The Experiences of Parents with a Child in Pediatric Hospice: An

Exploratory Study

Senior Thesis

Presented to

The Faculty of the School of Arts and Sciences
Brandeis University

Undergraduate Program in Health: Science, Society, and Policy
Wendy Cadge, Advisor

In partial fulfillment of the requirements for the degree of Bachelor of Science

by

Talia Loeb

May 2020
Abstract

Objectives. This research asks: “How do parents experience pediatric hospice care while their children are actively enrolled?” Current literature on parental experiences of hospice focuses on bereaved parents or simply on palliative care. This allows for the possibility of recall bias and the impact of grief on autobiographical memory. Focusing on parents whose children are currently enrolled also includes the perspectives of parents whose children are enrolled but not actively dying. This question will be analyzed from the perspective of the conditions that cause children to be enrolled in hospice, from parents’ direct experiences while enrolled, and from a policy perspective that shapes these experiences.

Methods. This is a qualitative, exploratory study. All data was collected through a literature review and through interviews with 9 parents whose children were enrolled at a hospice in Maryland at the time of their interviews, all conducted from November 2018 through November 2019. All data from interviews were thematically analyzed using Atlas.Ti.

Results. Hospice services provide invaluable support to families by providing relief, being a consistent resource, and giving respite care. However, there are some persistent frustrations with how the pediatric hospice care model is organized, primarily the renewal processes every two to six months, and how pediatric hospice is perceived by the general public. Parental experiences are influenced by a wide variety of factors including the hospice staff, respite, and individualization of care.

Conclusion. This information can be used to inform future research and policy decisions. Future research should reach beyond a singular hospice program, but this study highlights the existence of differences of experience between parents whose children are currently enrolled and parents whose children have died in hospice. Parents whose children are currently enrolled are less likely to report negative experiences, so further research should be conducted in this field.
# Table of Contents

Chapter 1: Introduction .................................................................................. 4

Chapter 2: Before Hospice Enrollment ................................................................. 22

Chapter 3: Experiences in Hospice ................................................................. 44

Chapter 4: Reflections on Experience ............................................................... 64

Chapter 5: Conclusion ...................................................................................... 77

Appendix ........................................................................................................... 82

Acknowledgements ............................................................................................. 85

References .......................................................................................................... 86
Chapter 1: Introduction

Topic Layout
Introduction
A Policy Overview
Hospice Functions
Autobiographical Memory and Grief
Study Methods
Chapter Outlines
Introduction

This paper seeks an answer to the following question: How do parents experience pediatric hospice care for their children while they are currently enrolled? We will walk through this experience along the journey of the parents themselves. What was life like prior to enrollment in hospice? What are their current experiences? What are the implications of these experiences from a policy perspective? Do these opinions differ if the parent is bereaved? Is there an effect of grief on autobiographical memory, and could this be the reason for any discrepancies in experience among bereaved parents and parents whose children are still alive?

Before diving into these questions, it is important to obtain a thorough background regarding the hospice system and the current policies in place.

Functions of Hospice Care in the United States

The function of pediatric hospice is to include the following: patient centered and family engagement, respect and partnership, quality, access and equity, care across the life span, continuity of care, and preparedness on the part of physicians.\(^1\) Hospice is a form of palliative, or comfort, care that focuses on the end-of-life or life-limiting conditions. The model of pediatric palliative and hospice care is “interdisciplinary in nature, encompassing the medical, psychosocial, and spiritual needs through education, research, advocacy, and quality outcomes.”\(^2\)

This includes a large team of caretakers, including parents, child life specialists, therapists, nurses, physicians, etc. The team for pediatric hospices is very similar to those in adult hospices, but they may also include a child life specialist, who helps the patient and siblings express

---

\(^1\) Section on Hospice and Palliative Medicine and Committee on Hospice Care, 2013

\(^2\) National Hospice and Palliative Care Organization, n.d.
emotions and maintain their childhood through the duration of enrollment.\(^3\) There are a few crucial differences between adult and pediatric hospice care that are essential to discuss in the context of this study’s motivation. Many hospices allow for pediatric patients to keep receiving curative treatments while enrolled. This can mean that children who are enrolled in hospice, though they have a life expectancy of six months or less, could actually live much longer than this requirement. These children may not be actively dying, meaning their conditions may not be terminal.

However, there are barriers to the accessibility to hospice programs for children. According to the American Academy of Pediatrics, “… few hospices currently have the capacity to care for infants, children, and adolescents…[and] insurance coverage is often restricted or limited.”\(^4\) Nevertheless, the Affordable Care Act does have a section pertaining to hospice and palliative care, deeming children with Medicaid or the Children’s Health Insurance Program (CHIP) can receive hospice and life-extending therapy.

There are different requirements for hospice diagnostic requirements for children than for adults. According to the Standards of Practice in 2009, there are four acceptable diagnostic categories for pediatric hospice: life-threatening conditions for which curative treatment is feasible but could fail (e.g. advanced or progressive cancer), conditions where early death is inevitable but treatment is done to prolong life and maintain its quality (e.g. cystic fibrosis or muscular dystrophy), progressive conditions without curative treatment options where treatment is entirely palliative (e.g. Tay-Sachs or Trisomy 13), and irreversible but non-progressive conditions with complex healthcare needs and high likelihood of premature death (e.g. severe

\(^3\) Pediatric Hospice, 2020.
\(^4\) Section on Hospice and Palliative Medicine and Committee on Hospital Care, 2013.
cerebral palsy or severe brain malformations). These categories differ from the standards of practice for adult hospice in that the children do not have to be actively dying and they can continue to pursue life-extending treatment while being enrolled in hospice.

There are four models of care for pediatric palliative and hospice care: hospital-based programs, hospice-based programs, free-standing pediatric hospice facilities, and community agency/long-term care facility-based programs. There are varying programs within each model. The hospital-based program includes designated beds for children enrolled and outpatient services, while the hospice-based programs have a dedicated hospice team and are generally attached to an adult hospice program. The other models are not commonly used in the United States. As of 2007, 36.6% of hospices have a formal pediatric program in place, and most of these programs primarily provide care for between 1 and 20 pediatric patients per year. Of the children that employ pediatric hospice, 17.1% are less than a year old, 67.5% are between 1 and 19 years old, and 15.5% are older than 19. There is no clear data about how many children are eligible for hospice and about how many children have passed away in hospice per year because of inconsistent policies across hospice services regarding who is eligible to enroll. This is possibly due to differences in policies in each state and in each hospice.

Hospice has been shown to prolong the lives of those who are eligible. A study investigating survival time of hospice patients showed “the majority of pediatric patients with cancer were still alive 1 month after enrollment, and 69.7% of all patients were alive at 1 year.” Given that most hospice programs and policies dictate the condition must be terminal or life-limiting and have a six-month-long prognosis if the condition is to run its course untreated,

---

5 National Hospice and Palliative Care Organization, n.d.
6 Friedbert, Sarah and Conrad Williams, 2015.
7 Friedbert and Williams, 2015.
8 Siden et al. 2014
having nearly 70% of patients survive past 1 year demonstrates the effectiveness of the program itself.

**History of Hospice Care**

The institution of hospice care as it is known today was first introduced in 1963 by Dame Cicely Saunders, who went on to found St. Christopher’s Hospice in England in 1967. Saunders went against the norm of standard medical practice at the time. She envisioned an interdisciplinary care team of physicians, nurses, social workers, chaplains, and patients with their families. The most radical idea of hers at that time was that decisions about care “should be driven by the wishes of patients, not by the opinions of specialists or the convenience of nurses or the rules of hospitals, government health programs, or insurance companies.”

The notion of home-based care and patient choice was gaining traction at this time with the release of Dr. Elisabeth Kubler-Ross’s book *On Death and Dying* in 1969. In the book, she argues for home care as opposed to institutional care for the dying and for patients to be involved in the decision-making process regarding their treatment. Dr. Kubler-Ross advocated for this position throughout her career, testifying in front of the U.S. Senate Special Committee on Aging in 1972:

> We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We should not institutionalize people. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home.

With the hope of providing this place for specialized care for the dying, hospice was introduced to the United States by 1974 in Connecticut by Nurse Florence Wald, yet would not...

---

9 Smith and Himmel, 2013.
10 National Hospice and Palliative Care Organization, n.d.
receive federal funding or accreditation until 1984.\textsuperscript{11} According to the National Hospice and Palliative Care Organization, hospice provides “medical care, pain management, and emotional and spiritual support” for both the patient and family.\textsuperscript{12} Its focus is centered in personalized caring rather than finding a cure, and for adult hospice users, they typically give up other hospital-based interventions or curative treatment. Beyond the realm of direct patient care at home, the hospice team works to provide bereavement support for the family after their loved one passes away. The interdisciplinary team of hospice workers includes a myriad of support, including but not limited to physicians, chaplains, bereavement counselors, social workers, nurses, volunteers, and home health aides.

While the first adult hospice in the United States was founded in 1974 and the first pediatric hospice in 1998, standards of practice in pediatric hospice and palliative care were not released until 2009.

\textit{A Brief Introduction into Hospice Policy}

As mentioned before, the United States established hospice accreditation in 1984.\textsuperscript{13} Hospice is regulated both on the federal level and the state level. I focused on pediatric palliative and hospice care in Maryland in this study. While I chose Maryland partially out of convenience, Maryland also has a diverse population, particularly around the Baltimore area. This allows for the possibility of wider demographic representation among study participants. On the federal level, the Centers for Medicare & Medicaid Services (CMS) under the Department of Health and Human Services determines the requirements for hospice services and programs.

\footnotesize{\textsuperscript{11} National Hospice and Palliative Care Organization, 2018.  
\textsuperscript{12} National Hospice and Palliative Care Organization, 2018.  
\textsuperscript{13} National Hospice and Palliative Care Organization, n.d.}
There are certain requirements mandated by CMS that a physician has to follow in order to enroll their patients into hospice. They must submit a written certification that includes a statement that prognosis is six months or less if illness runs its normal course, clinical findings and other documentation that supports this, signatures of physicians with the date signed and benefit period dates, a narrative explanation that supports the prognosis of 6 months, and a face-to-face encounter and attestation. While this is primarily for adult hospice, these are also required for admission into pediatric hospice care. Recertification for the patient in hospice occurs every six months.

The Centers for Medicare and Medicaid Services (CMS) also regulates how Medicare is used for treatment. Until the passage of the Affordable Care Act in 2010, if a pediatric patient were enrolled in hospice care, any treatment would have to be palliative, not curative, like is the case for adult hospice. In fact, Medicare Part D dictates that hospices should “provide individuals... with drugs and biologicals related to the palliation and management of the terminal illness as defined in the hospice plan of care... for prescription drugs to be covered under Part D when the enrollee has elected hospice, the drug must be for treatment of a condition that is unrelated to the terminal prognosis of the individual.” This says any patient that uses Medicare Part D for their prescription drugs when on hospice cannot have any curative medications for whichever condition is listed to have the six-month prognosis.

Maryland has a written code of regulations for hospice programs, operating under the federal protocol. Per Maryland regulation, there are two different hospice licenses that each last for three years: general and limited hospice care programs. A general hospice care program is “home-based or inpatient care involving medical, nursing, or other skilled health services,” while

---

15 CMS, n.d.
a limited hospice care program is “non-skilled hospice services in a home-based setting.”\textsuperscript{16} Each hospice has to develop its own policies and procedures for activities including the use of advance directives, addressing ethical dilemmas, administration of medications, management of complications, resuscitation initiation, provisions of in-patient hospice care, and much more.\textsuperscript{17} These standardizations allow for each program to have systematic methodology for treating patients and for addressing any issues that may come up.

On top of this regulation, Maryland dictates who must be a part of the Patient Interdisciplinary Team. This team is the crux of the hospice program, as together they provide all the care and make hospice distinct from other hospital and medical programs. The mandated team includes an attending physician, a physician with training in palliative care, a registered nurse, a social worker, a volunteer, a spiritual care counselor, and any other individuals as needed. These individuals could be allied therapists, dietitians, pharmacists, etc.\textsuperscript{18}

\textit{The Affordable Care Act and Medicare Influence on Hospice}

The Affordable Care Act was revolutionary in pediatric hospice care reform. It allowed for concurrent curative treatment in Section 2302 upon its passage in 2010. Not only did it “assure children can receive curative treatment upon the election of the hospice benefit for children enrolled in Medicaid or CHIP,” it also made hospice a required service under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provision for children enrolled in Medicaid.\textsuperscript{19} In other words, a child can use hospice care without ceasing treatment, but they still have to be within the last six months of their life should the disease run its normal course. That

\textsuperscript{16} Baltimore County Department of Aging, 2018.
\textsuperscript{17} Baltimore County Department of Aging, 2018.
\textsuperscript{18} Baltimore County Department of Aging, 2018.
\textsuperscript{19} Mann, 2010.
being said, individual states can include supplemental services and change eligibility to include those with life-limiting conditions using a waiver or State Plan Amendment.\textsuperscript{20} Maryland is one of the states that enacts this State Plan Amendment to allow children with life-limiting conditions to enroll in hospice care.

There were several precedents that allowed for the provisions passed in the Affordable Care Act. In 2005, Florida became the first state to support concurrent palliative and curative care for pediatric patients. This was followed by the passage of the Nick Snow Act of 2009 in California, which supported concurrent treatment for children in hospice. Other states had similar programs, including those in Illinois, Colorado, New York, North Carolina, and Washington. In New York, a waiver was passed for children that have physical disabilities so that they could receive hospice care at home rather than in a residential facility.\textsuperscript{21}

There have been some difficulties implementing this concurrent treatment provision of the ACA. Physicians still need to certify that the child is within the last six months of life, and prognosis can be difficult to determine, particularly when still in active treatment. Additionally, these physicians are limited to reimbursement services provided by Medicaid or Children’s Health Insurance Program (CHIP), and these provisions are largely hospice-only and community-oriented, which makes it challenging to provide palliative care early in a disease trajectory, thus leading to fragmented care. There is further possibility for disparities of care due to this provision only applying to Medicaid, not including children that are on private insurance or Medicare.\textsuperscript{22}

\textit{Hospice and Palliative Care Abroad}

\textsuperscript{20} District of Columbia Pediatric Palliative Care Collaboration, 2011.
\textsuperscript{21} Keim-Malpass et al., 2013
\textsuperscript{22} Keim-Malpass et al., 2013
Hospice is an institution that exists outside of the United States, but it has differing models depending on the country in which it is implemented. Pediatric hospice in the United States emphasizes inpatient hospital consultation with home-based hospice care, whereas Canada has a more blended model. Their hospices are hospital-community programs and separate inpatient programs that provide respite, symptom management, and end-of-life care.\textsuperscript{23} Their clinical staff is similar to that of the United States, including physicians, registered nurses, respiratory therapists, personal care aids, and counselors, though the United States mandates a more integrated and holistic care team.

