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# Resilience Through Relationships: Understanding Care for Children With Life-Limiting Illnesses

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Resilience Through Relationships: Understanding Care for Children With Life-Limiting Illnesses

A Thesis Presented

by

Madeline Cody

to

The Faculty of the College of Education and Social Services

of

The University of Vermont

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Last, I would like to thank all the families and clinicians that care for children with life-limiting illnesses today. From the very beginning, your unwavering dedication to helping these children was the motivation for this project. I hope this thesis can offer a glimmer of insight as to how we can improve the care and lives of children with life-limiting illnesses.

**Abstract**

My research was an attempt to understand current structures of care for children with life-limiting illness through the experiences and perceptions of clinicians and family members. My hope was to better understand the perspectives of these individuals in order to identify the strengths and challenges of caring for these children. The qualitative research methodology employed was Social Science Portraiture (Lawrence-Lightfoot, 1997), a methodology that seeks to elicit individual stories for themes, voice, relationship, and context. Cross-case themes were also explored. Three interviews were conducted and the participant pool consisted of three parents, one sibling and two clinicians. Interviews were transcribed, coded and used to create a “portrait” of each interview in order to determine themes relevant to caring for children with life-limiting illnesses. Themes of human capacity and building relationships were present across all three portraits. My project adds to the small but growing field of research about children with life-limiting illnesses and their families. The implications of this study will hopefully inform future researchers and medical professionals as they seek to improve the quality of care offered to this population.

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### **Terminology**

For the purpose of this thesis, the term “life-limiting illness” is being conceptualized as any medical diagnosis that prohibits or hinders one’s life. This paper will specifically focus on those life-limiting illnesses that affect children. Children will be used to include any persons under the age of 21. As defined by many experts, life-limiting illnesses are diseases marked by progressive deterioration and ultimately result in death for these children, most before adulthood (WHO, 2014). These conditions are severe and have enormous effects on both the child suffering from the illness and the family. They are also often referred to as life-limiting conditions, or terminal illnesses. The choice to use the term life-limiting illness is an attempt to be consistent with the language of social work research in this area and that of the National Association of Social Workers.

Additionally, the term “clinician” is used to refer to the professionals caring for children with life-limiting illness and their families. Clinicians is not limited to medical professionals, although the term does encompass doctors, nurses, physical therapists, occupational therapists, pharmacists, residents, and hospice workers who are supporting these children and their families. In this research study, the term will also include professionals not typically thought of as belonging to the medical field, such as social workers, child life specialists, psychologists and more. Non-medical clinicians are important actors in the care of this population and thus are included in the term “clinicians.” A distinction of profession will be made when needed.

## Introduction

### My Journey

My knowledge of health barriers began long before the conceptualization of this project. As a young girl, my loving father was diagnosed with Hodgkin's Lymphoma, a form of cancer that would eventually take his life before I was age seven. At that time, I was unable to understand the challenges he and my family faced as a result of his cancer. I was more concerned with waking him up to play with his hospital bed and listen to Goo Goo Dolls. However, over the past several years I have gathered bits and pieces about what his struggles were, even beyond the diagnosis. Nausea, pain, tiredness, constipation, and dizziness were no strangers to my father. These were concrete physical problems that caused him much suffering and reducing this suffering was a priority. However, we learned through his experience that our family's needs oftentimes included ones beyond those of the physical difficulties. My mother has recounted stories of driving my father down to Boston for treatment after working a sixty-hour week. My Aunts have shared stories with me about the emotional weight my father felt every time he needed to be admitted to the hospital. Leaving his family and life to stay for long stretches of time in the hospital was not something he looked forward to. My father and family's resilience in overcoming those barriers is something that I have truly admired since his passing, even sometimes without knowing it. Each and every day I try to carry his strength with me.

The impact from my father's experiences on my professional life did not surface until I was tasked with writing a formal literature review for my Social Work research class. Because Social Work is such a diverse profession, I had experiences in other areas of practice prior to this assignment. I had tested my skills in areas such as restorative justice, refugee work, gender equality, and working with people with disabilities. None of these areas grabbed me. I soon came

to realize that I had never had an opportunity inside or outside the classroom to explore the medical Social Work field. With my natural curiosity about my father's care and my lack of knowledge in this area of Social Work, I figured it would be a good fit for this particular literature review project.

After much consultation, I was able to narrow down my research topic to care for chronically ill children. While focusing on children allowed me to distance myself slightly from the experiences of my father, which kept my emotions in check, it also exposed me to similar types of care he encountered. During my initial literature review I wanted to know about the structures of care for these children. What were the best practices for care? What do professionals in these settings do to support this population in terms of the diagnosis? How do they support them after the diagnosis? Where are the gaps and strengths? What I found surprised me. I found that the body of research about this population is relatively small and for the most part in its infancy. Throughout my literature review I found myself repeating phrases like "there needs to be more research in this area" or "the limitations of this study are the small sample size."

