investigator: Lisa Crockett at 360/486-6655 or Lisa.Crockett@providence.org. By mail, the investigator can be reached at Providence Health & Services – Strategy & Business Development; 2024 Caton Way SW, Ste. 201; Olympia, WA 98502.

To Report Problems or Complaints

If you become dissatisfied at any point during the research study and/or detect a problem, please contact Lisa Crockett, student investigator, at Lisa.Crockett@providence.org or Dr. Paul Ellwood, supervisor, at Paul.Ellwood@liverpool.ac.uk. If you have a concern or complaint which you feel cannot be addressed by the student investigator or supervisor, contact the University of Liverpool's Research Governance Officer at ethics@liv.ac.uk or the IRB-Spokane at 509/343-2121. When contacting the Research Governance Officer or IRB-Spokane, you will be asked to provide the name or description of the study, the student investigator, and the details of the complaint you wish to make.

IRB-Spokane – #1890
APPROVED: 9-26-13

UNIVERSITY OF LIVERPOOL

STATEMENT OF INFORMED CONSENT

Title of Study: Palliative Care Needs of Pediatric Patients & Their Families: A Phenomenological Study of Multidisciplinary Pediatric Palliative Care Team Experiences [Short Title: Pediatric Palliative Care Study]

Student Investigator: Lisa A. Crockett (#H00016240) **Supervisor:** Dr. Paul Ellwood

---

	Initial Box:
I confirm that I have read and understand the "Informed Consent for Research Participants" for the Pediatric Palliative Care Study, dated September 23, 2013. I have had the opportunity to consider the information, ask questions, and receive answers that permit me to make an informed decision about participating in the research study.	☐
I understand my participation is voluntary, and I am free to withdraw from the study without repercussions at any time, whether before it starts or while I am participating.	☐
I understand the choice I make to participate or withdraw from the research study will have no bearing on my job or any work-related evaluations. In addition, my supervisor will not be informed of my participation or the responses I provide to the interview questions.	☐
I understand that I can ask at any time for access to the information I provide, and I also can request the destruction of that information if I wish. This includes the right to review and ask for deletion of the digital audio recording made during the interview.	☐
I understand confidentiality and anonymity will be maintained. I understand direct quotations or excerpts from my interview will be de-identified and may be used in the report(s). I understand my name will not be linked with the research materials, and I will not be identified or identifiable in the report(s) that result from the research study.	☐
I understand and agree for my interview with the student investigator to be audio recorded and consent to the use of these recordings to aid in the data analysis.	☐
I understand that I will be given an opportunity to review the report(s) prior to their publication. I have the right to ask for the addition, modification or deletion of statements that were excerpted from my interview with the student investigator.	☐
I hereby agree to participate in the Pediatric Palliative Care Study.	☐

Research Participant (please print): ____________________

Signature of Research Participant: ____________________

Date: ____________________

Student Investigator / Person Obtaining Consent (please print): ____________________

Signature of Student Investigator: ____________________

Date: ____________________

Informed Consent v2.0
September 23, 2013
LAC

IRB-Spokane – #1890
Approved: 9-26-13

LIST OF REFERENCES

Agency for Healthcare Research and Quality – U.S. Department of Health & Human Services. (2014) *Applying storytelling to health care innovation*. Available at: http://www.innovations.ahrq.gov/content.aspx?id=2800. (Accessed: 30 August 2014).

Ahern, K.J. (1999) 'Pearls, pith, and provocation: Ten tips for reflexive bracketing', *Qualitative Health Research*, 9(3), p. 407-411. [Online]. (Accessed: 21 September 2014).

American Academy of Hospice and Palliative Medicine (2013) *About AAHPM*. Available at: http://www.aahpm.org/about/default/index.html. (Accessed: 19 October 2013).

American Academy of Pediatrics (2010) 'Affirmation of value – standards of practice for pediatric palliative care and hospice', *Pediatrics*, 126(2), p. 488. [Online]. (Accessed: 1 November 2013).

American Academy of Pediatrics – Committee on Bioethics and Committee on Hospital Care (2000) 'Palliative care for children', *Pediatrics*, 106(2), p. 351-357. [Online]. (Accessed: 18 October 2013).