Hospice programs exist outside of North America as well. They all follow similar tenants of providing palliative care for children with terminal illness, though they vary slightly depending on geographic and political location. In South Africa, there are six established hospice programs, most of which provide care in the children’s homes, but many have day care centers for the children that provide support groups for adolescents and bereavement centers. Five of the six hospices have inpatient facilities that provide end-of-life care, symptom and pain control, respite care, and antiretroviral therapy, as the hospices in South Africa were made primarily to serve children with HIV/AIDS.\textsuperscript{24}

In Asia, there are numerous programs in India, Thailand, the Philippines, Indonesia, and Singapore. There are two significant programs in Singapore: the Assisi Children’s Center and the KK Women’s and Children’s Hospital. The former was originally an inpatient hospice unit, but they eventually established a home-care program primarily for adults, though ultimately accepted children. It also has a day care center for children with cancer. The latter program established a pediatric palliative care-team in 2004. This team includes two full-time nurses, a pediatric

\textsuperscript{23} Siden et al., 2014.
\textsuperscript{24} Marston et al., 2009
oncologist, a pediatric anesthetist, a palliative-care physician, and medical social workers. This hospital also has a neonatal hospice team.25

In Central and South America, several programs are formed with the help of various foundations. The roles of these teams differ slightly from programs in the United States and elsewhere. For instance, the Garrahan Hospital has a pediatric palliative care unit. This is an inpatient unit that provides the following services: assistance, teaching of other medical professionals, research, and treatment for cancer, cystic fibrosis, chronic obstructive pulmonary disease, osteogenesis imperfecta, and other conditions. The team in this inpatient unit includes pediatricians, a nurse, psychiatrist, pharmacologist, and physical therapist. Costa Rica’s program differs significantly, as it offers programs in the hospital, at home, and at a hospice called the Saint Gabriel Shelter. The program offers support therapy, bereavement therapy, home care, fundraising, and a hospice that offers personalized medical, psychosocial, and spiritual support.26

All of these international programs offer similarities to those of the United States. All aim to provide comfort care to the patients, while also offering bereavement services. Additionally, some of the programs have a similar care team, while also offering support to the family of the children enrolled.

**Autobiographical Memory and Grief**

Three studies similar to the present one describe the experiences of parents whose children died in pediatric palliative care and hospice services. Thienprayoon et al. in 2016 analyzed interviews with caregivers of children with cancer who were enrolled in hospice. These children all died three to seven years prior to the study. The goal of the Thienprayoon study is

25 Marston et al., 2009
26 Marston et al., 2009.
similar to this one outlined in this thesis—to investigate parental experiences, but theirs only addresses those of bereaved individuals. Parents primarily discussed medical provider communication, hospice expectations and utilization, and caregiver appraisal in terms of financial cost of caring for their child or in terms of being a liaison for other family members. The hospice would assist the parents in figuring out how to talk to their family members about their children’s conditions.\textsuperscript{27} van der Geest et al. in 2014 also described how 89 parents experience pediatric palliative care and hospice services. The parents’ children died from cancer between the years of 2000 and 2004, and these parents completed questionnaires. In every category (communication, continuity of care, and parental involvement), parents rated the services highly, which the authors then connected to lower levels of long-term grief.\textsuperscript{28} Lovgren et al. (2016) sought to explore the experiences of 48 parents concerning end-of-life care. The study population consisted of bereaved parents of children with Spinal Muscular Atrophy. The authors found that most parents wanted their children to die at home, and that communication with their physicians contributed to their child being able to die at home, rather than in a hospital.\textsuperscript{29} The recurring limitation in the Thienprayoon et al. (2016), van der Geest et al. (2014), and Lovgren et al. (2016) studies and in other current literature on the parental experiences of pediatric hospice and end-of-life care is their retrospective nature. All interviews and surveys were conducted after the child died, which introduced recall bias by way of complicated grief and the passage of a significant amount of time.

Several studies note the effects of grief on autobiographical memory. For example, Safer et al. (2001) explored long-term memories for grief reactions in order to know how accurately

\textsuperscript{27}Thienprayoon et al., 2016.  
\textsuperscript{28}van der Geest et al., 2014.  
\textsuperscript{29}Lovgren et al., 2016.
people can report on past states of emotion or experience. They found that recall was less than perfect for all grief-related variables, with objective change in intrusive ideation correlating with avoidant thoughts and grief symptoms. Similarly, Boelen and Huntjens (2008) found that 96% of bereaved parents had experienced intrusive memories four to seven years after the loss.

These intrusive memories can include images that are positive, that are of the death event, or that are negative. Intrusive memories are highly correlated with complicated grief, which can impact autobiographical memory by impairing retrieval of or enacting bias on specific memories. This means that in any aforementioned study in which investigators interviewed bereaved families, any presence of complicated grief could heavily skew memories of their experiences with healthcare providers. This demonstrates the necessity of research that primarily focuses on parents whose children are still alive and enrolled in hospice.

Similar studies have examined the parental and even pediatric experiences of palliative care, rather than hospice care. Hsaio et al. (2007) identified the aspects of physician communication that children with life-limiting illnesses and their parents perceived to be facilitative or obstructive in pediatric palliative care. Researchers asked children and parents individually a series of questions regarding the child’s palliative treatment. Children were asked questions such as, “What has it been like to be sick?” or “Do you think that (caregiver/provider/other) understood what it was like for you?” Similarly, parents of these children were asked whether the providers were helpful or not. The investigators were trying to identify the aspects of physician communication that children with life-limiting illnesses and their parents perceived to be helpful or harmful to their care. They found five themes regarding

---

30 Safer et al., 2001.
31 Boelen and Huntjens, 2008.
32 Maccallum and Bryant, 2008.
physician communication: relationship building, demonstration of effort and competence, information exchange, availability, and appropriate level of child and parental involvement. These aspects of communication (i.e. proving competence and involving parents and children in decision making) are recurrent in all these studies regarding palliative care and hospice, but their results in particular were limited by only addressing palliative care, whereas I am trying to learn about parental experiences of pediatric hospice care.

While it is important to examine past literature on pediatric palliative and hospice care, it is imperative to look at current literature regarding familial experiences of adult hospice care. It is important to look at this topic because there are fundamental differences between pediatric and adult hospice care and looking at the experiences of family members can provide a point of understanding for the experiences of pediatric hospice. The majority of pediatric hospice care occurs at home, and while hospice care for adults can also be at home, many geriatric patients receive their care in nursing homes, residential facilities, or freestanding hospice facilities. Oliver et al. (2014) investigated family members’ experiences with end-of-life care in nursing homes. They found that there were many barriers to high-quality end-of-life care and that it was extraordinarily important for family members to receive some support from the facility.

A similar conclusion was found in a study conducted by Gage et al. in 2016 that investigated family member experiences with hospice services in nursing homes. The investigators emphasize the experiences in terms of care coordination, support, and role confusion for the health care team. Parents in this study mentioned issues related to organization and collaboration on care delivery, but they were satisfied with the hospice’s ability to facilitate

---

33 Hsiao et al., 2007
34 National Hospice and Palliative Care Organization, 2019.
35 Oliver et al., 2014.
changes to improve the patient’s quality of life. The parents saw the hospice as an additional support and an extra set of medical eyes on the patient, someone who can catch something a nursing home staff member may miss. However, the role delineation between the nursing home and the hospice served as a barrier to the patient’s care, as the family would not know which group to turn to for certain issues. These studies have similar limitations to the studies that explore pediatric hospice experiences in that families were interviewed after the patient had passed away.

**Methods**

**Study Design**

This study is exploratory in nature. It is designed to investigate questions regarding the experience of pediatric hospice to see if it is different for parents while their child is enrolled compared to after the child dies. It is a qualitative, thematic analysis of individual responses. I investigated parents’ decisions to enroll their child in hospice, dynamics between parents and hospice staff, experiences in daily life, expectations for care, and management of stress. This information was the basis for comparison and formulation of generalization for parental experiences, which allowed me to identify whether there is perception bias for experiences (upon comparison with current published literature). This research method of qualitative interviewing for comparison/generalization is the most appropriate for the project because it allows for in depth perspective and insight into the experiences of these parents. All information and analysis for policy and scientific based inquiry was through a literature review.

**Participant Recruitment**

---

36 Gage et al., 2016.
Participants were recruited by the nurse manager at a hospice clinic in Baltimore, Maryland. She identified parents whose children were not in active crisis, as defined by her, and would be in a good position to interview. In order to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and ensure patient privacy, she did not to give me names or phone numbers of parents unless she obtained their consent to do so. My initial contact with parents included a phone call to set up an interview time and to gauge whether they were still interested. Based on this recruitment method, it was not possible to calculate a sampling fraction.

Only parents whose children were still alive and enrolled in hospice were eligible to participate in this study, although those whose children were sick or needed significant care during the recruitment process were not contacted until the issue causing active crisis had settled.

Procedure

Each parent that volunteered to participate was interviewed. Each interview lasted between 15 and 90 minutes. Each participant signed an informed consent form prior to the interview and was asked questions included in the interview guide shown in Appendix 1. For phone interviews, verbal consent was obtained. The same interview guide was used for both phone and in-person meetings and can be found in Appendix 2. In-person interviews were located in Baltimore, Maryland. I recorded each interview upon receiving consent. The participants were allowed to skip any question or withdraw from participation at any time. The recorder was turned off upon completion of the interview, unless the participant wished for it to be turned off earlier. I transcribed these interviews to code and analyze. Names and other
identifying information and all signed informed consent forms were kept confidential in a master-list in a locked file cabinet, and all data collected was stored on box.com.

**Evaluation and Analysis**

I transcribed each interview and analyzed them using question and thematic coding in Atlas.Ti, a qualitative data analysis and research software. Identifying the common themes led to the quotes that epitomize the parental experiences of pediatric hospice care. I then compared these themes and ideas presented in selected quotes to current literature on parental experiences of pediatric hospice of bereaved parents in order to establish whether there is a difference in the experiences when they are asked during enrollment and after they have passed away.

**IRB Approval Statement**

The study design and methodology were approved by the Greater Baltimore Medical Center Institutional Review Board in August of 2018 and approved for continuation of the study in August of 2019. The Brandeis University IRB ceded their review to the Greater Baltimore Medical Center Institutional Review Board. After the requisite three years, all data will be destroyed. The only people that have access to this data are myself and Professor Wendy Cadge.

**Chapter Outlines**

In this section, I introduced the reader to the world of pediatric hospice care. How does it function and how does it work? What does the existing literature say regarding parental experiences of pediatric hospice care? Then, I went through the study design for this research as a preface for the rest of the thesis, which outlines the process of going from diagnosis and enrollment in hospice care to the experiences while enrolled.
Chapter 2 focuses on parental experiences prior to hospice enrollment. This includes finding out about their children’s diagnoses and how they came to the decision to enroll in hospice. Chapter 3 then transitions into the experiences in hospice care. It describes the influences of respite, renewal, nurses, child life specialists, chaplains, support/relief, and daily life. With these experiences come parental goals for the future of their children’s care, described in Chapter 4. This chapter also outlines different policy positions for changing hospice as an institution.
Chapter 2: Before Hospice Enrollment

Topic Layout
Study Population
Diagnosis Experience and Conditions
Perceptions of Hospice
Enrollment
The journey to hospice care looks different for each family that decides to enroll their child. This chapter opens with the story of one parent.

One mother, whose child is 5 years old and has been enrolled in hospice for around 4.5 years, discovered that something was wrong eleven weeks after conception. Her physicians found a cystic hygroma in the ultrasound and advised her to get a blood test to determine if it was a chromosomal issue. The test confirmed a chromosomal problem at 15 weeks gestation, and physicians confirmed a diagnosis of full trisomy 18 after her child was born. However, to the parents’ dismay, most physicians with whom they spoke advised them not to follow through with the pregnancy. Due to their strong religious ties, the parents decided to continue the pregnancy. They connected with hospice care through a physician that shared the same faith as the family. The element of choice and the idea of support led them to meet with the hospice team perinatally. This meeting confirmed the mother’s desire to enroll, as they understood her desire to have her child on her own terms. She describes, “In a hard situation, it was the best thing that could have happened for us to run into.”

This story is unique and highlights how one parent came upon hospice prior to her daughter’s birth. However, what are the conditions and diagnoses that lead to the decision to enroll children in hospice? What are the parents’ perspectives, and did the perspectives of others influence their decisions? What was the reasoning behind enrolling? This chapter will explore the factors of the parental experience that exist prior to enrollment, including the diagnosis and condition, perceptions of pediatric hospice care, and decisions to enroll. I find that the conditions that cause parents to enroll their children in pediatric hospice vary significantly but are always life-limiting in some form. As with this mother and child, these conditions push parents to enroll in order to have extra support and increased quality of life both for the family and for the patient,
but these desires to enroll are hindered by perceptions of hospice care held by the parents’ social circles and the physicians of the child.

Study Population

To investigate the parental experiences of pediatric hospice care and to keep to the exploratory nature of this study, nine parents were interviewed as of December 2019. All of the parents interviewed were cisgender female mothers. Of these parents, 88.9% were married, while 11.1% were single. 55.6% had 2 children, 22.2% had 3 children, 11.1% had 4 children, and 11.1% had 1 child. Full demographic information of the parents can be found in Appendix 1. All referenced names below are pseudonyms.

Parental Experiences Prior to Hospice Enrollment

Diagnoses and Conditions

The primary diagnosis that caused each child to be considered for hospice care is listed in Table 1. Condition category is based on whether the primary diagnosis can be classified as neuromuscular, cardiovascular, cancer, or congenital. Neuromuscular was considered when the condition did not occur during birth and affects either the neurological system or the musculoskeletal system. Congenital implies that the child was born with the condition, whether through germ-line genetic mutation or de novo mutation. About a third of the study population fell under the neuromuscular category, whereas the other two-thirds are congenital.

Table 2 shows the same categorical distribution of pediatric hospice care patients for a different study population. This table provides background as to the typical population distribution of patients who are enrolled in pediatric hospice care, most of whom are diagnosed with a neuromuscular condition or with cancer. The purpose of this study is to help improve clinical practice of nurses by allowing them to aim conversations about hospice with families
that have the most need for it. Having this study explain the general distribution of who is using hospice care, based on diagnosis, comorbidities, age, etc. allows for contextualization for the rest of the study and how this study’s population can compare. Lindley and Shaw established a binary variable for various complex medical conditions that also fit the distribution of conditions in the present study.