This seemingly lack of research for children with life-limiting illnesses struck me. Realizing that there was not much known about the care for this population intimidated me at first, but on further thought it began to fuel my passion for understanding the needs of these children and families. The results of my literature review project in that class showed me just how much more space there is for knowledge. I became stimulated by the idea that I might possibly be able to fill that space with some of my own knowledge. I decided, then, that my Honors College thesis would focus on this topic.

## Literature Review

### Introduction

Before the early 2000's, the primary focus of pediatric care for children with life-limiting illnesses was to do everything medically possible to find a cure, or at the very least, prolong life as much as possible (Doorenbos et al., 2012). However, during the early 2000's, this paradigm shifted. The typical goal of finding a cure for these children was put on the back burner. The new focus was on optimizing the quality of care for these children and their families (Michelson & Steinhorn, 2007). Improving quality of life was the new focus and maximizing comprehensive quality health care soon became a national health priority (Michelson & Steinhorn, 2007). In 2000, the American Academy of Pediatrics declared that all children living with a life limiting illness should have access to quality pediatric palliative care throughout the course of their illness (Michelson, Koogler, Skipton, Sullivan, & Frader, 2006). The focus was no longer on the medical cure, but rather the overall emotional, mental, and physical wellbeing of the child and family. Quality of life, in many cases, is now valued over the length of the child's life. This new approach also encourages interventions and supports at every stage of care, from diagnosis to post-death.

In the United States 50,000 children die each year and more than 500,000 children are diagnosed with or have current diagnoses of a life-limiting illness. Most of these children are not expected to live past adulthood (Michelson, Ryan, Jovanovic, & Frader, 2009). Along with the change in thinking about care for this population, from finding a cure, to quality of life, the scholarly literature has given this population more attention as well. Researchers from multiple disciplines have begun to weigh in on palliative and end-of-life care for children with life-limiting illnesses. There is a growing consensus among scholars that there needs to be a universal

understanding of the effective interventions and models of supports for this population (Barbara Jones & Weisenfluh, 2003). These interventions and models should be specific to the needs of children with life-limiting illnesses and their families (Barbara Jones & Weisenfluh, 2003).

Relatively speaking, this research is in its infancy. Much of the current research about this topic is exploratory. We have only just barely begun to identify the needs for these children, as well as the appropriate supports clinicians can put in place to address these needs.

### **Significance to Social Work**

This new way of thinking about the care for children with life-limiting illness calls for input from multiple disciplines to understand all the needs of the child and family, even outside of the medical diagnosis (Robert et al., 2012). Quality of life is not defined solely by the physical experience, but also the emotional, mental and relational experiences. Social workers have long been providing end-of-life care in hospitals, hospice agencies, and community setting (Jones, 2008). However, with this new priority on both the physical and emotional comfort of these children and families, social workers' presence is even more clear (Doorenbos et al., 2012; Barbra Jones, 2008). These professionals are uniquely situated to help children with life-limiting illnesses and their families, and thus their knowledge and skills are in high demand (Barbara Jones & Weisenfluh, 2003). Unlike doctors and nurses who specialize in the diagnosis and treatment of medical needs, social workers have a role in assisting a people outside of the medical diagnosis (Jones & Weisenfluh, 2003). They bring to the table unique training in skills such as cultural competence, psychosocial training, knowledge of developmental needs of children, family-systems theory, theories of grief and anticipatory grief, and advocacy training that allow them to meet the very different needs a child may have (p. 424). Challenges such as financial burdens, environmental stressors, emotional needs, bereavement needs, spiritual

accommodations and more can all be addressed by these practitioners. They can also provide care on a continuum of development, offering support during diagnosis, treatments, death and bereavement. With the unique position social workers have in the care of families and children with a life-limiting illness, they are also important actors in the creation of structures of care for this population.

Although we know that social workers have a place in the direct care of these children and their families, it is also crucial to recognize the role they have on the policy level as well. In working with this population, they must have extensive knowledge about the medical system and the social, political, and environmental factors that shape it (Jones & Weisenfluh, 2003). Engaging with and changing systems, such as the medical system, is a daunting task and requires extensive knowledge of social systems and experience in policy practice. This extent of understanding is no small task for social workers. However, this profession requires a commitment to advancing people's wellbeing (NASW, 2008). Advancing the wellbeing of children with life-limiting illness sometimes requires fighting against these systems. Working with this population is a job meant for social workers who have an intense passion for advancing human rights and social justice on both the micro and macro levels of service. A multidimensional understanding of the needs of children with life-limiting illnesses is crucial in grasping the full breadth of needs these children and their families have (2003, p. 424). Without this full understanding of the multidimensional needs, we cannot contribute to improving the quality of life for this population.