Annells, M. (1996) 'Hermeneutic phenomenology: philosophical perspectives and current use in nursing research', *Journal of Advanced Nursing*, 23, p. 705-713. [Online]. (Accessed: 4 November 2013).

Barbour, R. (2007) *Introducing qualitative research: a student guide to the craft of doing qualitative research.* London: SAGE Publications Ltd.

Beech, I. (1999) 'Bracketing in phenomenological research', *Nurse Researcher*, 6(3), p. 35-51. [Online]. (Accessed: 21 September 2014).

Benini, F., Spizzichino, M., Trapanotto, M. and Ferrante, A. (2008) 'Pediatric palliative care', *Italian Journal of Pediatrics*, 34(4), p. 1-9. [Online]. (Accessed: 18 October 2013).

Biggerstaff, D. and Thompson, A.R. (2008) 'Interpretative phenomenological analysis (IPA): a qualitative methodology of choice in healthcare research', *Qualitative Research in Psychology*, 5(3), p. 214-224. [Online]. (Accessed: 1 September 2014).

Birkbeck University of London (2011) *Interpretative phenomenological analysis*. Available at: http://www.ipa.bbk.ac.uk/. (Accessed: 20 September 2014).

Brocki, J.M. and Wearden, A.J. (2006) 'A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology', *Psychology and Health*, 21(1), p. 87-108. [Online]. (Accessed: 1 September 2014).

Brook, L. and Hain, R. (2008) 'Predicting death in children', *Archives of Disease in Childhood*, 93(12), p. 1067-1070. [Online]. (Accessed: 18 October 2013).

Brosco, J.P. (1999) 'The early history of the infant mortality rate in America: 'A reflection upon the past and a prophecy of the future'', *Pediatrics*, 103(2), p. 478-485. [Online]. (Accessed: 18 October 2013).

Center to Advance Palliative Care (2013) *Defining palliative care.* Available at: http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc. (Accessed: 2 November 2013).

Center to Advance Palliative Care (2014) *National Palliative Care Registry reports*. Available at: https://registry.capc.org/cms/Reports.aspx. (Accessed: 19 October 2014).

Center to Advance Palliative Care and National Palliative Care Research Center (2011) *Report card: America's care of serious illness: A state-by-state report card on access to palliative care in our nation's hospitals*. Available at: http://reportcard.capc.org/pdf/state-by-state-report-card.pdf. (Accessed: 1 November 2013).

Centers for Medicare & Medicaid Services (2013) *Medicare hospice data: Medicare hospice data trends: 1998-2009.* Available at: http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare_Hospice_Data.html. (Accessed: 18 October 2013).

Clarke, K.A. (2009) 'Uses of a research diary: learning reflectively, developing understanding and establishing transparency', *Nurse Researcher*, 17(1), p. 68-76. [Online]. (Accessed: 22 September 2014).

Clisby, N., Shaw, S. and Cormack, M. (2013) 'Psychological impact of working with patients with cystic fibrosis at end-of-life, pre-transplant stage', *Palliative and Supportive Care*, 11(2), p. 111-121. [Online]. (Accessed: 25 October 2014).

Cohen, L., Manion, L. and Morrison, K. (2007) *Research Methods in Education*. Sixth edition. Abingdon: Routledge.

Creswell, J.W. (2007) *Qualitative inquiry & research design: choosing among five approaches*. Second edition. London: SAGE Publications Ltd.

Crockett, L. (2013) *Doctoral development plan: the scholar practitioner journey: my personal reflection about becoming a doctoral-level thinker, critical action learner & action researcher*. [Online]. Available at: University of Liverpool, Laureate Online Education, Blackboard. (Accessed: 11 January 2014).

Crotty, M. (1996) *Phenomenology and nursing research*. Edinburgh: Churchill Livingstone.

Crozier, F. and Hancock, L.E. (2012) 'Pediatric palliative care: beyond the end of life', *Pediatric Nursing*, 38(4), p. 198-203, 227. [Online]. (Accessed: 18 October 2013).