Table 1. Primary Diagnosis among Study Population

<table>
<thead>
<tr>
<th>Condition</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lennox-Gastaut Disorder</td>
<td>1 (11)</td>
</tr>
<tr>
<td>I-cell Disease</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Chromosomal Disorder</td>
<td>2 (22)</td>
</tr>
<tr>
<td>Upstream Binding Transcription Factor Mutation</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Hypoxic Ischemic Encephalopathy</td>
<td>2 (22)</td>
</tr>
<tr>
<td>Hypoxic Brain Injury</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Pontocerebellar Hypoplasia</td>
<td>1 (11)</td>
</tr>
<tr>
<td>Total N</td>
<td>9 (100)</td>
</tr>
</tbody>
</table>

**Condition Category**

| Neuromuscular | 3 (33.3) |
| Cardiovascular | 0 (0) |
| Cancer | 0 (0) |
| Congenital | 6 (66.7) |
| Total N | 9 (100) |

**Table 2. Primary Diagnosis for Pediatric Hospice Care Enrollment**

<table>
<thead>
<tr>
<th>Condition Category</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuromuscular</td>
<td>41 (53.95)</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>21 (27.63)</td>
</tr>
<tr>
<td>Cancer</td>
<td>32 (42.11)</td>
</tr>
<tr>
<td>Congenital</td>
<td>13 (17.11)</td>
</tr>
<tr>
<td>Total N</td>
<td>107 (100)</td>
</tr>
</tbody>
</table>

Comorbidities are common with both adult and pediatric hospice patients, and exist when a patient is diagnosed with more than one condition, as certain diagnoses can leave a person more susceptible to further illness. Again, the present study sample was compared to that of the

---

38 Lindley and Shaw, 2014.
Lindley study, as it shows a similar distribution with a larger sample size (n=76). Lindley and Shaw (2014) outlined the comorbidity categories. The majority of patients have 0 or 1 comorbidity. Only one patient in the present study had three or more comorbidities. The distribution is shown in Table 3. This tells us that it is more common for patients enrolled in pediatric hospice to have fewer co-morbidities in addition to their primary diagnosis that led them to hospice care.

<table>
<thead>
<tr>
<th>Number of Comorbidities</th>
<th>Study Sample, n (%)</th>
<th>Lindley, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>8 (88.9)</td>
<td>35 (46.05)</td>
</tr>
<tr>
<td>2</td>
<td>0 (0)</td>
<td>24 (31.58)</td>
</tr>
<tr>
<td>3+</td>
<td>1 (11.1)</td>
<td>17 (22.37)</td>
</tr>
<tr>
<td>Total n</td>
<td>100</td>
<td>76 (100)</td>
</tr>
</tbody>
</table>

Comparing the Lindley study to the present study shows another distribution of comorbidities and conditions with a larger sample size. Additionally, it highlights some key differences that may be left out of this study. For instance, about half of the Lindley study sample have two or more comorbidities, and about 42% of the Lindley sample has a primary diagnosis of cancer, whereas none of the primary diagnoses of this study are cancer. Understanding the conditions contextualizes decision to enroll in hospice care and the experiences that these parents have while enrolled, because the diagnoses impact familial daily life, describe the patients’ abilities, determine how much support a family needs in caregiving, and shorten patients’ lives. First, we will walk through the neuromuscular conditions: hypoxic ischemic encephalopathy and hypoxic brain injury. Then, we will discuss the congenital conditions. These serve to contextualize the experiences prior to enrollment in hospice.

*Hypoxic Ischemic Encephalopathy and Hypoxic Brain Injury*
These two diagnoses are similar in that both involve a hypoxic incident. Hypoxic Ischemic Encephalopathy (HIE) typically results when the baby is deprived of oxygen during delivery, and is a form of hypoxic brain injury, or an injury that occurs from a hypoxic (oxygen-deprived) incident (e.g. cardiac arrest). Each case of hypoxic brain injury is unique, and the symptoms and effects depend on the parts of the brain affected by the oxygen depletion.\textsuperscript{39}

If oxygen deprivation happens for too long, brain tissue is destroyed, causing serious impairments, including epilepsy, developmental delay, motor impairment, neurodevelopmental delay, and cognitive impairment.\textsuperscript{40} Because of the severity of cell death in HIE patients, 40-60\% of affected infants die by the age of two or have significant disabilities caused by its pathophysiology of primary then secondary energy failure. The former is the result of the initial decline of cerebral blood flow, wherein adenosine triphosphate (ATP) production decreases. ATP is the primary source of energy in the body. It is involved in numerous mechanisms that maintain cell functions, most notably the sodium-potassium pumps. The malfunction of these pumps results in massive depolarization of neurons, thus allowing too much calcium to remain in the cell. This results in cerebral edema, ischemia, microvascular damage, ultimately leading to apoptosis or necrosis of the cells.\textsuperscript{41} Secondary energy failure, also called “reperfusion injury” occurs due to the buildup of free radicals in the blood,\textsuperscript{42} which damages neuronal tissue.

Aside from the serious impairments, other symptoms include depressed heart rate and respiratory rate, seizures, pale skin, absent reflexes, and an Apgar score of less than three for longer than five minutes. Treatment for HIE and other hypoxic brain injuries depends on the

\textsuperscript{39} Shepherd Center, 2020.  
\textsuperscript{40} Cerebral Palsy Foundation, 2020  
\textsuperscript{41} Allen and Brandon, 2011.  
\textsuperscript{42} Hope for HIE, 2019.
extent of oxygen depletion, though therapeutic hypothermia has shown to reduce disability and death.

One-third of the parents interviewed have a child with either a hypoxic brain injury or HIE. One parent, called Florence, described the aforementioned process of hypothermia for her child, who is 9 months old and has been enrolled for 6 months: “When he was transported to the NICU, they had him under the cooling protocol, which means he was hypothermic purposefully so they could protect whatever areas of the brain hadn’t been damaged and as they warmed him up and gave us what expectations may be, it [our hopes] changed.” Multiple parents discussed their expectations continually changing due to their children’s deteriorating conditions since birth. Florence described how her daughter’s condition “just got worse and worse and she never improved, even for a day” after depicting how she would be able to walk one day, need assistance the next, and then need a wheelchair the next week. The parents’ experience of having a child with HIE and with a hypoxic brain injury appears to involve adjusting expectations and hopes for the future. The parents whose children have HIE or a hypoxic brain injury are Florence, Rose, and Bethany. Rose’s child is 23 months old and has been enrolled for 8 months, whereas Bethany’s is 8 months old and has been enrolled for 8 months. These conditions encouraged parents to enroll in hospice care for the supportive care and end-of-life management. It is notable that all the children enrolled in hospice for these conditions were enrolled as infants, and all for supportive care due to the results of oxygen depletion.

I-Cell Disease

---

43 Shepherd Center, 2020.
44 Hope for HIE, 2019.
*all study participants will henceforth be referred to by pseudonyms. See Appendix 1 for more details
I-Cell disease, also known as mucolipidosis II or Leroy Disease, is a rare inherited metabolic disorder in which fatty substances and complex carbohydrates are accumulated within cells. It is caused by a mutation in GNPTA gene that leads to a deficiency in an enzyme involved in the synthesis of mannose-6-phosphate, resulting in decreased intracellular levels of lysosomal enzymes. An autosomal recessive trait, these decreased levels cause craniofacial abnormalities, skeletal malformations, and other symptoms including hearing loss, severe delays in development of motor skills, growth delays, and frequent respiratory infections. Children with I-Cell often pass away in childhood, as treatment is palliative in nature. The terminal aspect of the condition can qualify a child with I-Cell for hospice care. The mother whose child has I-Cell disease and is enrolled in hospice, called Margaret, described how she enrolled her son right away after diagnosis because her daughter previously had the condition and passed away on hospice care. Her son is now 3 years old and has been enrolled since birth.

*Trisomy 13 and Trisomy 18*

If a person has a trisomy condition, there are three copies of one chromosome, resulting in 47 total chromosomes instead of the typical 46. The three most common types are Down Syndrome (Trisomy 21), Edward Syndrome (Trisomy 18), and Patau Syndrome (Trisomy 13), the latter two of which are present in the study. The risk for trisomy increases with advanced maternal age, and they can be detrimental to the individual that has it.

Trisomy 13 occurs in 1 in 16,000 newborns, of whom more than 80% do not survive past the first month of life, with only 5-10% surviving past the first year. Those that survive have numerous complications, including breathing difficulty, deafness, feeding problems, heart

---

45 National Organization for Rare Disorders, 2019.
failure, seizures, increased risk of cancer, and severe intellectual disabilities.” Despite all these complications, the prognosis is still unpredictable. One parent called Helen noted, “they were giving two weeks of life, and briefly, we just did one day at a time, and here we are 16 years later.” Her child is 16 years old and has been enrolled for a month for supportive care.

Trisomy 18 is more common, occurring in 1 in 5,000 births, though most affected fetuses do not live to term. Only 5-10% even live past the first year of life, and those who do have various complications. These include slow growth before birth, low birth weight, small jaw, and small mouth. Other researchers also believe that extra copies of certain genes on this chromosome disrupt normal development. Similar to trisomy 13, prognosis and the physical condition of a child with trisomy 18 is unpredictable. As described by Ruth, her daughter had graduated from hospice a couple years ago because she was too healthy, but after getting sick with pneumonia, she reenrolled for supportive care. In the present study, one parent (Ruth) has a child with trisomy 18, and one parent (Helen) has a child with trisomy 13. The former’s child is 5 years old and has been enrolled for 4.5 years, while the latter’s is 16 years old and has been enrolled for a month.

**Upstream Binding Transcription Factor Mutation**

A mutation in the upstream binding transcription factor (UBTF) can result in a condition called Child-Onset Neurodegeneration with Brain Atrophy (CONDBA). It is characterized by progressive cerebral and cerebellar atrophy, which can result in developmental regression, absence of language, and intellectual disability. This UBTF is located on chromosome 17, and

---

46 Genetic and Rare Diseases Information Center, 2019.  
it plays a crucial role in ribosomal RNA transcription.\textsuperscript{50} Disrupting this transcription significantly impacts the way that ribosomes can operate and can ultimately cause neurodegeneration. UBTF mutations have numerous clinical features in addition to this neurodegeneration, including abnormality of the digestive system, musculature, nervous system, and growth.\textsuperscript{51} One mother (Anna), whose child is 18 years old and has been enrolled for 2 years, enrolled in the study describes the primary clinical presentation as gut failure, but she slowed developmental progression at age 2 and started regressing at 7 or 8 years old. Her mother describes her condition: “her body’s as healthy as a horse but the signals from the brain to everything are what’s failing. She lost her ability to swallow, so she’s on a feeding tube, but even so... [muscular] requirements of the gut to process food isn’t working properly.” This neurodegeneration in tandem with feeding issues qualifies her for hospice care.

\textit{Pontocerebellar Hypoplasia}

Pontocerebellar Hypoplasia (PCH) refers to a group of related conditions that affect to development of the pons and the cerebellum in the brain. The former is responsible for transmitting signals between the cerebellum and the rest of the brain, while the latter coordinates movement. There are multiple types, but we will focus on PCH type 2, an inherited autosomal recessive disorder, which is characterized by a lack of voluntary motor skills, difficulty swallowing, absence of communication, impaired vision, and seizures.\textsuperscript{52} According to researchers, “No patient with classical PCH type 2 ever achieved the milestones of sitting, crawling, standing, walking, talking, or developed meaningful social contact skills,” and death is

\textsuperscript{50} Genetics Home Reference, 2020.
\textsuperscript{51} MedGen, 2020.
\textsuperscript{52} Genetics Home Reference, 2020.
typically attributed to respiratory and infectious complications.\textsuperscript{53} Most children with this condition die before age 10.\textsuperscript{54} According to Marie, the parent enrolled in the present study, her child’s condition was not inherited, but rather a random error. The gene that is responsible for pons and cerebellar development is truncated, becoming nonfunctional. When Marie’s son was born, he was breathing too fast, acted lethargic, and was not crying. Upon MRI confirmation of PCH2 after his birth, the physicians confirmed that he was going to die, thus he was eligible for hospice care. While now he is almost 3 years old, he has been enrolled for about 2.5 years.

\textit{Lennox-Gastaut Disorder}

Lennox-Gastaut is a severe seizure disorder that is not often responsive to anti-epileptic medications. It is extraordinarily rare, with a frequency of 1 to 2 per million people, less than 5% of all cases of childhood epilepsy. Many cases are caused by existing neurological abnormalities, and most children with the syndrome have intellectual disabilities and delayed development of motor skills.\textsuperscript{55} There is no formal definition for Lennox-Gastaut, though it is classified as epileptic encephalopathy, which is a group of conditions in which progressive cognitive dysfunction results from seizures. One 25-year-old patient’s mother, called Mary, describes her daughter’s deteriorating condition:

She has intractable seizures that are not controlled well with medication, and it’s a progressive disorder, so she has slowly lost skills and abilities... so she, at the peak of her … developmental abilities, she was crawling, standing, cruising around furniture, using both hands. She was vocalizing, making every vowel, consonant sound there was, kind of doing like a babbling sound, you know babbling toddler sounds. And she was curious and playful and interactive and extremely social …. but she has a lot of other diagnoses that are related to those original diagnoses. She’s quadriplegic, cerebral palsy now... she has restrictive lung disease. She has a colostomy. She has to [be] catheterized quite

\textsuperscript{53} National Organization for Rare Disorders, 2020.
\textsuperscript{54} Genetic and Rare Diseases, 2020.
\textsuperscript{55} Genetics Home Reference, 2020.
frequently because of her seizures. She’s just in a... she can go into a coma-like state from a seizure activity that she has. She has a trach, is on a ventilator.

While the numerous complications are a result of her comorbidities, Lennox-Gastaut contributes to a lot of stress for her parents in their experience through the hospice system as they search for solutions for the seizures due to their inability to be controlled by typical seizure medications. She has been enrolled for about 3.5 years.

All these conditions have variable effects, whether they are terminal or life-limiting, genetic or neuromuscular, but they all influence how parents decide when and how to enroll. All these conditions are serious, have long-lasting consequences for the individuals that have them and for their families, and because of this, describing the conditions contextualizes the experiences with hospice care. Through all the experiences that I will explore in this and in future chapters, it is important to keep in mind these conditions. However, the primary experiences that influence a parents’ decision to enroll are the reaction and level of support for the child’s diagnosis, as described in the next section.