### **Limitations of the Literature**

The literature about children with life-limiting illnesses is scarce and the body of research is filled with gaps and unanswered questions. This might be due to the fact that children and

families in these situations are considered a vulnerable population. Institutional Review Boards and research governing bodies have determined that there is significant risk of re-traumatization for participants from this population when they are asked to reflect upon their experiences. The effect of this determination on the literature is two-fold. One result is that many studies survey clinicians rather than the families about care. This approach, of course, has both its pros and cons. It is beneficial because it avoids potential re-traumatization of the families and allows the researcher to understand care from a clinician's perspective. What it neglects is the deeper emotional challenges that families experience. The other methodological approach when faced with this barrier is to interview or conduct focus groups of family members, mostly parents, about their experiences long after their child has passed away. The barrier to this method is the lack of real-time emotional feedback. This approach also results in fewer research participants, affecting the ability of the researcher to generalize the results. Typically, only parents who feel strongly about the care their families received agree to participate in these types of studies. Both of the aforementioned research designs provide strengths and challenges. After reviewing both, I decided to design my research study using the former approach. For many reasons, this method was best suited to the work I wanted to accomplish with the resources that were available to me. An ideal study would hopefully include aspects of each and would result in a better understanding of the strengths and challenges in caring for these families.

In addition, the sensitive nature of this topic contributes to the lack of published research that exists. Talking about the death of a child raises some hard questions about the meaning of life, mortality, and the relationship between life and death that people might not be comfortable talking about (Basu, 2013). Whether this hypothesis explains the lack of attention this topic receives, in the end, is not really the issue. The hurdle clinicians, researchers, and families

dealing with these situations must overcome is the silence that surrounds this population and the care these families receive. Yet people need to begin having these hard conversations about the care for children with life-limiting illnesses. This is a type of care that affects the most vulnerable members of our society and should be treated as equally important as any other societal problem.

Due to the recent spike in attention to this subject, the literature on children with life-limiting illnesses is just beginning to pick up speed. Building a body of research from multiple disciplines takes several decades. Despite the barriers, the social work profession has outlined a national agenda for social work research in palliative and end-of-life care for children with life-limiting illnesses (Kramer, Christ, Bern-Klug, & Francoeur, 2005). Social workers share an ethical duty with other professions to uncover and test evidence-based intervention and supports for this population (Kramer et al., 2005). In the coming years clinicians working with this population are going to see an influx in the research, but for now, we must work with the little research we have to best support these children and families.

### **Decision Making**

Decision-making is one of, if not the most, researched area of care for children with life-limiting illnesses. The decisions made by these families and clinicians are, in most cases, life changing. The choices made have ramifications that affect the child mentally, emotionally, and physically and therefore should be goal directed and based on a universal understanding of the illness trajectory and the potential consequences of treatment or no treatment (Himmelstein, 2006). Family, friends, relatives, and clinicians are all affected by the decisions made about these children. Families and physicians are making hard decisions such as what interventions will be needed and when. They also decide if there should even be any intervention and if so, to what

extent. These decisions often come down to the family defining what quality of life means to them. Even extreme decisions, such as keeping the child on a ventilator, need to be made. These are decisions to be made in conjunction with many discussions about the goals of care and the potential outcomes of these decisions.

The literature is undecided about whether or not decision-making techniques that are already being used by clinicians are working to facilitate decisions that are in the best interest of the child. One study found that generally parents were satisfied with the care their child received and the decisions that were made. However, 20% did feel dissatisfied with being included in decisions (Gilmer, Foster, Bell, Mulder, & Carter, 2012). Some parents even experienced extreme situations of being told in the waiting room by the pediatrician that they needed to make an immediate decision about taking their daughter off life support (Gilmer et al., 2012). This situation is an extreme case and cannot be generalized as the experience of all families making decisions, but is a situation that should be avoided at all costs. Situations like those remind us just how important it is to further understand the decision-making needs of families.

There is overwhelming agreement in the literature that both families and clinicians think that decision making is a crucial element in terms of care for children with life-limiting illnesses (Gilmer et al., 2012; Michelson et al., 2006). Parents in one particular study felt that end-of-life decision making was absolutely crucial to their care, and warrants more research (Michelson et al., 2006). They believed that an increased attention to the topic of decision making would in turn increase medical clinicians awareness of the diversity in parent opinions (p. 1336). Differences in culture, race, age, values, and socioeconomic status influence not only how families understand the situation of their child with a life-limiting illness, but also how they will come to certain decisions about their child's care. Although these varying opinions about

decisions may result in different outcomes for children and families, being able to make these decisions empowers families to make ones they can live with (Barbara Jones & Weisenfluh, 2003).