Davenport, R.K. (2012) *Qualified clinical psychologists' experiences of working with children with life-limiting conditions: a qualitative study*. Ph.D. thesis, University of Hertfordshire. [Online]. (Accessed: 25 October 2014).

Davies, B., Contro, N., Larson, J. and Widger, K. (2010) 'Culturally-sensitive information-sharing in pediatric palliative care', *Pediatrics*, 125(4), p. 859-865. [Online]. (Accessed: 1 November 2013).

Davies, B., Sehring, S.A., Partridge, J.C., Cooper, B.A., Hughes, A., Philip, J.C., Amidi-Nouri, A. and Kramer, R.F. (2008) 'Barriers to palliative care for children: Perceptions of pediatric health care providers', *Pediatrics*, 121(2), p. 282-288. [Online]. (Accessed: 1 November 2013).

Dowling, M. (2004) 'Hermeneutics: an exploration', *Nurse Researcher*, 11(4), p. 30-39. [Online]. (Accessed: 21 September 2014).

Downing, J., Boucher, S., Nkosi, B., Steel, B. and Marston, J. (2014) 'Transforming children's palliative care through the International Children's Palliative Care Network', *International Journal of Palliative Nursing*, 20(3), p. 109-114. [Online]. (Accessed: 11 October 2014).

European Association of Palliative Care (EAPC) Taskforce (2013) 'IMPaCCT: standards for paediatric palliative care in Europe', *European Journal of Palliative Care*, 14, p. 2-7. [Online]. (Accessed: 2 November 2013).

Feudtner, C., Kang, T.I., Hexem, K.R., Friedrichsdorf, S.J., Osenga, K., Siden, H., Friebert, S.E., Hays, R.M., Dussel, V. and Wolfe, J. (2011) 'Pediatric palliative care patients: a prospective multicenter cohort study', *Pediatrics*, 127(6), p. 1094-1101. [Online]. (Accessed: 18 October 2013).

Feudtner, C., Santucci, G., Feinstein, J.A., Snyder, C.R., Rourke, M.T. and Kang, T.I. (2007) 'Hopeful thinking and level of comfort regarding providing pediatric palliative care: A survey of hospital nurses', *Pediatrics*, 119(1), p. 186-192. [Online]. (Accessed: 1 November 2013).

Feudtner, C., Silveira, M.J., Shabbout, M. and Hoskins, R.E. (2006) 'Distance from home when death occurs: A population-based study of Washington State, 1989-2002', *Pediatrics*, 117(5), p. 932-939. [Online]. (Accessed: 1 November 2013).

Fraser, L.K., Miller, M., Hain, R., Norman, P., Aldridge, P., McKinney, A. and Parslow, R.C. (2012) 'Rising national prevalence of life-limiting conditions in children in England', *Pediatrics*, 129(4), p. 923-929. [Online]. (Accessed: 18 October 2013).

Friebert, S. (2009) 'NHPCO facts and figures: pediatric palliative and hospice care in America', *National Hospice and Palliative Care Organization*. Available at: http://www.nhpco.org/sites/default/files/public/quality/Pediatric_Facts-Figures.pdf. (Accessed: 18 October 2013).

Friebert, S. and Huff, S. (2009) 'HNPCO's pediatric standards: a key step in advancing care for America's children', *National Hospice and Palliative Care Organization*. Available at: http://www.nhpco.org/sites/default/files/public/ChiPPS/Peds-Standards_article_NL-0209.pdf. (Accessed: 18 October 2013).

Froedtert & Medical College of Wisconsin (2010) *Palliative care program*. Available at: http://www.froedtert.com/SpecialtyAreas/PalliativeCareProgram/. (Accessed: 19 October 2013).

Goldman, A., Hewitt, M., Collins, G.S., Childs, M. and Hain, R. (2006) 'Symptoms in children / young people with progressive malignant disease: United Kingdom children's cancer study group / paediatric oncology nurses forum survey', *Pediatrics*, 117(6), p. 1179-1186. [Online]. (Accessed: 1 November 2013).