**Hopes and Fears of Diagnosis**

Having a child with a terminal diagnosis affects parents differently. Hopes and fears change with time, but numerous parents reported feeling devastation with the news with some fear about the prognosis and survival:

> It was a mix of devastation and feeling grateful that we were her parents and that we could be there for her... It was always a mix, but always devastating, but we... always focused on the little joys that... and big joys that she gave us for just being in our life. Our devastation was always for her (1).

After giving birth, Ruth described, “We were praying for like a few hours with her after she was born that she would be alive... So that’s what we were hoping for. We were fearing that we would lose [my daughter] before we got to meet her.” Similarly, Helen described learning
about her son’s diagnosis: “It was devastating. It was the worst thing to... to receive. You know, you’re just celebrating a life, but at the same time, he comes with a death sentence.”

Parents also experienced a misunderstanding of their children’s conditions and what to expect, a general fear of the unknown. Rose recalled, “I didn’t have any hope because I wasn’t understanding the level of... the seriousness of her condition. At the time I didn’t have any hope, but I think that’s because I didn’t understand it. And, my fears were if she was going to make it.” Florence similarly recalled, “There’s no real kind of guide as to what... his life will turn out to be, how long he’ll live, all these kinds of things, so it [expectations] just changes every month,” while Bethany recalled, “At first we didn’t think it was going to be that bad, so it didn’t worry me as much, but as time went on, it went really bad and that was hard to accept. I had a perfect pregnancy, and it was a shock. You think you get to a certain point in your pregnancy and you’re clear, but that’s not the case.” With many conditions that are terminal, it is difficult to estimate prognosis or the future of said conditions. Nevertheless, prognosis is important to for physicians that are managing any symptoms for the child, as these symptoms and the expectations surrounding prognosis can negatively affect the parents after their child’s passing. Because Maryland hospice law permits enrollment for life-limiting conditions as well as terminal ones, these parents were able to consider hospice as an option for this kind of care and management.

**Perceptions of Hospice Care**

Two-thirds of the interviewed parents had heard of pediatric hospice prior to enrollment, whereas one-third had not. That being said, the individual perception of hospice care was fairly universal throughout the study population. Despite an overwhelmingly positive experience

---

56 Latha et al., 2016.
shared amongst all the parents, there were still several barriers to initial enrollment that were due to stigma on the part of physicians, healthcare workers, and other individuals in their lives. Even when receiving this care, the stigma was ever-present.

Physicians have a tendency for therapeutic optimism bias, often attributed to fear of blame and lawsuits, and this bias is apparent in the parents’ experiences of pediatric hospice prior to enrollment. One parent, having discovered the potential for hospice in Atul Gawande’s *Being Mortal*, introduced hospice care as an idea for her daughter’s plan, recalling that they had never sincerely discussed the concept with them. The physician responded by asking Mary, “How do you know about this? Have you felt—has anyone—I have to ask you, have you felt coerced, has anyone talked you into this, have you felt pressured by anyone?” Florence had a similar experience with hospital staff, reporting, “They [physicians] said there was a stigma associated with it... I guess based on what the others’ experiences had been before, they said that ‘we won’t... push you to be in that situation, we’ll just kind of go this initial route...’” It is possible that the physicians acting concerned upon mention of hospice reinforces the stigma that is already associated with the program. Families often choose to enroll in hospice because it was recommended by their physician so, by worrying of coercion upon initial discussion of hospice, physicians could be pushing parents away from hospice even if it was something in which the family was initially interested or if it was something from which the patient could benefit.

Bakanic et a. (2014) indicates that only a small majority of physicians were prepared for relating to end-of-life issues, while a strong majority of them agreed that there should be a stronger emphasis on communication with hospice patients and families in their continuing

57 McAteer and Wellbery, 2013.
58 Thienprayoon et al., 2016.
Many of those respondents also expressed discomfort in discussing death. This communication deficit could lead to this hesitance to refer patients to hospice, even suggesting the idea that the parent was coerced into bringing it up. Mary described this phenomenon when she brought up the idea of enrolling her child, aged 21, in hospice care. Many of the parents with younger children did not express experiences of physician bias, especially those that were enrolled at birth, like the children of Margaret and Ruth.

With stronger education into hospice and palliative care issues, physicians could bridge the gap between public perception of pediatric hospice and perception of those who are enrolled. There appears to be conflicting mentalities between individuals whose children are enrolled in pediatric hospice care and individuals who are not part of that group. The former’s mentality tends to be great appreciation for hospice as an institution providing a safe place to discuss the child’s care, support for the entire family, and bereavement services. The latter’s mentality could potentially reflect those of individuals who do not know the differences between adult and pediatric hospice care. The former’s mentality can be illustrated through Anna’s experience with her daughter’s gastroenterologist, who recommended hospice to have control over treatment, and as will be discussed in future chapters, Anna and the other mothers interviewed expressed the high level of support of having hospice. However, the latter’s mentality is reflected in Rose closing her interview by saying, “A lot of people think when a patient is on hospice care that they’re going to die. That’s not true. Hospice care is for people who are not going to get better… And it’s a blessing for the family. It helps with grief before…” Anna and Rose illustrate how perceptions from those enrolled and those that are not differ significantly. Physicians can act as a bridge by explaining differences between adult and pediatric hospice care.

---

59 Bakanic et al., 2014.
Per federal regulation, an individual is eligible for hospice care if they are certified as being terminally ill with a life expectancy of six months or less.\textsuperscript{60} This is also true for pediatric hospice care, but pediatric care allows for concurrent curative treatment, while adult hospice care only allows for palliative treatment. The six-month prognosis itself creates a barrier, as prognosis can be subjective according to the individual physician. One study concludes that clinicians’ predictions are frequently inaccurate, ranging from 86 days underestimate to an overestimate of 93 days.\textsuperscript{61}

Nicholas Christakis investigates prognostication in medicine in his book \textit{Death Foretold: Prophecy and Prognosis in Medical Care}. He cites several studies that illustrate the extent of error in determining prognoses for patients. In his own study with 365 physicians determining survival for 504 patients, most of whom were being admitted to hospice, found that only 20\% of predictions were accurate. Similarly, a different study found that 54 percent of cases had overestimates for prognosis.\textsuperscript{62} While this book was published over twenty years ago, a recent study also found that:

\begin{quote}
Clinicians’ specific predictions range from underestimating by half to a sixfold overestimation. One large prospective cohort study of 2036 locally advanced or metastatic cancer patients accessing palliative care services found that 45\% predictions were overestimates, 35\% accurate, and 20\% underestimates.\textsuperscript{63}
\end{quote}

To be considered “accurate,” a patient’s death has to be within 33\% of the prediction.\textsuperscript{64}

However, this data, present both today and twenty years ago, shows an overall tendency for clinicians to overestimate how long their patients are going to live. When considering hospice care’s eligibility requirement of having a prognosis of six months, it is possible that physician

\begin{itemize}
  \item White et al., 2016.
  \item White et al., 2016.
  \item Christakis, 2001.
  \item Chu et al., 2020.
  \item Christakis,. 67; Chu et al., 2020.
\end{itemize}
tendency to overestimate would limit those who would otherwise want to use, enroll in, and benefit from hospice.

Given the importance of prognosis in providing hospice care, the frequent inaccuracies can suggest one possible reason for delayed referral and one possible avenue for implications of hospice in the eyes of the public. In their eyes, suggesting a six-month prognosis could mean that the physician is denying possibility for a cure.

The general public perception of pediatric hospice care is widely misunderstood as ‘giving up,’ which can create numerous barriers to enrollment in pediatric hospice care.

According to Finestone and Inderwies (2008):

There are consumer barriers to access to hospice, with various attitudes, and misinformation, including that they must forgo all treatment. The National Hospice Foundation reveals 75% of Americans do not know that hospice care can be provided in the home and 90% do not realize that hospice care is fully covered through Medicare.65

A significant number of people do not know the simplest tenants of hospice care, and this suggests a high prevalence of other common misconceptions of hospice: that hospice is a place, hospice is only used when there is no hope, hospice hastens death, and is only for the last few days of life.66

The parents interviewed for this study also noted these misconceptions among the general public. Mary recalled:

I remember one time, checking in on Facebook and there was a mom, and she... broke my heart because she was in hysterics because the doctors had talked to them about hospice care for her son. And, she absolutely declined and was angry, really angry at them for making the suggestion... I don’t know how you can change that cultural feeling that hospice is giving up.

---

65 Finestone and Inderwies, 2008.
66 Davanzo et al., 2019.
A few other parents expressed similar sentiments, suggesting that a lot of people equate hospice with immediate death (Rose) and that the parent gave up hope by enrolling their child in hospice (Bethany). Most parents directly counter these misconceptions with their experiences. Anna implied that her friends were surprised when she said that hospice was great for the family, while both Margaret and Bethany claim that hospice has given them much more quality time with their children despite their condition and prognosis.

However, these parents also fell into the same misconceptions of pediatric hospice prior to their own enrollment, but their perceptions quickly shifted upon enrollment. As mentioned before, two-thirds of the interviewed parents had heard of pediatric hospice prior to enrollment. Multiple parents expressed the sentiment of feeling closed-minded or feeling like hospice would mean giving up (Mary and Bethany), or feeling as if hospice did not apply to their situations (Anna, Marie, and Bethany). Anna even admitted, “I was aware of hospice... just for the very, very end of life, of course with adults, and it meant you were imminently dying. So, I’d heard of it, but I certainly didn’t apply it to my situation,” but she pointed out that she now has the options of prolonging and promoting life in pediatric hospice.

**Decisions to Enroll**

Despite the presence of physician bias and generalized fear of referring someone to hospice care, physicians were the primary referral source for the parents enrolled in this study (55.6%). The rest of the parents were referred by social workers, hospital case workers, or they advocated for the program themselves. While the various perceptions of pediatric hospice care somewhat hindered the decision to enroll, each parent decided to enroll their child for similar reasons: increased quality of life, increased support, and increased decision-making for end-of-life.
One of the basic tenants of hospice care is prioritization of quality of life over quantity of life. For each individual, this has a different meaning, whether it involves cessation of all curative treatment or just limits certain treatment options. Due to pediatric hospice’s flexibility of services and permission of continuation of curative treatment in tandem with palliative care, many parents chose to enroll for the increased quality of life. Bethany, a mother whose child has been enrolled in hospice for seven months, described that she enrolled “for palliative care, rather than curative care. So, the difference being like other doctors trying to prolong and keep going at all costs, and palliative being quality of life and comfort.” Additionally, Florence, whose child has been enrolled for six months, described hospice as a guide: “Once you’re in it, you understand that it doesn’t have to be this whole end-of-life thing. That’s not how the nurses approach it, it’s not how the doctors approach it. That’s not how any of the staff approach it, and they approach it as being a guide in helping him grow in the best way that we can.” Physicians and nurses on hospice do not tell parents to treat their kids one way or another; there is an element of choice, of flexibility that the parents have described as a benefit of being enrolled.

For Rose, the quality of life would mean not focusing on her condition: “My goal with joining hospice care is for her to be comfortable with not just focusing on her sick diagnosis but try to focus on her everyday life.” For Marie, it meant accepting the terminal condition and ceasing certain treatments: “... when my husband and I decided to not move forward with the intubation, we started to remove all of these things from him to allow him to just be free of all of these... artificial things inside of his body, and we prepared for him to basically... to pass away... we wanted him to have a good quality of life...” Similarly, Bethany said, “A couple weeks later, we called her again and we met with her in person, and we had just realized she was going to die regardless of anything we did and it was just a matter of when and how much support we had.”
That’s when we decided to really work with hospice because it wasn’t a matter of would she live or should she die, it was just when she is going to die.”

Acceptance of terminal illness proved to be difficult for many of the parents, as several of these patients were continually in and out of the hospital prior to enrollment in hospice, and ultimately, the parents saw this as a hindrance to quality of life. Mary, whose daughter was 21 when she enrolled in pediatric hospice, cited this quality of life as her reasoning for enrollment: “There was no quality—not enough. Not enough. And so, I asked the doctor, ‘What if she was in hospice?’” Similarly, one Florence described the desire to stay at home and how her child had been in the hospital for half his life by saying:

... he was hospitalized again when he was about 3 months [old] and he was in the PICU for a month. When they were getting ready to prepare us for discharge they offered [hospice] again, and that’s when we heard about it and when we decided to try it out.

Being a frequent flyer in the hospital often involves physicians making decisions that prolong life, thus directly contradicting the desire of many parents to improve quality of life and to prevent any unnecessary suffering.

The flexibility of hospice in treatment decisions was enticing for numerous parents. For Florence, this flexibility provided the final push to enroll. For Anna, it gave the opportunity to have control over their child’s treatment, as they were advised by their physician:

You guys as parents need to think about what you want because if there’s an emergency, she ends up in the hospital, the physicians are going to do what they think is right, whether it’s surgery or do this or do that... the end-of-life decision... need to be firmly in place for her, and I would recommend... hospice.

Having hospice extends the power of decision-making back into parental hands, but it can also take away the decision-making process. Should the child remain in and out of the hospital, the physicians would continue to prolong life, and it would ultimately be the parents’ decision to cease care at the last moments, to withdraw any life support. Bethany did not want to have this
power. She described the desire for her child to be the one to decide when it is time, and she felt that hospice would have the knowledge to navigate this and know when it is her time or if she is sick.

Additionally, the resources provided by hospice (support, respite, and weekly nursing care) were an incentive for enrollment in hospice. When a child is enrolled in hospice, they tend to have complex life-limiting conditions that result in physical limitations and deteriorating health. This places the demand for round-the-clock medical care that is primarily provided by the parents. Without hospice, often these parents have no opportunities for breaks, and this can cause significant burnout and other mental health consequences. Anna described how she “was just distraught, and I physically walked into [hospice]... and I just said, ‘I need help.’ Broke into tears, and they picked me up in the palms of their hands and from there, we got the process started with them.”

This highlights the complex familial dynamic involved with caring for a child that has a life-limiting or even life-threatening condition. Parents are expected to provide multiple levels of care, whether it be physical, emotional, or social, but they also act in an advocacy role for their child. These parents are also more likely to have depressive symptoms and suffer from social isolation for numerous reasons including but not limited to the frequent hospitalization and caregiving tasks. According to one study, 25.5% of parents whose children have progressive life-threatening conditions experienced clinical levels of anxiety, 25.2% experienced mild depression, and an additional 12.5% fell under the major depression range. Hospice can provide an extra support system and was the reason why Margaret immediately enrolled her son.