Finally, when it comes to making decisions for children with life-limiting illnesses we must understand this: Who are the decision-makers? It is important to recognize there is a large spectrum of decision-making roles (Doorenbos et al., 2012). On one end of that spectrum is the belief that families should be the sole decisions makers. The other end of that spectrum is when parents wish to delegate the decision-making power to medical clinicians (p. 305, 2011). Most research about family-centered practice argues for the power to be shared by clinicians and family members. Social workers can be helpful in facilitating this shared decision-making role between clinicians and families (Barbra Jones, 2006). Social workers come from a theoretical background of self-determination and empowerment that can be useful in reminding clinicians that families deserve shared power in the decisions made about their child. These practitioners can facilitate communication with families and time-crunched medical clinicians, so parents can have accurate information and recommendations.

Although most of the current literature focuses on clinicians and parents' role in the decision-making process, it is important to distinguish children as very capable decision makers in regards to their own care (Barbara Jones & Weisenfluh, 2003). "Children have the capacity for autonomy, choice, and thoughtful decision-making and should be included throughout the treatment process" (p. 423). Children as decision makers is not well understood in the literature, therefore, research must focus on making the standard of care a shared decision-making process between children, families and clinicians (Himmelstein, 2006).

### **Communication**

Communication is another key aspect of the care for children with life-limiting illnesses. A breakdown in effective communication can happen on many levels including, parent to child, parent to medical professional, child to medical professional, social worker to medical professional, one medical department to another, social workers to family, or one staff member to another (Contro & Sourkes, 2012). Unfortunately, fragmented communication among these parties can have devastating physical and/or emotional consequences for the child and family. On the flip side, strong communication can help improve the quality of care for the family because it makes them feel supported and empowered. Strong communication is open, educational, and involves active listening by all participants. The literature recognizes that communication can be both a barrier and strength when working with children with life-limiting illnesses and their families.

The importance of effective communication when working with this population cannot be overstated. “Excellent communication skills are essential in the PICU setting because of the high-stakes decisions; critical informational needs of families; and the numerous potential differences in cultural beliefs, understanding, values, and preferences between clinicians and families” (Doorenbos et al., 2012). Communication also builds trusting relationships between the clinicians and parents, better ensuring that the hopes and wishes of both the family and the clinician are heard and understood (Robert et al., 2012). Effective communication between these two parties is influenced by honest communication, comprehensive and understandable information sharing, and clinicians’ body language (Basu, 2013). It is important to note, then, that parents view open and fluid communication between all actors as vital to their child’s care, particularly communication among family members (Robert et al., 2012). The importance of open communication among family members, such as parent to child, often goes unnoticed in the

literature. One group of parents who sensed their child was aware of her/his imminent death were encouraged to discuss this situation with their child, a conversation most might try to avoid (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004). However, no parent in that cohort reported later regretting having talked to his or her child about death (p. 1175). Fluid and strong communication between all parties involved in the care of children with life-limiting illnesses is in the best interest of the child. This communication allows for trusting relationships and better decisions to be made about the care of that child.

When there is a breakdown in communication, social workers can play an important role in mending that obstacle ((Doorenbos et al., 2012). Given the right communication interventions these clinicians can facilitate communication among parents and other practitioners to diffuse confusion about the diagnosis and have fruitful dialogue about the decision to be made (Barbra Jones, 2006). Social Workers are trained to facilitate the creation of human relationships, and an important element of any relationship is open and honest communication.

One of the ways clinicians can avoid fragmented communication for all actors is by using family care conferences to share information between family members and care providers (Doorenbos et al., 2012). These conferences are typically used to mutually determine the goals of care (p. 306). They can be formal or informal and ideally would include everyone who might be involved in the care of the child (p. 306). Discussions are centered on medical condition, prognostic information, psychosocial information, and decision-making (p. 307). These conferences are often coupled with a general guideline for improving communication between clinicians and families, called VALUE, which is a five-step approach to improving communication (Curtis & White, 2008). VALUE embodies 5 core values of listening including; valuing family statements; acknowledging family emotions; listening to family; understanding

the patient as a person; and eliciting family questions (Curtis & White, 2008). Interventions such as these can have lasting outcomes including: reduced symptoms of anxiety; depression; and PTSD for families (Lautrette et al., 2007). In addition, evidence-based tools similar to family care conferences and VALUE-5 can result in congruent goals and decisions for the child by the parents and clinicians (Hinda et al., 2012).