Graunt, J. (1662) *Natural and political observations mentioned in a following index and made on the bills of mortality*. 1939 reprint. Baltimore: The Johns Hopkins Press.

Gysels, M., Shipman, C. and Higginson, I.J. (2008) 'Is the qualitative research interview an acceptable medium for research with palliative care patients and carers?', *BMC Medical Ethics*, 9(7), p. 1-6. [Online]. (Accessed: 14 September 2014).

Hain, R.D.W. (2004) 'Paediatric palliative medicine: a unique challenge', *Pediatric Rehabilitation*, 7(2), p. 79-84. [Online]. (Accessed: 19 October 2013).

Hammill, C. and Sinclair, H. (2010) 'Bracketing – practical considerations in Husserlian phenomenological research', *Nurse Researcher*, 17(2), p. 16-24. [Online]. (Accessed: 14 September 2014).

Hentschel, R., Lindner, K., Krueger, M. and Reiter-Theil, S. (2006) 'Restriction of ongoing intensive care in neonates: A prospective study', *Pediatrics*, 118(2), p. 563-569. [Online]. (Accessed: 1 November 2013).

Himelstein, B.P., Hilden, J.M., Boldt, A.M. and Weissman, D. (2004) 'Pediatric palliative care', *New England Journal of Medicine*, 350(17), p. 1752-1762. [Online]. (Accessed: 2 November 2013).

Howell, S. (2007) 'Pediatric palliative care', *Pediatrics*, 120(1), p. 244-245. [Online]. (Accessed: 1 November 2013).

Jasper, M.A. (1994) 'Issues is phenomenology for researchers of nursing', *Journal of Advanced Nursing*, 19(2), p. 309-314. [Online]. (Accessed: 22 September 2014).

Jennings, P.D. (2005) 'Providing pediatric palliative care through a pediatric supportive care team', *Pediatric Nursing*, 31(3), p. 195-200. [Online]. (Accessed: 3 November 2013).

Jessup, R.L. (2007) 'Interdisciplinary versus multidisciplinary care teams: do we understand the difference?', *Australian Health Review*, 31(3), p. 330-331. [Online]. (Accessed: 4 July 2014).

Keele, L., Kennan, H.T., Sheetz, J. and Bratton, S.L. (2013) 'Differences in characteristics of dying children who receive and do not receive palliative care', *Pediatrics*, 132(1), p. 72-78. [Online]. (Accessed: 20 October 2013).

Kirolos, I., Tamariz, L., Schultz, E.A., Diaz, Y., Wood, B.A. and Palacio, A. (2014) 'Interventions to improve hospice and palliative care referral: a systematic review', *Journal of Palliative Medicine*, 17(8), p. 957-964. [Online]. (Accessed: 18 October 2014).

Knapp, C.A., Madden, V., Wang, H., Kassing, K., Curtis, C., Sloyer, P. and Shenkman, E.A. (2011) 'Pediatric nurses' attitudes toward hospice and pediatric palliative care', *Pediatric Nursing*, 37(3), p. 121-126. [Online]. (Accessed: 2 November 2013).

Koch, T. (1999) 'An interpretive research process: revisiting phenomenological and hermeneutical approaches', *Nurse Researcher*, 6(3), p. 20-34. [Online]. (Accessed: 21 September 2014).

Kolarik, R.C., Walker, G. and Arnold, R.M. (2006) 'Pediatric resident education in palliative care: A needs assessment', *Pediatrics*, 117(6), p. 1949-1954. [Online]. (Accessed: 1 November 2013).

Kumar, S.P. (2011) 'Reporting of pediatric palliative care: a systematic review and quantitative analysis of research publications in palliative care journals', *Indian Journal of Palliative Care*, 17(3), p. 202-209. [Online]. (Accessed: 1 November 2013).

Lantos, J.D. and Meadow, W. (2009) 'Variation in the treatment of infants born at the borderline of viability', *Pediatrics*, 123(6), p. 1588-1590. [Online]. (Accessed: 2 November 2013).

Levetown, M. (2008) 'Communicating with children and families: From everyday interactions to skill in conveying distressing information', *Pediatrics*, 121(5), p. 1441-1460. [Online]. (Accessed: 1 November 2013).