---

67 Grinyer, 2012.
68 Koch and Jones, 2018.
69 Siden and Steele, 2015.
in hospice when he was born with the same condition that his older sister had. She describes that
the discussion of enrolling in hospice provided “relief, because it was like an extra support
system and we already had a lot of family behind us, but it was just somebody outside of the
circle.”

Similarly, Helen desired “... a little more help, a little more support... I will have someone
there to be able to support me through the process, someone to reach to when I need extra help
with [my child], and someone that will always be real with me, only a phone call away when
something goes wrong.” Extra support was a primary reason for enrolling in hospice, and it
continued throughout their experiences in hospice, which the next chapter will discuss.

**Conclusion**

In this chapter, I discussed the range of conditions that lead to parents enrolling their
child in pediatric hospice care and the process by which these parents came to this decision.
Contrary to the assumption that most children in pediatric hospice have cancer, this study
population consisted primarily of children with neuromuscular or congenital conditions. Whether
it was because of physician bias or others’ opinions of hospice, external perceptions of pediatric
hospice care influenced parental decisions to enroll, but parents are pushed toward hospice by
their need for extra support and the desire to focus care on quality of life rather than purely
curative treatment. This does not appear to vary by age or condition, as the ranges for age of
enrollment for extra support goes from birth to 16 years old. However, it appears as if older
children are more likely to be enrolled so that the parents can have support, but also have more
control over future treatment. Mary and Anna both referenced this, and they enrolled their
children at ages 21 and 16, respectively.

From here, I will transition to the experiences of these parents while they are enrolled.
Chapter 3: Experiences in Hospice

Topic Layout
First Home Visit
  Respite
  Renewal
  Nurses
  Relief
  Family
  Individualization
  Religious Influence
Negative Experiences
  Daily Life
“I feel like I have a second support system and I feel like they’re my family when I’m overwhelmed… I have somebody to come to” (Rose).

“… if this wasn’t hospice, she would be in [the] ICU right now, crying, just in such despair, staring, not responding to me, going into seizures, rolling herself into seizures because there’s no reason to fight them” (Mary).

These testaments from parents whose children are currently enrolled demonstrate just some of the advantages of having this care. Knowing the experiences of parents allows for evaluation of existing programs and future policy initiatives, discussed in Chapter 4.

I will begin with a description of a typical first home visit, then investigate the various experiences that parents have while their children are enrolled in pediatric hospice care. I argue that parents’ experiences are influenced by respite, the renewal process, their relationships with the nurses, the support and relief they are given, the family-focused care, individualization of care, their religious influences, and any changes to their daily lives.

The parents enrolled in the present study recalled few negative experiences or comments regarding their care, whereas previous literature shows a mixture of positive and negative experiences. When asked about negative experiences, all but one of the interviewed parents replied, “None,” while one only mentions her frustration with the renewal process and the lack of community awareness of pediatric hospice care. It is possible that this stems from the experiences of parents with the bereavement process and the effects of grief on autobiographical memory.

First Home Visit

After deciding to enroll their child, parents begin their experience in pediatric hospice care. The first step after enrollment is starting home visits. While all the parents described their first home visits differently, it was aptly summarized by Rose, whose child has been enrolled for 8 months:
My first home visit, they broke everything down, what hospice care is for the family, the patient, and what measures they’re going to take during the whole process of making sure the child, the patient, is comfortable and what we can do to help you with your everyday life. So... they did an assessment, checked her vital signs, talked about her diagnosis, what are my goals for her, what do I want out of hospice care, and why I want to sign her up.

Essentially, a home visit is characterized by the nurse visiting and doing a physical examination of the child. The hospice staff also have a discussion of various needs with the parents, including whether the family has all the necessary equipment, if they have all the medications they need, and other forms of familial care, according to Bethany. While primarily conducted by the nurse, home visits can involve any member of the care team, including social workers, chaplains, child-life specialists, the physician, etc. The first home visit often has multiple individuals talk to the patient and the parents in order to have a better idea of how to serve their needs. Many of the parents described the first home visit as comforting, but a little overwhelming due to the number of people.

That being said, Marie, whose child is almost three years old and has been enrolled for most of his life, said, “It wasn’t until they came to our house and walked us through everything [that] we understood what they do and how it would benefit us and help us.” It gives the parents the opportunity to seek answers for all their unanswered questions: What do we expect? How do we do this? What is the respite program? What resources do I now have?

**Respite Care Adds Relief and Allows for Keeping Other Relationships**

Many hospice services provide “Respite Care,” a program in which the patients can stay in the hospice facilities for up to 72 hours in the care of nurses while the family takes care of other household matters. Six of nine of the interviews mentioned the benefits of the hospice’s respite care program. Respite care provides a huge help for families, giving a sense of renewal
for both patient and family. One parent cited it as the reason she and her husband could go on a
vacation for the first time in years, while another argued that it gave her the opportunity to allot
more time to her other children. Another mother described herself feeling reinvigorated after a
couple days of respite care, while also beaming about the quality of care for her child and the
child’s happiness having been able to interact with more people.

However, they describe the program as different than leaving their child with any
babysitter, as one mother said, “I can go and not think about whether he’s being taken care of. I
know he’s being taken care of because the people that are working with him, they’re adequately
trained, and they’re professional, and they know what they’re doing.” Respite care is provided by
the nursing staff, who are well-versed and trained for the child’s specific needs. They consult
parents prior to the visit, and if anything happens, they call the parent. This means that the
absence of a phone call means the parent does not have to worry about the well-being of their
child. Beyond the respite nursing care, this program also provides a playroom for the children,
thus allowing for socialization and stimulation during their visits to the inpatient unit. This
differentiates itself from adult hospice organizations, which are often full time residential in-
patient facilities.

That being said, some parents have reported difficulties with using the respite services
and expressed discontent about some policies in place for the service. Florence notes her son’s
aversion to being away from home. She said, “Nothing that the staff did wrong, but really just
his, I think, kind of anxiety, kind of being away from home and his parents, that the secretions
[become] uncontrollable. His oxygen levels dropping... until that’s kind of handled, we’re
forgoing the hospice stays, the respite stays.” This limits her accessibility to the respite service.
Rose gushed about respite stays, but also expressed discontent about one of the hospice’s policies: “... the only thing I would change is when your child is in there for respite, when they go 5 days out of each month, if I call them and ask if they can send pictures of her, they can’t send pictures because of HIPAA. I want that to change because I want pictures of her when she’s in there.” She cites respite as being the greatest benefit of being enrolled in hospice care, but this discontent could potentially discourage some parents from sending their children for many days at a time.

The primary reason that respite is consistently listed as the time to recharge and be able to shift focus on other children. Eight out of nine of the mothers have more than one child. One study from the *World Journal of Clinical Pediatrics* explores the situations of siblings of children who require palliative care, arguing that siblings “suffer from deprivation of love since their parents are fully occupied with the care for the ill child.”\(^{70}\) While this may seem like a harsh choice of words, the parents’ interviews suggested that respite gives them the time and energy to remedy this issue. Anna mentioned that respite “helped us establish and rekindle a relationship with him [son] that is so much better and focused on him.” Similarly, Helen expressed that “I can just have that time for myself and with my two other girls.” Respite, in this way, allows parents to cultivate relationships with all their children in situations in which this could be difficult due to the complex medical needs of one child.

On top of the facilitation of parent-child relationships, respite helps the parents prevent burnout. Parents with children with life-limiting illnesses spend an average of nine hours per day focused on their medical needs.\(^{71}\) This can lead to significant burnout and social isolation, as well as strain any existing relationships. Without time to recharge, the parents will not be as well

---

\(^{70}\) Classen, 2012.
\(^{71}\) Koch and Jones, 2018.
equipped to act as a caregiver. Rose mentioned, “That’s [Respite’s] the best benefit because at least you don’t feel overwhelmed, you get me-time because you can’t take care of the child if you’re not taking care of yourself.” Anna expressed that she was able to take a vacation with her husband for the first time in years once they enrolled. The opportunities for this respite help to foster an overall positive impression of hospice care due to this reduced burnout and chance to prioritize other important relationships, in addition to the parent-child one.

*Effects on Family*

Hospice is not just for the patient receiving the services. It is also meant to care for the entire immediate family, including any parents or siblings. Seven out of nine parents in the study mention this familial care, a focus placed on the family that, in some cases, actually saved their family dynamic, whether it was the marriage itself or assisting in establishing a bond between siblings via the child life specialist. Some parents also claimed that hospice has become like family to them due to the immense help that they give and the ready access to their services.

*Child Life and Sibling Assistance*

Child Life Specialists are those that are clinically trained in the developmental impact of illness and injury. These professionals assist children and their families cope with chronic illness, loss, bereavement, and other circumstances. Typically, there will be a child life specialist employed with a pediatric hospice service, and they will assist with the patient’s perception and preparation for their illness, but also will help their siblings. As mentioned in Chapter 1 of this study, the conditions of the children enrolled in pediatric hospice are severe and life-limiting.

---

This can have a significant impact on children, and with child life specialists, they are able to cope and form bonds with their siblings, as described by Ruth, who has another daughter:

... the child life specialist... gave us good times, as good times as we could have in the midst of a situation that was hard. She would plan activities so [her older sister] could interact with her. It’s kind of hard to figure out how to interact with her. She’s not verbal, but those visits with [child life] were so helpful because it helped them to form a relationship, as siblings, and gave ideas of how, for me to do that in her absence.

Similarly, Marie, who has three children in addition to her son that is enrolled, described child life as being particularly helpful for her other children to cope with his condition and interact with him. Through child life, children with life-limiting conditions can develop relationships with their siblings, and as a result, these siblings can better handle their condition and death. One study investigating perceptions of pediatric hospice among English- and Spanish-speaking families also found that child life made a huge difference in their experience with hospice care.

While much of child life involves play and establishing normalcy, it also plays a role in psychological preparation for both the patient and their siblings. With the stress that comes with caring for a child with a life-limiting condition, parents can have difficulty assessing the needs of their other children. Florence similarly said, “I have an older daughter who’s 12, who is trying to set up time to just talk with [child life specialist] and see how she’s feeling; things I may not be able to get because I’m so busy taking care of [my son] medically....” Child life and hospice care in general provides this extra level of support that can heal family dynamics and help siblings cope with the potential loss of their brother or sister.

Outside of child life, being on at-home hospice has assisted with the stress experienced by siblings of children that are enrolled by allowing the family to be at home more than at the hospital and allowing for enough support for parents to also spend time with siblings. Mary

---

described the difficulty in consistently being in the hospital. She was never home for her other children, she missed holidays, and her daughter became increasingly stressed by hospital visits prior to her enrollment in hospice. However, upon enrollment, both the patient and her sisters became much more comforted: “My other daughters are much more comforted knowing that she’s going to be here when her time comes, not in the hospital, and that’s always been... hard for [her sister]. She has a lot of anxiety about hospitals, and so... I don’t have to put them through that anymore.”

Similar to the benefits of having respite, simply being on hospice allows for the reconnection of families. Anna described how she also has a son in college “who has sort of been swept along in the tide of all this. And it’s [hospice] really helped us establish and rekindle a relationship with him that is so much better and focused on him.” It is important for parents to be able to develop and maintain relationships with all of their children, and hospice assists with this for parents whose children have terminal or life-limiting illness.

*Improved Marriages and More Personal Help*

Two mothers mentioned that hospice helped their relationship with their husbands due to the extra support both with their child and for themselves. Anna described:

> So, my quality of life and my family’s quality of life has gone up immensely. So has my relationship with my husband, which you know... Having a child with special needs is like doomsday for 80% of families that have one... end up divorcing, but... it has been a lifesaver for that as well. They’re very good... they bring up really hard to talk about topics that need to be talked about, which then gives us a sounding board to talk about concerns and things. It’s hard for [my husband] and I to support each other when we don’t know what we’re doing, so to have, whether it’s [the doctor] or the therapist to help us... see more clearly on things... It’s been a great change since we’ve come into hospice for all of these reasons.

In this statement, she describes how hospice allows her husband and her to discuss important issues that would otherwise be swept under the rug.
Similarly, Mary, whose daughter has been enrolled for 3.5 years, described how:

if this wasn’t hospice, she would be in ICU right now, crying, just in such despair, staring, not responding to me, going into seizures, rolling herself into seizures because there’s no reason to fight them. (unintelligible) foggy, the seizures that she has. Awful. Every single holiday that there is, she’s missed at least once in her life—Christmas, and I have too. My daughters miss me. You know, Christmas, Thanksgiving, weddings, Halloween, you know... fourth of July. Every holiday. Her birthday, my birthday. And... our quality of life... we feel a little more normal since we’ve entered into hospice care, you know? (1)

This highlights how hospice can restore a sense of normalcy and allow for typical family functions with holidays and being able to relax at home. Mary also argues that hospice “supports not only your child that’s medically fragile, but also supports their siblings, so that the family survives, so that the marriage survives.” This family-oriented care allows for improved family dynamics, as well as an acting mediator for parents who may be struggling deciding what to do regarding their child’s treatment, who may be struggling with their marriage and communication, and whose quality of life may have declined due to complex medical needs.

As mentioned above, the parents have access to hospice staff, particularly the social worker. Rose described having the social worker has significantly helped her mental health. This, in addition to all the other support provided by the hospice service has been an invaluable service to families. As described by Helen, who has a sixteen-year-old son enrolled, “It goes and revolves around my family, revolves around my son. And that does not have a price, for everything, it does not have a price.”

**Relief in Some Caregiving Duties & Not Having to Go to the Hospital**

The single theme reflected in all interviews for this study was the relief felt when they enrolled in pediatric hospice care. Prior to enrollment but after the diagnosis, daily life significantly changed for parents. Suddenly, with the role of caregiver added to their plate, they
were unable to work or continue their education. While none of them regretted their decisions to become the primary caregiver, they noted a big relief when they enrolled in the hospice service. They see the quality of care given to their child and see marked improvement in the quality of life for both the child and the family.

Quality of life was a direct result in the relief of some caregiving duties and the ability to obtain medical equipment through the hospice service. No longer do the parents have to remember to call in prescriptions; they also now have a resource to figure out which doctor would be beneficial to talk to. They have a nurse who comes by once a week to check on the child and the family. However, the most important—they no longer were consistently in and out of the hospital. Because of this, families were able to spend more time together, and there was less stress on the children. One patient, according to her mother, would always shut down when they arrived at the hospital due to the uncertainty of procedure and length of stay. Mary has reported the family being infinitely less stressed and happier since starting hospice.