When implemented proactively, communication interventions empower families and create opportunities to exchange information and understanding about the medical circumstances, acknowledge and address family emotions, explore patient and family preferences, explain the process of decision making, and affirm nonabandonment by the clinical team (p. 308).

Being heard and understood for these children and families is absolutely fundamental to quality care and the wellbeing of these families.

### **Pain and Symptom Management**

Interdisciplinary teams working with children with life-limiting illnesses must also be concerned with addressing the pain and suffering of these children. Most of the research on how to manage this pain and suffering is from the medical literature. One study found that children who died between 1990 and 1997 in the Dana Farber Cancer Institute in Boston experienced substantial suffering in the last month of their lives, despite the best efforts by physicians to reduce this suffering (Wolfe et al., 2000). The most common symptoms of suffering among these children were fatigue, pain, dyspnea or trouble breathing, and poor appetite (p. 330). Although not all of these symptoms affected every child in the study, 89 percent of the children experienced “a lot of suffering” from at least one these symptoms (p. 330). Other symptoms included nausea, constipation, and diarrhea (p. 330). Pain and symptom management is certainly

something clinicians must be concerned about when working with children with life-limiting illnesses or at the end of life. Reducing pain and suffering should be a priority.

The social work research in this area is inadequate. Many publications acknowledge that pain and symptoms management is and should be a primary concern for clinicians who are working with children in these situations, yet seemingly few have identified the best methods for addressing these needs (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Gilmer et al., 2012). One social work study found that the doctors, nurses and social workers dealing with a child's pain know very little about the proper methods for reducing her/his suffering (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Thankfully, parents and family members have been pleased with how the pain symptoms have been handled by hospital staff workers and believe that every possible option is exhausted to comfort their child (p. 1250).

### **Financial Burden**

Medical care for children with life-limiting illnesses can be a daunting financial burden to parents. Many families experience a large amount of added stress due to the financial burdens of caring for their child (Cadell, Kennedy, & Hemsworth, 2012). This stress, especially for families with children needing lengthy medical care, can take a toll on the family's emotional and mental health. Some parents recommended a special dispensation from hospital-related bills and payment (Robert et al., 2012). They felt a heavy emotional weight when hospital bills were arriving during funeral preparations (Robert et al., 2012). They reported that they would much rather these bills come after the funeral (Robert et al., 2012). Social Workers can be advocates for a request like this to hospital executive teams and billing departments.

An additional barrier that was explored very little in the literature is the challenge of getting health insurance and Medicaid benefits. Families in these situations are tasked with

battling insurance companies to get help covering the large medical bills that pile up as a result of this type of care. Things like full-time nurses, personal care assistants and high-tech equipment all need to be paid for in some way. A major responsibility of Social Workers working with these families is to help families navigate this complicated world of insurance in order to help reduce this financial stress for families. This might not be what we think of as “typical Social Work practices,” however helping families through this process is part of Social Workers’ commitment to social and economic justice. Unfortunately, insurance and financial barriers are an area of care that needs further exploration and understanding. Highlighting why and how clinicians can best support these families in their financial situation is an area that needs to be addressed in the literature.

### **Cultural Considerations**

Research about cultural supports for children with life-limiting illnesses is a growing area of research. With increasing evidence of major health disparities in America, cultural competence has been a recent area for discussion across all health disciplines (Crawley, 2005). Culturally competent health care is rapidly becoming recognized as an integral part of quality health care (Davies, Larson, Contro, & Cabrera, 2011). As a result, the social work and medical research communities have responded with an increase in attention to this area of care. Although this influx has taken part in the larger understanding of quality health care, not as much attention has been given to cultural competence in pediatric care (p. 71). Children, along with adults, face glaring cultural barriers in health care (p.71). These barriers include cultural, racial, ethnic and linguistic obstacles to receiving quality health care. Outcomes such as mortality differences and differences in services based on race or ethnicity have been reported in the literature (Crawley, 2005). For example, it has been proven on several accounts that Blacks, and Hispanics have

received inadequate pain management compared to non-Hispanic white people (K. Anderson, Mendoza, & Valero, 2000). This reality holds true throughout all hospital departments that might deal with pain and symptoms management (Crawley, 2005). This, of course, is not a testament to the scope of discrimination racial and ethnic minorities experience in accessing quality health care, but rather another disturbing example of the inequalities that exist today in our health care system.