Lewis-Beck, M.S., Bryman, A. and Liao, T.F. (2004) *The SAGE encyclopedia of social science research methods*. London: SAGE Publications Inc.

Linton, J.M. and Feudtner, C. (2008) 'What accounts for differences or disparities in pediatric palliative and end-of-life care? A systematic review focusing on possible multilevel mechanisms', *Pediatrics*, 122(3), p. 574-582. [Online]. (Accessed: 1 November 2013).

Luft, H.S. (2006) 'What works and what doesn't work well in the US healthcare system', *PharamacoEconomics,* p. 15-28. [Online]. (Accessed: 8 November 2014).

Lyon, M.E., Garvie, P.A., McCarter R., Briggs, L., He, J. and D'Angelo, L.J. (2009) 'Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families', *Pediatrics*, 123(2), p. 199-206. [Online]. (Accessed: 1 November 2013).

Malim, T., Birch, A. and Wadeley A. (1992) *Perspectives in psychology*. First edition. Hampshire, England: MacMillan Press.

Marchessault, J., Legault, A. and Martinez, A. (2012) ‘Providing in-home palliative care within a generalist caseload: a chance for nurses to reflect on life and death’, *International Journal of Palliative Nursing*, 18(3), p. 135-141. [Online]. (Accessed: 3 November 2013).

Maxwell, J.A. and Mittapalli, K. (2008) ‘Explanatory research’, in Given, L.M. (ed.) *The SAGE encyclopedia of qualitative research methods*. Second edition. London: SAGE Publications, Inc.

McCabe, M.E., Hunt, E.A. and Serwint, J.R. (2008) ‘Pediatric residents’ clinical and educational experiences with end-of-life care’, *Pediatrics*, 121(4), p. 731-737. [Online]. (Accessed: 1 November 2013).

McClain, B.C. and Kain, Z.N. (2007) ‘Pediatric palliative care: A novel approach to children with sickle cell disease’, *Pediatrics*, 119(3), p. 612-614. [Online]. (Accessed: 1 November 2013).

Meier, D.E. (2011) ‘Increased access to palliative care and hospice services: opportunities to improve value in health care’, *The Milbank Quarterly*, 89(3), p. 343-380. [Online]. (Accessed: 18 October 2014).

Meier, D.E. and Beresford, L. (2007) ‘Pediatric palliative care offers opportunities for collaboration’, *Journal of Palliative Medicine*, 10(2), p. 284-289. [Online]. (Accessed: 3 November 2013).

Mellor, C., Heckford, E. and Frost, J. (2011) ‘Developments in paediatric palliative care’, *Paediatrics and Child Health*, 22(3), p. 115-120. [Online]. (Accessed: 19 October 2013).

Meyer, E.C., Ritholz, M.D., Burns, J.P. and 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), p. 649-657. [Online]. (Accessed: 1 November 2013).

Miller, E.G., Laragione, G., Kang, T.I. and Feudtner, C. (2012) ‘Concurrent care for the medically complex child: lessons of implementation’, *Journal of Palliative Medicine*, 15(11), p. 1281-1283. [Online]. (Accessed: 2 November 2013).

Muckaden, M., Dighe, M., Balaji, P.D., Dhiliwal, S., Tilve, P., Jadhav, S. and Goswami, S. (2011) ‘Paediatric palliative care: theory to practice’, *Indian Journal of Palliative Care*, 17, p. 52-60. [Online]. (Accessed: 2 November 2013).

Munhall, P.L. (1994) *Revisioning phenomenology: nursing and health science research*. New York: National League for Nursing Press.

National Center for Healthcare Statistics (2009) ‘Delayed childbearing: more women are having their first child later in life’, *NCHS Data Brief*, 21, p. 1-8. [Online]. (Accessed: 24 August 2014).

Newmayer, S.W. (1911) ‘The warfare against infant mortality’, *Annals of the American Academy of Political and Social Science*, 37(2), p. 288-298. [Online]. (Accessed: 18 October 2013).