Comparatively, Florence described the experience she had in which she was able to avoid driving her child to the hospital:

She drove from the last family she had been at, came all the way out here, checked him and was on the phone with the doctor that was on duty, and they provided different remedies... We were able to take care of him at home, and it was an amazing experience to me because it showed to me like, ‘Hey, we can take care of our child, like absent of any critical illness that would need to be taken care of at the hospital.’

This experience provided relief for the mother, as it proved that the hospice team would be accessible, as promised, 24 hours per day, 7 days a week. However, it also demonstrated the competency of the care team in following the wishes of the family and avoiding the hospital whenever possible. The same mother as above cited this support as the sole reason for enrollment: having the extra help so that they can be caregivers at home instead of staying in a
hospital setting. Marie described hospice care as the kind of support that cannot be obtained elsewhere in healthcare. In her words, hospice makes caring for her terminally ill child doable.

This service and support develop through the continued relationship that the parents have with the staff. In one family’s story, the child “graduated” from hospice, as she was too healthy to continue receiving the service. However, she became sick again, resulting in a trip to the Emergency Room. Even though the family was not enrolled with the hospice service, Ruth called the nurses, who came right down and re-enrolled her daughter. This occurred because “the relationships had already been built and I could hold them in my mind. The supportiveness of themselves, with visiting us and their presence, but also just knowing they are there in case we need anything.” Most of the families reported this constant feeling of support. It relieves parents of numerous difficulties in caregiving, such as figuring out prescription refills, scheduling with different providers and practitioners, and ensuring proper equipment for the home and for transport.

**Nurses Provide the Most Support**

As one of the questions asked of the parents was “Who has been the most helpful in this hospice experience,” it is interesting that the overwhelming majority of mothers credited the nurses. Each family gets assigned a case nurse, who comes to the house once per week, but is always available by phone if the parent has questions. The hospice service also provides a 24/7 hotline to provide parents with a resource should something occur in the middle of the night. One mother described the nurse as “more like family, because they’re just so close... they would help with anything.” The nurses handle medication renewals and refills, direct parents to the correct providers for their needs, collect lab work at home, and serve as a consistent presence for the family during the end-of-life period. The parents describe their work as priceless and lifesaving.
Of the nine mothers interviewed for this study, seven mention the nurses as a great asset to the care and treatment of their children, primarily due to the immense amount of communication and meetings. Anna cited weekly interactions, as well as multiple episodes of communication between each meeting, but the largest help from the nurse stems from being a singular person to contact: “it’s a timesaver in so many ways because you spin your wheels trying to call and see people... it’s an anxiety and worry and stress saver immensely.” Similarly, Marie said:

They’re the ones helping us process things, helping us think about different things, like their perspectives. Helping us think about who’s the next specialist to go to or how can... help us work through and process different things... helping us have a better game plan and making sure we’re all on the same page.

Perhaps one of the largest roles the nurses play is being a liaison of information for the patient and the family to the rest of the hospice team. As mentioned in Chapter 1, the hospice team consists of numerous medical professionals as part of an interdisciplinary team. Thus, communication of the parents’ and children’s wishes are of the utmost importance. Marie expressed her gratitude to the team for speaking with each other. This enhances her trust for the practice: “You won’t get someone where someone will have no idea what’s up with your child, who your child is, like they know your child by name. They know what’s going on. They know what they look like; I mean it’s just so reassuring to have that because this is the hardest thing I’ve done in my whole entire life.” Margaret expressed a similar sentiment, saying that her nurse “always gets the right people involved if we need help.”

A couple parents also mention the nurses and other hospice staff members being particularly helpful in having an outlet for expressing their own emotions when feeling overwhelmed and being a comfortable presence: “... just somebody I can talk to about my child who has an understanding of it” (Florence). Bethany described her nurse as “...giving us a lot of
information, being understanding, listening to our concerns, I guess just comforting...” Rose summarizes the relief of having hospice:

Before hospice care, I felt overwhelmed, I felt like I didn’t have an outlet. I felt like I was taking on too much that I can handle. I felt like I couldn’t talk to nobody about it because nobody understands medical, what she’s going through. I hate explaining certain things because it’s like too much to explain. So, I can’t just call up my friend and talk about my child’s diagnosis because they won’t understand what I’m talking about, but I can pick up the phone and talk to a social worker or talk with a... talk to a nurse and explain what [name]’s going through and they will understand.

Overall, nurses are the backbone of the pediatric hospice care experience for parents. They provide consistency in care through communication with the care team, acting as a comforting presence, and the sustained relationship with the parents.

*Individualization of Care by these Providers*

Five out of nine of the parents regarded a benefit of hospice being the individualistic, holistic care. Hospice treats their patients like regular children while also taking into account individual parental wants and needs regarding treatment. While five of the parents mentioned this characteristic of hospice care, Florence summarizes it by discussing when her child has to be suctioned:

We’ve had experience with hospitals where our child needs incredibly frequent suctioning, I mean probably more than the average HIE child, I’m guessing, maybe not, but he needs high level of suctioning. I mean sometimes we do it every 10 minutes, but they don’t give it in the hospital because they have numerous patients and even though the nurses may have 1 or 2 patients they take care of, I just think the level of attention they give is good but it’s not what he gets at hospice as well, just a personal touch to care, that love the children there.

Each week, the hospice team meets and discusses each patient, what they found out during the previous home visit, and how to proceed. This allows for increased individualization of care, according to Helen. There is no comparison of one patient to the next; each person is different,
and each case is different. The doctors fix problems as they come up and help develop solutions that would be beneficial and align with the goals set by the parents, as expressed by Ruth, Florence, and Rose.

**Renewal Causes Stress Despite This Support**

Although the renewal process varies depending on the hospice agency and insurance and even varied across the four mothers interviewed for this study, there was frustration with the process and a desire for the hospice enrollment to be the only requirement to keep the service. Each insurance company has varying requirements as to the consistent evaluation of the need for hospice services. Two of nine mothers mentioned this as a source of stress. Mary reported having to be checked every six months, while another said it was as often as every 2 months. She says, “It’s so frustrating that we have to have the burden to have to emotionally go through this fear and go through, you know, just having to even voice about where [my child] is every two months...” This adds another element of stress, because failing to demonstrate need during the evaluation means losing the services that hospice provides. This will be an element for further discussion in Chapter 4 of this thesis, dedicated to policy recommendations and how to use the results presented in this chapter.

**Religious Influences Can Provide Relief from Stress**

Four mothers mentioned some aspect of religion with regard to their healthcare since their child was first diagnosed, whether it be before or after enrollment in hospice. Religion has served as an outlet for community despite complex medical needs and unknown futures. Prior to enrollment, Marie and her family decided to do a baptism for their son with family and close friends, while Ruth used her religion to remain faithful and optimistic during her pregnancy after
tests indicated that her child would have a chromosome disorder. During enrollment, Mary describes her daughter’s involvement in the church and its organizations. Religion is a present theme in the parents’ lives, but in hospice, the religious and spiritual care is performed by a chaplain.

One study published in the *Journal of Pastoral Care and Counseling* investigated people’s experience with pastoral care in a hospital. They found that 36% of respondents felt that the pastoral practitioner’s friendly and pleasant demeanor was the most helpful aspect of the visit. Overall, the study found a general positive impact of pastoral and spiritual care, with the majority of respondents cited the most helpful aspect of talking with the chaplain as simply having someone to talk to.\(^74\) The purpose of the chaplain in hospice care is similar: to provide non-denominational spiritual support and counseling.\(^75\) In this study, several parents described the benefits of having a chaplain, whether the parents themselves identify as religious or not. Anna described, “I’m a nonreligious person, but I had the fellow, the pastoral guy that came to see me was... Buddhist and whatever too so it worked out well. But they were very, very helpful and sometimes providing prospective or outlook when you’re mired...” On the other hand, Ruth partially enrolled her child in hospice per the suggestion of a physician that shared the same religious faith as hers. She described having faith issues throughout her experience, but the chaplain helped with this. She also described that the hospice experience resulted in having more faith: “There’s more of a sense that I’m being held by God or the people that He sends to us.” As shown by these two mothers, the chaplaincy was beneficial for parents no matter their religious orientation. It is another element of support within the hospice service.

\(^72\) Ashton et al., 2016. 
\(^75\) Gilchrest, 2020.
Overall, Few Negatives, if Any, About Care Compared to Bereaved Parents

As mentioned above, intrusive memories are associated with complicated grief thereby impairing retrieval of certain memories or enacting bias on others. In a study addressing parents’ experiences of pediatric palliative care, the researchers found a correlation between the higher ratings of communication and continuity of care and lower levels of long-term grief.\(^{76}\) In addition, several themes emerged in the study from 2016 conducted by physicians at the Cincinnati Children’s Hospital Medical Center that reflected several negative feelings toward the care received in pediatric hospice. For instance, some parents disliked the personality of their hospice nurse, disliked being told to not return to the hospital, or disliked the pain and symptom control given to their child.\(^{77}\) All of the families interviewed in this study had their children enrolled in hospice prior to their deaths. It is possible, therefore, that there is a connection between grief and perceptions of pediatric hospice care, which would account for the lack of negative comments by the parents interviewed for this study.

Hospice Care and Parental Daily Life

With the increased support and resources offered through pediatric hospice care services, daily life significantly changes after enrollment. This section will describe this change from first diagnosis to after enrollment.

Before Enrolling in Hospice, After Diagnosis

A generality among all the parents’ experiences prior to enrolling in hospice was the difficulty in balancing medical caregiving with spending time with family, experiencing their child as an individual, and getting time for themselves. Additionally, they cited a lack of

\(^{76}\) van der Geest et al., 2014.  
\(^{77}\) Thienprayoon et al., 2016.
understanding from their peers and other family members, as few people they knew also had children with life limiting illnesses.

Some children’s diagnosis was marked by a regression in cognitive functioning, which made daily life hard for the entire family. Anna described this phenomenon:

Instead of a child gaining skills, right, and getting more independent from her parents, it was the other way, so daily life became... stopped working outside of the house and it became all about negotiating IEPs and OT appointments and became consumed with medical visits and therapy visits, and... tests and MR... millions and millions of tests, and helping [her]... still couldn’t put her shoes... dress her, daily bathing, reading books, making sure she could get up and down stairs, finding a better car seat, finding some way that she could sit in the school bus and not fall to the floor, you know. So, it became a seat for in the shower, you know... a bed, she was entrapped, so there was months and years of trying to get a bed that was safe—safety bed for her, through insurance. Feeding her, oh my god, the years and years where she couldn’t swallow. It got to the point where we were spending hours at the table trying to get her to swallow enough food. Took a lot—... so daily life became a swirl of not normal, not typical. [My son] suffered greatly through this as well. Did as much as we could, never enough.

This feeling of not doing enough led some parents to experiencing depression, feeling like they have no one to talk to about their situation, as felt by Florence and Rose. The complex medical needs, similar to what the mother above described, can also result in social isolation. Bethany described, “We know that something horrible could happen at any moment and we’d have to respond,” while Margaret described how there are certain ways to handle her son and his condition, and most people are not comfortable with it. She describes that she cannot have anyone watch him, which had heavily impacted her life trajectory. She is no longer able to go to work or go back to school. Along the same lines, Rose “felt like I was locked up.... my child requires 24/7 care and home nursing wasn’t providing a lot, so I felt like I needed help.”

Despite the difficulty in having a child with a life-limiting condition, it was clear in speaking with these mothers that there is an overwhelming love for their children, with the desire
for hospice care to help with support and the medical and psychosocial aspects of having a child with such a condition.

*Daily Life After Enrollment*

Six mothers described significant changes to daily life after enrolling in hospice care. Two described no change because their child has been enrolled since birth, and one cited significant change. There is more of a feeling of normalcy and having increased support in the care for their child, having people who will understand, according to Mary and Rose. Florence even describes life as being more management and feeling optimistic about her child having a decent life.

In addition to the increased support, the primary change has been with the medical aspect of care. Daily life can still be intense with all the equipment and medications still required, given that hospice care for children does not involve cessation of all curative treatment. Marie describes the intensity of getting her son and her other three children ready for the day:

I have 4 kids. [He] is one of the four. Our daily life is very intense, lots going on, and a lot of moving parts. [He] has his whole slew of medications that he needs to take. [He] does have spasms and he also has seizures, so he takes medications for that. He also takes medications—he takes a lot of medications for pulmonary issues, like inhalers, and breathing treatments that help keep his lungs healthy... that helps him shake up his saliva that might be in his lungs. He can’t cough it up on his own. So basically, [he] takes 45 minutes to get himself together, to just get [him] situated and ready to go in the morning. That’s just [him]. I also have 3 other kids I have to take care of, and I have a husband that travels for work weekly. He travels every single week, so like we’re really busy, so I will say that [hospice] comes and see [him] weekly, they check in with us daily, they know what is going on, my nurse knows what’s going on with [him].

In this quote, this mother describes how hectic her daily life can be, even from the start. She says that having hospice does not assist with the intensity of days like that, but it is a huge help to have a medical team regularly involved. Similarly, Anna, whose daughter has a UBTF mutation that presents in gut failure, describes how hospice minimizes the amount of time spent in a doctor’s office and prevents the condition from worsening. Seeing so many specialists is
stressful, but hospice makes it easier. However, Margaret and Helen described that while the support and medical care improved, their daily life did not change in other aspects. They both describe not being able to work due to their children’s conditions. Without assistance and other forms of support for childcare, this is unlikely to change.

**Conclusion**

In this chapter, I describe how parents’ experiences are influenced by respite services, renewal processes, nurses, child life specialists, chaplains, and support/relief that simultaneously provides individualized care and family-oriented holistic care. I find that the individualized and family-oriented care are influenced by this needed support. The hospice staff help the family adjust to the life-limiting or life-threatening conditions according to their individual needs, whether the patient’s siblings need help bonding with them or the parents need a third-party to guide in decision-making or take over caretaking for a couple days to rekindle relationships. The presence of respite services, nurses, child life specialists, and chaplains provides additional support, without which caring for the child with a life-limiting condition and even caring for oneself and the rest of the family would be significantly more difficult. This support is only possible through holistic treatment with attention spent on both the child and their family. While daily life changed significantly regarding support and assistance with medical care, other aspects of daily life did not change as a result of enrollment.