The Social Work research has weighed in on cultural disparities in health care, particularly for children with life-limiting illnesses. One study of Mexican American families found perceived discrimination against these families due to race, English proficiency, socio-economic status, and appearance (Davies et al., 2011). The research participants reported feeling hurt, saddened and confused by the differential treatment they and their child received (p. 73). Presumably because of power imbalance, few parents spoke up about this differential treatment (p. 73). Mexican American parents and children in this study were not alone in reporting a perceived discrimination by hospital staff workers (p. 74). Despite the increase in attention to this subject, millions of Americans belonging to minority groups, including children with life-limiting illnesses from diverse backgrounds, still receive inadequate health care, Social Work research has attempted to shed light on these disparities in health care, but by no means has yet accomplished this. Finding ways to change the behaviors of hospital staff workers and the medical system as a whole to be more culturally sensitive and competent is a necessity to helping children with life-limiting illnesses receive the best possible care.

Culture for children extends far beyond the traditional sense of the word. It is important to understand that children participate in several cultures as they develop and mature (Barbara Jones & Weisenfluh, 2003). They are part of the culture of childhood, culture of their families,

culture of their peers, and for children with life limiting-illnesses they are involved in the culture of the treatment facility and medical team providing their care (p. 433). Growing up and learning who you are is hard enough, but for children growing up with a life threatening illness, trying to understand themselves and their culture is almost unimaginable. Identifying with these multiple identities puts an enormous weight on children, which is why understanding the impact of culture is absolutely necessary for clinicians to grasp. Culture is not limited to the racial and ethnic understanding for children with life-limiting illnesses and must be understood in the larger context of cultural identity.

### **Spiritual Considerations**

If there is ever a time when individuals question their spiritual beliefs, it is when a child is diagnosed with a life-limiting illness (Barbara Jones & Weisenfluh, 2003). In this time of deep questioning and searching for meaning, many parents either experience a strong sense of strengthening their spiritual beliefs or they find that they move away from their traditional beliefs as a result of parenting a child in this situation (p. 434). Spiritual support for these children and their families should be of the utmost importance for clinicians working with this population. Much of the research sheds little light on this aspect of care. Some studies from the social work research mention its importance, but say very little about the best way to spiritually support these children and their families (Barbara Jones & Weisenfluh, 2003). It is not enough to just know this is an important area of care; social work and medical research needs to identify specific ways in which clinicians working directly with this population can better support these children and families during a time of challenging and questioning of beliefs.

### **Lack of Education for Staff**

One distinct theme in the literature was the severe lack of education and training for medical professionals working with children with life-limiting illnesses. There is essentially no formalized educational training for these professionals (Basu, 2013). Most medical residents and fellows report having none to moderate levels of training, knowledge, experience, competence and comfort in caring for children with life-limiting illnesses (Michelson et al., 2009). These same residents and fellows advocated for an improvement in training in regards to discussing prognosis, pain control, and delivering bad news to the children and families (p. 451). Efforts to improve medical professionals' knowledge and experience base in assisting these families is clearly needed. This is not solely the research disciplines' responsibility. Hospitals, medical schools, undergraduate universities, and more all play a role in better educating clinicians about the challenges and barriers to caring for children with a life-limiting illness.

Of course, the Social Work profession shares a responsibility in educating future clinicians about how to best care for these children from a social work perspective. Despite the high demand for Social Workers to be a part of the teams caring for this population, there is no formalized education or empirical evidence to guide social workers working with this population (Contro & Sourkes, 2012). Currently, these clinicians are going into this work blind (Contro & Sourkes, 2012). The only knowledge they have about this kind of work comes from experience (Contro & Sourkes, 2012). Most social workers in these settings seek in-depth supervision in times of confusion. This lack of education for social workers, and presumably for medical clinicians as well, takes a toll not only on the child and family receiving the care but also on the clinicians. One study found that Social Workers often experienced feelings of despair and failure when they became acutely aware of the lack of knowledge and training they had (Contro et al., 2004). One can only assume this phenomenon results in similar feelings of despair for medical

professionals who have a lack of knowledge in caring for children with life-limiting illnesses. An increase in education and training for medical and Social Work clinicians will not only benefit the children and families but also increase the efficacy and emotions of the clinical team members.

### **Bereavement Services**

Bereavement services include any support families receive after their child with a life-limiting illness has passed away. The literature on these types of services is scarce, perhaps because bereavement services have been incorporated into palliative care services. However, even the palliative care literature has very little information on effective methods for supporting families after the death of a child. Parents view bereavement services with the utmost importance (Robert et al., 2012). They have articulated their need for preparation and education about what to expect after the child passes. How to handle their child's room, how to address their other children and how to resume normal responsibilities of parenting and day-to-day life are relevant discussion topics (Robert et al., 2012). This transition back to "normal life" is not an easy one. The transition should be accompanied by grief counseling for all members of the family. Social Workers and other clinicians have identified that preparation for families after the death of a child is inconsistent and inadequate (Contro & Sourkes, 2012). Follow-up after death is also inconsistent and many families tend to "fall through the cracks" and never end up receiving any form of bereavement care (p. 31). One Social Worker expressed, "there is a lack-of systematic follow-up with families after the death of a child. There needs to be funding and hospital support for bereavement activities" (p. 31). From both the family and clinician perspectives, there is a gap in bereavement services for the family after the death of their child.