Polkinghorne, D.E. (2919) ‘Phenomenological research methods’, *Existential-phenomenological perspectives in psychology.* New York: Plenum Press.

Pousset, G., Bilsen, J., De Wilde, J., Benoit, Y., Verlooy, J., Bomans, A., Deliens, L. and Mortier, F. (2009) ‘Attitudes of adolescent cancer survivors toward end-of-life decisions for minors’, *Pediatrics*, 124(6), p. 1142-1148. [Online]. (Accessed: 2 November 2013).

Pringle, J., Drummond, J., McLafferty, E. and Hendry, C. (2011a) ‘Interpretative phenomenological analysis: a discussion and critique’, *Nurse Researcher*, 18(3), p. 20-24. [Online]. (Accessed: 1 September 2014).

Pringle, J., Hendry, C. and McLafferty, E. (2011b) ‘Phenomenological approaches: challenges and choices’, *Nurse Researcher*, 18(2), p. 7-18. [Online]. (Accessed: 20 September 2014).

Pritchard, M., Burghen, E., Srivastava, D.K., Okuma, J., Anderson, L., Powell, B., Furman, W.L. and Hinds, P.S. (2008) ‘Cancer-related symptoms most concerning to parents during the last week and last day of their child’s life’, *Pediatrics*, 121(5), p. 1301-1309. [Online]. (Accessed: 1 November 2013).

Providence Health & Services (2012) *Providence record retention standards, November 2012*. Intranet. (Accessed: 28 September 2014).

Providence Health & Services (2014a) *A snapshot of Providence*. Available at: http://www2.providence.org/phs/Documents/FactSheet2.pdf. (Accessed: 6 October 2014).

Providence Health & Services (2014b) *About Providence: creating healthier communities together*. Available at: http://www2.providence.org/phs/Pages/default.aspx. (Accessed: 6 October 2014).

Providence Health & Services (2014c) *Acceptable use of information & information systems, Policy #PROV-PSEC-802.* Internal organizational policy. Intranet. (Accessed: 28 September 2014).

Providence Health & Services (2014d) *Children’s hospice & palliative care*. Available at: https://www2publishing.providence.org/kingcounty/facilities/providence-hospice-of-seattle/our-services/pages/children'shospicepalliativecare.aspx. (Accessed: 6 October 2014).

Providence Health & Services (2014e) *Information system electronic access controls, Policy #PROV-PSEC-804*. Internal organizational policy. Intranet. (Accessed: 28 September 2014).

Providence Health & Services (2014f) *Providence Hospice and Home Care of Snohomish County*. Available at: http://washington.providence.org/in-home-services/hospice-and-home-care-of-snohomish-county/. (Accessed: 6 October 2014).

Providence Health & Services (2014g) *Records retention & disposal, Policy #PROV-ICP-715*. Internal organizational policy. Intranet. (Accessed: 28 September 2014).

Providence Health & Services (2014h) *The Sunflower Program*. Available at: http://washington.providence.org/clinics/providence-supportive-care/services/pediatric-palliative-care/. (Accessed: 6 October 2014).

Providence Health & Services (2014i) *TrinityKids Care*. Available at: http://california.providence.org/trinitycare/our-services/trinitykids-care/. (Accessed: 6 October 2014).

Providence Health & Services (n.d.) *Consent documents – approved, Policy #CLIN-IRB-0010*. Internal organizational policy. Intranet. (Accessed: 28 September 2014).

Providence Health & Services (n.d.) *Other research reports and papers published – non-human experimentation, Policy #ADMIN-RSCH-0090*. Internal organizational policy. Intranet. (Accessed: 28 September 2014).

Reid, F.C. (2013) ‘Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas’, *International Journal of Palliative Nursing*, 19(11), p. 541-547. [Online]. (Accessed: 11 October 2014).

Reid, K., Flowers, P. and Larkin, M. (2005) ‘Exploring lived experiences’, *The Psychologist*, 18(1), p. 20-23. [Online]. (Accessed: 20 September 2014).

Remke, S.S. and Schermer, M.M. (2012) ‘Team collaboration in pediatric palliative care’, *Journal of Social Work in End-of-Life and Palliative Care’,* 8(4), p. 316-338. [Online]. (Accessed: 3 November 2013).