The experiences recalled by parents whose children are currently enrolled in pediatric hospice care differ from those of bereaved parents. In one previous study, parents whose children had died focused on elements of care such as continuity of care and specific parental
involvement, while connecting these to the impact of these services on long-term grief.\textsuperscript{78} This was a common theme with numerous studies, as they did focus on bereaved individuals. This focus on grief is obviously not present in this study, as the parents’ children are still alive, so many parents described how the individuals involved in hospice are beneficial to them, rather than the experiences of the condition itself. For instance, one study asked participants questions in the following categories: understandings/expectations of hospice, experience of hospice, quality of care, trust of the healthcare system, health literacy, and discrimination. Some themes that arose from this study focus on the aspects of hospice not yet experienced by the parents in this study: preparation for death and bereavement. This study also brings to light several negatives of the hospice experience that was not expressed in the present study.\textsuperscript{79}

Another meta-analysis investigating the palliative care and end of life care experiences of children with cancer and their parents found primary themes of symptom prevalence and care management, end of life trajectory and perspective, and decision-making, which involves disagreement between parent and child, as well as choosing to continue therapeutic measures or not.\textsuperscript{80} While some of these things overlap those of the present study, the focus differs depending on what stage of treatment and the proximity to end-of-life. It appears, based on the literature and this study, that being close to death or bereaved changes the focus of experience to be on symptom management and on the condition in conjunction with hospice or palliative care, while the parents in this study focus on the benefits of this type of care for the entire family and its holistic approach.

\textsuperscript{78} Van der Geest, 2014.
\textsuperscript{79} Thienprayoon et al., 2016.
\textsuperscript{80} Montgomery et al., 2016.
Chapter 4: Reflections on Experience

Topic Layout
Goals for the Future
Parents’ Perspectives on Changes to Hospice
Policy Recommendations
“We don’t know what his life will turn out to be, so we’re doing everything on our end as far as different specialties, different medical providers that he’s going to see, trying to improve his life” (Florence).

“The main goals of [my child’s] hospice care is really to make sure that we are focusing on quality of life… we are never going to do things with [him] like intubating him or putting a trach in him or doing things like CPR on him, because we know that if we do these things, the underlying condition is still there” (Marie).

These two quotes highlight how the goals for hospice can vary for pediatric patients. Whereas adult hospice is primarily focused on end-of-life, pediatric hospice can have two profoundly different tracks: continue trying different curative interventions or simply interventions needed to maintain quality of life at the end of life. While these two goals are not mutually exclusive, the former would include procedures such as intubation, cardiopulmonary resuscitation, chemotherapy, or other potential treatments to save the child’s life, while the latter allows for natural progression of the condition with minimal intervention or curative treatment.

How do parents make these decisions on which track to take? What happens for the future? What are the parents’ goals for the future of their children’s hospice care? Where do we go from here? How do we use these parents’ perspectives to inform future policy and future studies on pediatric hospice care? This chapter examines these questions. I argue that the perspectives of parents, both those whose children have died and those whose children are still alive and enrolled in hospice, help inform changes in hospice to make it a more holistic and accessible form of care for children with life-limiting or life-threatening conditions through telehealth options and advocacy at the federal level.

**Parental Goals for the Future of their Children’s Care**

Goals for the future depend primarily on parental wishes and patient condition. With the option of curative treatment for children enrolled in hospice care, children are able to live longer
with these life-limiting and life-threatening conditions. Additionally, with many previous studies into parental experiences of pediatric hospice care focusing on bereaved parents, there is still a question of how parents decide what their goals are. This section attempts to answer that question. I argue that there are two general pathways for parents of children who are enrolled in this care, curative and palliative, but in both cases, parents hope for consistency in care and in the team.

Most of the parents in this study adapted the primary goal of maintaining quality of life through palliative treatment. The rationale for solely pursuing palliative treatment differed from parent to parent, but the general theme remained keeping the child as comfortable as possible and acknowledging that the underlying condition would not go away. Nevertheless, no matter what the desired treatment path is, the hospice team walks them through the process. According to Ruth, “They’re so good at being with the family where they’re at. They walk alongside, they don’t tell what to do, and they support whatever the decision is that the family has. But at the same time, they give me every kind of information that I need.”

With this guidance, parents can be highly involved in decision-making and have the proper support system needed for when a child dies, as mentioned by five of the mothers. This decision-making is guided through medical advice regarding what certain decisions would mean for the child: “Every time we add, we do a different intervention that we have to do, my husband and I and the hospice team, we are really talking and really thinking about, ‘Okay, if we don’t do this, what does this mean for [my son]? What does the outcome mean for [my son]? Does that mean he’ll be in more pain? Does it mean he’ll be in more discomfort?’” (Marie).

Outside of being a support to the parent, the primary goals for the future of the children’s hospice care are to maintain quality of life and allow for normalcy:
Our goals for the future are... maintaining [her] quality of life. Meaning that each day brings a comfortable and brings some joy, where she’s able to feel some joy. And a goal would be to not push her past what is a life that I think she would want for herself, or I would want for myself. I think the hardest part is you know, for me, for our family, I want to not push life at all costs. (Anna)

This quote summarizes the palliative goals for many of these parents: comfort, joy, and as high quality a life as possible.

Marie pointed out that while they are trying to maintain quality of life, part of the reason she decided to enroll in pediatric hospice was because there was still an option for curative treatment. While this was not a prevalent idea among most parents enrolled in this study, about 20% of children that are enrolled in pediatric hospice care have cancer, and of children that are receiving palliative services and are at the end-of-life, about a third of them are still receiving chemotherapy. Chemotherapy can act as both curative and palliative treatment. This could mean that parents of children with cancer may be more willing to enroll their children in hospice due to the known life-threatening nature of the condition and the prevalence of support given by the organization. Therefore, within the realm of this study and current literature review, it is unknown how many pediatric hospice patients receive curative treatment, but given that it is an option, parents can choose it as a goal for the future of their children’s care and allowing this combination of curative and palliative treatment expands accessibility of this service within the pediatric sector.

Curative treatment can be intertwined with palliative care to increase quality of life. For some parents, their child does not have a well-understood condition. Prognosis is unknown, so even while enrolled in hospice, parents may be seeking new treatment opportunities, as described

---

81 NHPCO, 2015.
82 Piana, 2015.
by Florence: “We don’t know what his life will turn out to be, so we’re doing everything on our end as far as different specialties, different medical providers that he’s going to see, trying to improve his life.” Ultimately, the parents in this study strive for increased comfort and higher quality of life, no matter whether they are actively trying to prolong life or not.

**Parents’ Perspectives on Changes to Hospice Care**

Analyzing the above goals that parents have for their children’s care shows parental priorities of increased comfort and quality of life. While parents are satisfied with the hospice service as it currently exists, they expressed multiple aspects of the system that they would like to change to assist in these goals. When considering the future of pediatric hospice care, we can look at numerous angles and perspectives (including but not limited to policy, administration, treatment, etc.). Three parents directly expressed changes that they would want to see. None stem from criticism of their current hospice providers, as they are limited by existing state and federal policy that regulates the system. These changes include normalization of pediatric hospice, increased flexibility for communication during respite, and loosened restrictions of provider scope of practice.

Mary gave the suggestion for increased normalization of hospice care. As discussed in previous chapters, there is an associated stigma with pediatric hospice. Physicians think that parents were coerced to mention it, and physicians are hesitant to suggest it because of fear that parents would think they are ‘giving up’ on their children. This was a problem that Mary encountered frequently prior to her daughter’s enrollment in hospice care. She compares a possibility for change to the steps that lead to geriatric hospice:

> You know how in nursing homes, we have assisted living, then older people, they go to some kind of senior living place, and then it’s assisted living, then a nursing home. There’s a gradation.... I wish there was the same kind of gradation of hospice so that the hospice that is forever ingrained in everyone’s mind as the care you receive in the last
three weeks of life, remained hospice, but then there’s this care that looks just like hospice, but we call it this when you’re at this stage, and before that, there’s this, you know what I mean? So, there’d be these three steps of care, and they’d all be called something different.

In this quote, she suggests renaming the system because of its association with elder care. With adult hospice, patients cannot continue to receive curative treatment, which does seem to skew perspectives on pediatric care. However, she suggests a similar gradation of care. In adult situations, often individuals start with assisted living, then a nursing home, and then hospice, which can be done in the home or in a nursing home. These “three steps of care,” as she refers to it, could provide an avenue for care for children with life-limiting or life-threatening conditions.

The second request, mentioned by Rose, was the option to lift the rigidity of HIPAA during respite visits. While she is not advocating for eradication of privacy protections for children that are using respite services, she expresses her discontent of not being able to see her child electronically should she want to:

Okay, I was saying that the only thing I would change is when your child is in there for respite when they go 5 days out of each month, if I call them and ask if they can send pictures of her, they can’t send pictures because of HIPAA. I want that to change because I want pictures of her when she’s in there.

For a parent whose child has a serious life-limiting condition, not being able to see their child or to receive updates outside of a phone call can cause a lot of anxiety. As mentioned in chapter 3, many parents feel that the hospice team act like a family and have good communication about the child’s care and treatment, whether palliative or curative. Potentially changing the rules within respite could allow for increased satisfaction regarding the level of communication. Parents want to know how their child is doing in respite, and pictures can provide a method of updating parents during their stay.
Lastly, Florence expressed interest in increasing the scope of practice for hospice nurses and other providers:

...They have a level of care that they’re legally allowed to give, and then they can’t go any further than that, so they can’t provide interventions for their patients past a certain point, but a hospital can. If that could change, because I think what they provide is more personal care, it’s not like an entire ward full of patients… So, if they had the ability to intervene more, you know, like why do we have to transport our children in an ambulance to the hospital once they reach a certain level legally that they’re allowed to give care.

A common reason for parents to enroll their children initially is to avoid constant trips to the emergency rooms and the hospitals. However, there is a limit to what hospice nurses and other providers can do while enrolled in home care. If a patient’s needs go out of this scope of practice, the provider may suggest that they take the child to the hospital. Some issues parents encounter with hospital-based care include parental role negotiation, stressed communication with the health care team, and involvement in decision-making.\(^8\) Several parents in this study expressed similar problems, with an addition of an inconsistent care team (Mary). Having a dedicated home-team that is responsible for care allows for increased communication and streamlined care.

According to one study that investigated parental attitudes and perceptions of in-hospital pediatric nursing, 49% of parents agreed with the statement, “I would have been more involved in the care of my child in hospital if I did not have other family commitments,” and 75% agreed with the statement, “Parents should routinely stay with their child while their child is in hospital.”\(^9\) These figures exemplify some of the parental narratives in the study. Mary always stayed with her daughter when she went to the hospital, while Anna expressed difficulty in accessing their child’s physician due to physical barriers. Additionally, most of the parents in this

---

\(^8\) Uhl et al., 2013.
\(^9\) Young et al., 2006.
study (89%) have more than one child. Trying to balance family life and being in and out of the hospital is difficult to do and having home care causes life to be more manageable (Florence).

These three suggestions provide a general framework for future policy suggestions. Overall, parents are looking for accessibility, reduced stigma, and possibility for a more advanced scope of practice in order to reduce the number of hospital visits. There are numerous ways to accomplish these goals, but policy provides a direct avenue for change on the state level.

*Where Do We Go from Here? State Policy Recommendations*

There are several options for change regarding pediatric hospice based on parental recommendations, and this section will briefly discuss three of them while contextualizing them within the larger framework of policy focuses for the National Hospice and Palliative Care Organization. The three policy recommendations include expansion of renewal policy, increased avenues of communication for practitioners with parents, and increased accessibility of hospice care in general through insurance options and more education for specialists in hospitals on the pediatric hospice model.

*Expansion of Renewal Policy*

The hospice in which all participants in the study are enrolled requires recertification of eligibility for services every six months per state and local hospital policy. This stems from the typical hospice eligibility requirement of having a six month or less prognosis if the disease or condition were to progress without intervention. The Medicare/Medicaid waiver allows for the utilization of curative treatment for children, which complicates prognostication. Additionally, if the patient’s physicians believe that the patient has a prognosis of greater than six months, the child could lose access to the integrated, multifaceted nature of hospice care.
Increased Avenues of Communication

As mentioned above, there is one mother who expressed discontent with the inability to see pictures of her child while in respite care. The solutions for this are not well explored within the realm of hospice. However, telemedicine and telehealth has been around as early as the early 20th century, when radios were used to give medical advice to clinics. The earliest use of hospital-based telemedicine was at the Nebraska Psychiatric Institute and Norfolk State Hospital for psychiatric consultations in the late 1950’s and early 1960’s.  

Even as recently as January of 2020, a Colorado hospice and palliative care organization called TRU Community Care launched a telehealth platform. It allows for remote patient monitoring and a virtual care platform. The American Telehealth Association says that this platform is used for clinical education programs, patient support and education, health information exchange, clinical decision support, electronic health records and laboratory systems, and disaster response support. This includes monitoring of symptoms and video consults, visits, or family meetings. Based on these uses, hospices could adapt a telehealth platform to increase communication while a patient is in respite, while ensuring HIPAA compliance. The current COVID-19 pandemic could also have implications for the possibility of telehealth and telemedicine. Traditionally, it is difficult to adapt telehealth because of clinician unwillingness to adopt it because of its perception of being abnormal and complicated. Additionally, there were no clear policies set for reimbursement of services by insurance companies and telehealth requires the entire system to be supportive of this new method of

85 Nesbitt, 2012.
87 Bishop et al., 2019.
delivering care.\textsuperscript{88} However, with the pandemic requiring rapid shifts to the healthcare system, the use of telehealth by hospital systems as grown significantly and is likely to maintain its position after the pandemic has subsided.\textsuperscript{89} With this increased use, telehealth may have improved perception by clinicians and may be more likely to be adapted or advocated for by physicians and hospice providers.

\textit{Increased Accessibility}

The state of Colorado conducted a policy audit for their waiver program, which allows pediatric patients to access curative treatment while also enrolled in pediatric hospice. According to this audit, around 28\% of children had no record of receiving waiver services while enrolled, and for those who have received these services, utilization is low. They attribute this to inefficient care planning, lower access to providers that provide waiver service, and the inability to guarantee bereavement counseling programs through this agency. In order to fix the utilization of the waiver program, they recommend comprehensively defining palliative/support care, providing training, and enforcing care planning requirements, increasing resource development efforts, ensuring bereavement counseling, and reevaluate the rates structure for the Pediatric Hospice waiver program.\textsuperscript{90} While these are not the same problems faced by the state of Maryland, they provide a good background for potential policy implementations.