### **Pediatric Palliative Care**

Pediatric Palliative Care, as a method for caring for children with life-limiting illnesses, has gained major attention in the literature. The World Health Organization has defined pediatric palliative care as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.(WHO, 2014)

The Initiative for Palliative Care outlined the goals of this type of care in 6 domains, which are support for family units, communication, shared decision making, relief of pain, continuity of care, and bereavement support (Michelson & Steinhorn, 2007). Many of these domains overlap with the areas this literature review has identified as the important areas of care for children with life-limiting illnesses. Palliative care is focused upon improving quality of life, or helping patients live their lives to the fullest (Himmelstein, 2006). In addressing physical, psychosocial, and spiritual concerns of the child, multidisciplinary teams that engage in this work can improve the overall well being of the child and family (Michelson & Steinhorn, 2007). Multidisciplinary teams include doctors, nurses, social workers, chaplains, child life specialists, pharmacists, physical and occupational therapists, and any other clinicians who may be useful in the care of the child and family (p. 213).

Palliative care can be distinguished from respite and hospice types of care because it addresses the needs of patients far beyond those at death (p. 213). This type of care begins at diagnosis or even intake, and continues beyond death by supporting families post-death through bereavement services (p. 213,). One study found that palliative care services helped remedy

inadequate communication, prevented procedural mistakes, and facilitated coordination of care with multilingual and multicultural patients (Contro, Larson, Scofield, & Sourkes, 2002). As a method of caring for children with life-limiting illnesses, pediatric palliative care is becoming the standard type of care offered to these children. As of 2000, the American Academy of Pediatrics recommended that all children living with life-threatening or terminal conditions should have access to quality pediatric palliative care throughout the course of their illness (Pediatrics, 2000).

Social workers, as multidisciplinary team members, are important actors in pediatric palliative care. As a profession involved in the research, development and education in this type of work, social workers have called for a national agenda for the social work research in palliative and end-of-life care (Kramer et al., 2005). They agreed that the research domains social work researchers must be engaged in include; mental health concerns, cultural disparities, gaps in care, communication, quality of care, decision making, pain and symptom management, bereavement, and creating a national curriculum for social workers coming into this type of care (Kramer et al., 2005). The National Association of Social Workers has developed a specific set of standards for these clinicians working in palliative and end-of-life care (Robert et al., 2012). The standards involve: “Ethics and Values, Knowledge, Assessment, Intervention/Treatment Planning, Attitude/Self-Awareness, Empowerment and Advocacy, Documentation, Interdisciplinary Teamwork, Cultural Competence, Continuing Education, Supervision, Leadership, and Training” (NASW, 2004). These standards are proposed guidelines for how these clinicians should interact, document, and engage with this population. These are of course other standards that hospitals and varying agencies utilized in these situations. Social workers must balance the standards of the professional governing body, the NASW and their own hospital and agencies standards. Despite this balance, it is slowly being recognized that social

workers are important actors on these teams and bring a unique perspective to the table and thus, should develop their own professional standards for working in pediatric palliative care teams.

### **Discussion of Literature**

This literature review was an attempt to understand the major themes in the literature about the methods and structures of care for children with life-limiting illnesses. Several areas of care for children and their families resulted from the content analysis of the literature. These areas include: decision-making; communication; pain and symptom management; cultural consideration; spiritual considerations; financial burdens; bereavement services; staff education; and pediatric palliative care. The two areas of care most discussed in the literature were decision making and communication. These areas of care seemingly present the most problems for the people involved in the care of these children, parents and clinicians. In response, hospitals and agencies working with these children have begun to adopt methods of palliative care for this population. As a result, pediatric palliative care is the fastest growing body of literature in this topic area. Palliative care is becoming the standard of care for this population, and as such, requires a body of research to inform clinicians about how to best implement and utilize this care method. The future of research for children with life-limiting illnesses will have a major focus on palliative care for this population.

Furthermore, the results of this content analysis have implications for my future research with this population. The identified areas of care for this population will be further explored in my interviews with family members and clinicians. Decision-making, communication, cultural/spiritual considerations, financial burdens, bereavement services, pain and symptom management, education for staff members, palliative care services and other identified areas of care will all be further explored and understood in this study.