Robinson, M.R., Thiel, M.M., Backus, M.M. and Meyer, E.C. (2006) ‘Matters of spirituality at the end of life in the pediatric intensive care unit’, *Pediatrics*, 118(3), p. 719-729. [Online]. (Accessed: 1 November 2013).

Rogers, S.K., Gomez, C.F., Carpenter, P., Farley, J., Holson, D., Markowitz, M., Rood, B., Smith, K. and Nigra, P. (2011) ‘Quality of life for children with life-limiting and life-threatening illnesses: description and evaluation of a regional, collaborative model for pediatric palliative care’, *American Journal of Hospice*, 28(3), p. 161-170. [Online]. (Accessed: 2 November 2013).

Rose, P., Beeby, J. and Parker, D. (1995) ‘Academic rigour in the lived experience of researchers using phenomenological methods in nursing’, *Journal of Advanced Nursing*, 21(6), p. 1123-1129. [Online]. (Accessed: 21 September 2014).

Ruston, C.H. and Catlin, A. (2002) ‘Pediatric palliative care: the time is now!’, *Pediatric Nursing*, 28(1), p. 57-60. [Online]. (Accessed: 18 October 2013).

Samwell, B. (2012) ‘From hospital to home: journey of a child with complex care needs’, *Nursing Children & Young People*, 24(9), p. 14-19. [Online]. (Accessed: 9 August 2014).

Santucci, G., Kang, T.I. and Feudtner, C. (2007) ‘Pediatric palliative care: in reply’, *Pediatrics*, 120(1), p. 245. [Online]. (Accessed: 1 November 2013).

Schacht, R. (1972) ‘Husserlian and Heideggerian phenomenology’, *Philosophical Studies*, 23(5), p. 293-314. [Online]. (Accessed: 21 September 2014).

Smith, J.A. (2007) ‘Hermeneutics, human sciences and health: linking theory and practice’, *International Journal of Qualitative Studies on Health and Well-being*, 2(1), p. 3-11. [Online]. (Accessed: 22 September 2014).

Smith, J.A., Flowers, P. and Larkin, M. (2009) *Interpretative Phenomenological Analysis Theory: Method and Research*. London: SAGE Publications Ltd.

Smith, J.A. and Osborn, M. (2003) *Qualitative psychology: A practical guide to research methods*. London: SAGE Publications Ltd.

Spathis, A., Harrop, E., Tobertshaw, C., Elverson, J. and Lapwood, S. (2012) ‘Learning from paediatric palliative care: lessons for adult practice’, *Palliative Medicine*, p. 777-779. [Online]. (Accessed: 2 November 2013).

Stayer, D. (2012) ‘Pediatric palliative care: a conceptual analysis for pediatric nursing practice’, *Journal of Pediatric Nursing*, 27, p. 350-356. [Online]. (Accessed: 18 October 2015).

Steele, R. and Davies, B. (2006) ‘Impact on parents when a child has a progressive, life-threatening illness’, *International Journal of Palliative Nursing*, 12(12), p. 576-585. [Online]. (Accessed: 2 November 2013).

Steele, R., Cadell, S., Siden, H., Andrews, G., Quosai, T.S. and Feichtinger, L. (2014) ‘Impact of research participation on parents of seriously ill children’, *Journal of Palliative Medicine*, 17(7), p. 788-796. [Online]. (Accessed: 19 October 2014).

Stevenson, M., Achille, M. and 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), p. 566-577. [Online]. (Accessed: 2 November 2013).

Swinney, R., Lu, Y., Lee, A., Rubin, D. and Anderson, C. (2007) ‘The role of support staff in pediatric palliative care: their perceptions, training, and available resources', *Journal of Palliative Care*, 23(1), p. 44-50. [Online]. (Accessed: 3 November 2013).

Taylor, R. (2014) *The spoke before the hub: turning the healthcare delivery model upside down.* Available: http://www.us.jll.com/united-states/en-us/Research/JLL-Ambulatory-Care-February-TrendSpot.pdf. (Accessed: 13 October 2014).