It is clear based on the Colorado audit that one of the key recommendations is providing adequate training regarding hospice. As mentioned in the present study, several parents were under the impression that physicians were hesitant to recommend hospice because of the

\textsuperscript{88} Smith et al., 2020.
\textsuperscript{89} Bekaii-Saab, 2020.
\textsuperscript{90} Symanski, 2011.
associated stigma. By providing a training for pediatric specialists, this stigma can be reduced, and parents would be able to make an informed decision regarding their children’s care.

The current waiver that allows for curative treatment is operated through Medicare and Medicaid/CHIP. There is no clear consensus regarding hospice policy for private insurance, so further research is necessary to address this form of insurance.

**Federal Policy Focuses for NHPCO and Purpose of a Focus on Policy**

The National Hospice and Palliative Care Organization (NHPCO) is a membership organization for providers and professionals that care for people who have life-limiting or life-threatening illness. Based in Washington D.C., they are a leading legislative advocacy organization in the interests of hospice and palliative care patients and providers. In January 2019, the NHPCO published a brief that they distributed to congresspeople to outline their legislative agenda and advocacy priorities, which are outlined as follows.

The first priority is structural reform of the Medicare hospice benefit, which would allow hospice patients (regardless of age) to access concurrent curative care, improve upstream access to palliative care, reform the six-month prognosis barrier, and reduce regulatory hurdles of accessing hospice care. The other priorities are coverage for community-based palliative care services, expanded access to hospice services, and reduction of regulatory burden while protecting program integrity.\(^9^1\) Although these priorities were oriented toward general hospice care rather than solely pediatric, these priorities of the NHPCO mirror the sentiments expressed by parents in this study, particularly for increased accessibility and adjusting the six-month prognosis barrier.

---

\(^9^1\) Hospice Action Network, 2019.
Several bills have gone through Congress within the last couple of years that reflect these goals, though none have passed yet. The first is the Palliative Care and Hospice Education and Training Act. Originally passed in the House of Representatives in 2017, it was referred to a Senate committee on health, education, labor, and pensions in the summer of 2018. This bill had eight parts, most of which were focused on education and research. It includes training grants and contracts for physician training on palliative care, establishes fellowship programs and palliative care and hospice education centers to improve the training of interdisciplinary health professionals, and provides for a national campaign to increase awareness of palliative care. The second bill, called the Rural Access to Hospice Act of 2019, allows health centers to receive payment under Medicare for hospice services. The third, called the Patient Choice and Quality Care Act, was introduced in the Senate in 2017. It requires the Centers for Medicare & Medicaid Services to create and test a new Medicare model for advanced illness and care management. It is meant to allow patients with serious illnesses to engage in planning processes that align with their goals. This includes hospice programs. Focusing on policy allows for the analysis of realistic change in current hospice implementation and regulation.

Additionally, another argument for reform and increased accessibility of hospice care is that it has been shown to save money within the healthcare system. One longitudinal study sought to better understand the value of Medicare hospice by examining the relationship between length of hospice enrollment and overall Medicare costs. They found that for the four different periods of enrollment, the healthcare costs for those enrolled in hospice was significantly lower compared to those who were not enrolled in hospice. For instance, for a group that was enrolled

---

92 Engel, 2018.
93 AAHPM, n.d.
for 15-30 days, those that were enrolled in hospice had $10,383 in Medicare expenditures, whereas those that were not enrolled in hospice had $16,814. Those enrolled also had fewer hospital admissions, intensive care unit admissions, hospital days, readmissions, and hospital deaths.95 When applying this notion of saving healthcare spending through hospice to the pediatric population, some studies recommend that insurance companies expand accessibility to hospice care by eliminating eligibility restrictions related to life expectancy and by including outlier payments for costly hospice patients.96

**Conclusion**

Parents expressed two different pathways for their goals for the future: curative and palliative. These options are made possible by recent policy changes to the hospice system as a result of the Affordable Care Act that allow for concurrent enrollment in hospice care while receiving curative treatment. However, no matter whether the parent is seeking curative treatment or simply trying to maintain or improve quality of life, all the parents expressed a desire for continuity of care with their team.

In the last part of this chapter, I explored the different policy positions for changing the system of hospice care. The NHPCO leads hospice advocacy in the United States and have pushed three bills recently into Congress, though none have passed under this administration. Continued analysis of hospice policy and financing is required in order to decide on the best course of action to enact changes that are desired by parents whose children are currently enrolled in hospice care.

---

95 Kelley et al., 2013.
96 Field and Behrman, 2003.
Chapter 5: Conclusion

Topic Layout
Summary of Study
Strengths and Limitations
Future Directions
Summary of Study

This study is an exploratory study to uncover the parental perspectives and experiences of pediatric hospice care while their children are still enrolled. This perspective was missing in current hospice literature, which primarily focused on bereaved parents. Based on interviews with nine parents in Maryland whose children are currently enrolled in pediatric hospice care, I found that these services provide an invaluable support to families by providing relief, being a consistent resource, and giving respite care. However, there are some persistent frustrations with how the pediatric hospice care model is organized, primarily the renewal processes every two to six months and with how pediatric hospice is perceived by the general public.

As explored in chapter 1, numerous studies have explored the relationship between autobiographical memory and grief. Therefore, with most studies focusing on bereaved parents, there could be a gap in knowledge in this field. Grief can cause gaps in autobiographical memory and can disrupt the normal pathways for memory formation. This inherently causes a possibility for recall bias for bereaved parents. It is possible that parents that experience the grief of losing a child would develop this complicated grief, thus necessitating research that focuses on parents whose children are alive and actively enrolled in hospice in order to get a complete picture of parental experiences.

Additionally, the Affordable Care Act allowed for concurrent curative treatment and for some states to allow pediatric patients with life-limiting conditions to enroll in hospice care. With hospice literature focusing on bereaved parents, the parents of children who have life-limiting, but not terminal conditions are left out of the narrative. This study sought to explore whether the experiences of parents whose children are actively enrolled differed from those whose children have died as described in previous literature. Overall, the parents in this study
were less likely to report negative experiences, and any that were reported were not institution-specific, but rather aspects of the hospice system as a whole that they would change.

In Chapter 2, I discussed the various conditions that lead parents to enroll their children in pediatric hospice care and how they made that decision. Overall, parents are pushed toward hospice because of their need for extra support and their desire to focus on quality of life over quantity of life, but they were hindered in making this decision because of physician bias, opinions of others, and perceptions of hospice care. However, as discussed in Chapter 3, once enrolled, parents’ experiences are influenced by respite, renewal processes, nurses, child life specialists, chaplains, and support with individualized and family-oriented holistic care. Additionally, the parents whose children are currently enrolled did not focus on grief or negative experiences. The focus shifted to the interactions with the hospice staff and the service as a whole rather than on patient symptoms and the end-of-life experience like in previous studies.

Lastly, in Chapter 4, we discussed the parents’ goals for the future of their children’s hospice care. Most of the parents expressed hope for continuing palliative treatment and maintaining a high quality of life. In chapter 4, we also explored different policy options based on the parental recommendations and also based on those of the National Hospice and Palliative Care Organization. Overall, the direction for hospice policy aims for increasing accessibility through insurance changes and through education for providers that can refer parents to this service.

Strengths and Limitations

Being an exploratory study, the data presented in this thesis cannot be generalized. The small sample size (n=9) also dissuades the study from being generalizable. Additionally, the method of recruitment for parents lends itself to selection bias, as the nurse manager specifically identified parents that may be interested in participating and follow the criteria set by the hospice
itself. Parents are more likely to agree to participate if they have positive experiences and are satisfied with their experience. The interviews were conducted over the phone, which limits the number of parents that could participate, as it is time consuming and requires English proficiency and a phone. Lastly, the demographic data collected did not account for class, race, ethnicity, socioeconomic status, or religion, all of which could be addressed in follow-up research. However, excluding this demographic data could bias the results of this study by not demonstrating how the sample compares to the general population.

In order to maintain HIPAA-compliance in this process, the clinical manager at the hospice in Baltimore performed all recruitment measures. She reached out to patients that would be interested and whose children are not in critical condition. This provides another form of selection bias, as all decisions to whom to reach out were made through this individual.

That being said, this study design highlights the need for the inclusion of parents whose children are actively enrolled. It includes individuals who otherwise would have been excluded from studies about pediatric hospice care. Additionally, it spans the realm of science, society, and policy, which allows for a comprehensive overview of hospice within this exploratory study.

Lastly, this study eliminates the issue of recall bias in the study of parental experiences, as all children were actively enrolled in hospice. If a child died prior to the scheduled interview, the parent was automatically excluded from the study to eliminate the possibility of grief impacting study results and the possibility of significant recall bias.

Future Directions

Future research should reach beyond a singular hospice program, but this study highlights the existence of differences of experience between parents whose children are currently enrolled and parents whose children have died in hospice. Extending to other programs would provide
more generalizability to the experiences, as well as have a wider range of perspectives on the system. Having a complete picture of how parents experience pediatric hospice care could inform future policy decisions by providing quantitative and qualitative research results. It could also help parents who have never experienced the program to understand it.
Appendix

Appendix 1. Parent Demographics and Identifications in Paper

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Number of Children</th>
<th>Marital Status</th>
<th>Household Composition</th>
<th>Age of Child Enrolled</th>
<th>Time Enrolled (in months)</th>
<th>Primary Diagnosis</th>
<th>Comorbidities</th>
<th>Heard of Pediatric Hospice Prior to Enrollment?</th>
<th>Gender of Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>3</td>
<td>Married</td>
<td>Husband + Daughter</td>
<td>25 years</td>
<td>42</td>
<td>Lennox-Gastaut Disorder</td>
<td>3+</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Margaret</td>
<td>2</td>
<td>Married</td>
<td>Husband + Son + Brother and Sister-in-Law</td>
<td>2 years</td>
<td>48</td>
<td>1-cell Disease</td>
<td>0-1</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Helen</td>
<td>3</td>
<td>Married</td>
<td>Husband + 3 children</td>
<td>16 years</td>
<td>1</td>
<td>Chromosome 13 Disorder</td>
<td>0-1</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Anna</td>
<td>2</td>
<td>Married</td>
<td>Husband + Daughter</td>
<td>18 years</td>
<td>24</td>
<td>Upstream Binding Transcription Factor Mutation</td>
<td>0-1</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Ruth</td>
<td>2</td>
<td>Married</td>
<td>Husband + 2 Children</td>
<td>5 years</td>
<td>54</td>
<td>Trisomy 18</td>
<td>0-1</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Marie</td>
<td>4</td>
<td>Married</td>
<td>Husband + 4 children</td>
<td>3 years</td>
<td>30</td>
<td>Pontocerebellar Hypoplasia</td>
<td>0-1</td>
<td>No</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Bethany</td>
<td>1</td>
<td>Married</td>
<td>Husband + Child</td>
<td>8 months</td>
<td>7</td>
<td>Hypoxic Ischemic Encephalopathy (HIE)</td>
<td>0-1</td>
<td>No</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Florence</td>
<td>2</td>
<td>Married</td>
<td>Husband + 2 children</td>
<td>9 months</td>
<td>6</td>
<td>Hypoxic Ischemic Encephalopathy (HIE)</td>
<td>0-1</td>
<td>No</td>
<td>Cisgender Female</td>
</tr>
<tr>
<td>Rose</td>
<td>2</td>
<td>Single</td>
<td>2 children</td>
<td>23 months</td>
<td>8</td>
<td>Hypoxic Brain Injury</td>
<td>0-1</td>
<td>Yes</td>
<td>Cisgender Female</td>
</tr>
</tbody>
</table>
Appendix 2. Interview Guide

Title: The Experiences of Parents with a Child in Pediatric Hospice: An Exploratory Study

Thank you for agreeing to participate in this study. I’m hoping to learn about your experiences with having your child enrolled in pediatric hospice. I will ask about your child’s diagnosis and condition, referral to hospice, specific experiences with hospice, hopes for the future, and your daily life. Do you have any questions for me before we start?

I. Diagnosis and Condition
   a. Would you walk me through your child’s diagnosis?
   b. How did you feel in the beginning about your child’s diagnosis? What were your hopes and fears?
   c. When did the discussion of hospice care begin? Who initiated it?

II. Referral to Hospice
   a. Had you heard of hospice prior to your child’s enrollment?
   b. When was the idea of enrollment first discussed? Can you tell me about the conversation?
   c. What was running through your head during this discussion?
   d. Tell me about your decision to enroll your child. What was the reasoning?
   e. How long have you been enrolled in hospice?

III. Dynamics with Hospice Workers
   a. What was your first impression of the hospice service?
   b. Tell me about the first home visit.
   c. Tell me about your hospice experience and your experiences with the hospice workers.
   d. What were your expectations for the hospice workers?
      Followed by: Have they fulfilled these expectations?
   e. How do you feel about the quality of care?

IV. Benefits and Drawbacks of Hospice Care
   a. What have been the best experiences with hospice?
   b. What have been the greatest benefits to having hospice care?
   c. What have been some of your negative experiences? Is there anything you would want to change?

V. Hopes for the Future
   a. What is your hope for the future? What are your goals with the future of your child’s hospice care?

VI. Effects on Daily Life
   a. How has your daily life changed since your child was first diagnosed?
      Since your child was first enrolled in hospice?
   b. Do you feel that you have adequate support in caring for your child?
   c. Who has been the most helpful in your hospice experience?

VII. Conclusion
   a. Is there anything else that you would want to share with me?
Demographics
- Name
- Email Address
- Gender
- Number of Children
- Marital Status
- Household Composition
- Time enrolled in hospice
Acknowledgements

I would like to thank several people for their support throughout this experience. First, without my thesis advisor, Wendy Cadge, none of this would have been possible. Thank you for encouraging me in my research and being a constant support throughout my undergraduate experience. Additionally, thank you to the Jerome A. Schiff Undergraduate Fellows Program for granting me initial funding and support for this project.

Next, thank you to Mary Tiso and Abbey Peko-Spicer, who assisted in recruitment of parents for interviews, and to Cathy Demmitt and the Greater Baltimore Medical Center Institutional Review Board for approving this study.

Thank you to all the parents that spoke with me for this project. I hope you are all well and continue to receive the support you need.

Thank you to Dr. Wangui Muigai and Dr. Thuy Lam for being readers for my Thesis Committee. Thank you to Dr. Cindy Thomas for granting me permission to complete this thesis within the Health: Science, Society, and Policy program.

Lastly, thank you to all my family and friends that are always supportive of my endeavors and encouraged me throughout this process. I would never be where I am without you.
References


CMS. Medicare Part D Hospice Care, Medicare Part D Hospice Care (n.d.).


Documentation Requirements for the Hospice Physician Certification/Recertification.
Loeb 87