Thompson, L.A., Knapp, C., Madden, V. and Shenkman, E. (2009) 'Pediatricians' perceptions of and preferred timing for pediatric palliative care', *Pediatrics*, 123(5), p. 777-782. [Online]. (Accessed: 1 November 2013).

Thornton, L. (2005) 'The model of whole-person caring: creating and sustaining a healing environment', *Holistic Nursing Practice*, 19(3), p. 106-115. [Online]. (Accessed: 8 November 2014).

Thorpe, R. and Holt, R. (2008) *The SAGE dictionary of qualitative management research*. London: SAGE Publications Ltd.

Tuckett, A.G. (2005) 'Part II: Rigour in qualitative research: complexities and solutions', *Nurse Researcher*, 13(1), p. 29-42. [Online]. (Accessed: 3 November 2013).

Ullrich, C. and Morrison, R.S. (2013) 'Pediatric palliative care research comes of age: what we stand to learn from children with life-threatening illness', *Journal of Palliative Medicine*, 16(4), p. 334-336. [Online]. (Accessed: 2 November 2013).

U.S. Census Bureau (2014a) *Annual estimates of resident population for selected age groups by sex for the United States, states, counties, and Puerto Rico Commonweatlh and Municipios: April 1, 2010 to July 1, 2013*. Available at: http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk. (Accessed: 10 November 2014).

U.S. Census Bureau (2014b) *State & county QuickFacts*. Available at: http://quickfacts.census.gov/qfd/index.html. (Accessed: 8 October 2014).

Van Alst, D. (2012) *"I really don't need you to talk for me. I can talk for myself": A phenomenology of participating in life decisions while in foster care.* Ph.D thesis, Columbia University. [Online]. (Accessed: 19 July 2014).

van Manen, M. (1990) *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario, Canada: The University of Western Ontario.

Vollenbroich, R., Duroux, A., Grasser, M., Brandstatter, M., Borasio, G.D. and Fuhrer, M. (2012) 'Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals', *Journal of Palliative Medicine*, 15(3), p. 294-300. [Online]. (Accessed: 18 October 2015).

Wagstaff, C. and Williams, B. (2014) 'Specific design features of an interpretative phenomenological analysis study', *Nurse Researcher*, 21(3), p. 8-12. [Online]. (Accessed: 20 September 2014).

Ward-Smith, P., Linn, J.B., Korphage, R.M., Christenson, K., Hutto, C.J. and Hubble, C.L. (2006) 'Development of a pediatric palliative care team', *Journal of Pediatric Health Care*, 21(4), p. 245-249. [Online]. (Accessed: 3 November 2013).

Wertz, F.J. (2005) 'Phenomenological research methods for counseling psychology', *Journal of Counseling Psychology*, 52(2), p. 167-177. [Online]. (Accessed: 14 September 2014).

White House (2014) *Health care that works for Americans*. Available at: http://www.whitehouse.gov/healthreform/healthcare-overview. (Accessed: 11 October 2014).

Williams, C., Cairnie, J., Fines, V., Patey, C., Schwarzer, K., Aylward, J., Lohfeld, L. and Kirpalani, H. (2009) 'Construction of a parent-derived questionnaire to measure end-of-life care after withdrawal of life-sustaining treatment in the neonatal intensive care unit', *Pediatrics*, 123(1), p. 87-95. [Online]. (Accessed: 2 November 2013).

World Bank (2013) *Health expenditure, total (% of GDP)*. Available at: http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS. (Accessed: 1 November 2013).

World Health Organization (2013) *WHO definition of palliative care*. Available at: http://www.who.int/cancer/palliative/definition/en/. (Accessed: 18 October 2013).

World Health Organization (2014) *Palliative care is an essential part of cancer control*. Available at: http://www.who.int/cancer/palliative/en/. (Accessed: 19 October 2014).

Zwerdling, T., Hamann, K.C. and Kon, A.A. (2006) 'Home pediatric compassionate extubation: bridging intensive and palliative care', *American Journal of Hospice and Palliative Care',* 23, p.224-228. [Online]. (Accessed: 1 November 2013).