## **Methodology**

### **Objectives**

The purpose of this research was to gain a greater understanding of care for children with life-limiting illnesses through the experiences of family members and clinicians. While research on care for this population has been steadily increasing, there is still very little known about the needs of these children and their families (Barbra Jones, 2006). By using the insider-knowledge of family members and medical clinicians' perceptions, I hoped that this study would reveal common themes about the strengths and areas needed for growth in the care of this vulnerable population. Also, I hoped that the stories and experiences shared would remind future researchers and professionals in this field that the needs of this population are diverse. Life-limiting illnesses do not discriminate; they affect people of all backgrounds and cultures. We must remember that the needs of each individual family or child will change with context. Equipped with the right tools and knowledge, we can hope to support each family in a way that is unique to their needs. This research, I hope, is a step forward in understanding the unique needs of the participants in this study, as well as a contribution to the larger knowledge about care for children with life-limiting illnesses.

### **Research Question**

This study will seek to address the following research questions: What are the current strengths in care for children with life-limiting illnesses? What are the current areas that need improvement in this type of care? What are the experiences of family members with a child with a life-limiting illness? What are the experiences of medical professionals working with this population? How do these experiences overlap?

### **Methods**

Qualitative methodology was a perfect fit for this research project because it allowed the researcher to fully understand the human experiences of the participants (Engel & Schutt, 2013). Human behavior is dynamic and constantly changing, thus cannot be understood entirely through measurements and numbers but rather through the stories and experiences of people (Johnson & Christensen, 2008). This is also true with the experiences of the people involved in the care of children with life-limiting illnesses. Because this methodology is exploratory in nature (Johnson & Christensen, 2008), it allowed the researcher to take the position of an explorer, uncovering the themes and trends from the participants' stories. The themes that emerged from each story led the researcher to make larger conclusions about the overall phenomenon of caring for a child with a life-limiting illness.

Within the scope of qualitative research the researcher narrowed the methodology to the method of Social Science Portraiture. This is a genre of inquiry and representation that seeks to combine the arts and sciences in an effort to capture the complexity and nuances of human experience (Lawrence-Lightfoot & Davis, 1997). In creating an artistic portrait, the researcher seeks to record and interpret the perspectives of the people they are studying by focusing on the context, voice, relationship, and themes of the participants (Lawrence-Lightfoot & Davis, 1997). It is underpinned by a postmodern philosophy, assuming that individual reality is unique and diverse (Robbins, Chatterjee, & Canda, 2011). Additionally, portraiture predicts that common themes of human experience can arise from individual stories and experiences. In developing the narratives, the portraiture searches for the "central story" (Lawrence-Lightfoot & Davis, 1997, p. 12). The purpose of these portraits becomes connecting the experiences of the research participants to the larger understandings of human experience (p. 10). A great portraiture can generate themes from the voice, values, perspectives, beliefs, and background of a few, and

connect their experiences to a larger universal understanding of love, relationship, connectedness, heart-break, suffering, and hardship. Sara Lawrence-Lightfoot (1997), the pioneer of this methodology, believes this connection of the individual's reality to broader human circumstance is an act of intervention:

They are also inevitably acts of intervention. In the process of creating portraits, we enter people's lives, build relationships, engage in discourse, make an imprint...and leave. We engage in acts (implicit and explicit) of social transformation, we create opportunities for dialogue, we pursue the silences, and in the process, we face ethical dilemmas and a great moral responsibility. (p. 11)

Through the story of connectedness, the researcher hoped to encourage social transformation and change. In this research, the portraits are drawn from the experiences of families and clinicians. The themes of each portrait are highlighted and the narrative whole created by the researcher is the platform for the audience to connect to the broader themes of relationship and suffering embedded in these human stories.

A portraitist develops a complete portrait by illuminating four key dimensions; context, voice, relationship, and emergent themes (Lawrence-Lightfoot & Davis, 1997). Context is a thick description of the research setting through the geographical, physical, historical, cultural, and aesthetic characteristics (p. 41). Voice "is the individualistic impression of the researcher on the portrait" (p. 106). Relationship is the co-constructing of relationship and reciprocity between researcher and participant (p. 135). Last, emergent themes are the common trends that surface from the interpretive insight, analytic scrutiny, and aesthetic order drawn by the portraitist (p.185). These themes serve as the point of connection between the participants' stories and the

larger human experience. Each of these four dimensions can be thought of as a piece of a quilt. If we stitch them together, we can create a whole quilt or a whole story.

Inherently portraiture lends itself well to Social Work research because it resists the documentation of failures (Lawrence-Lightfoot & Davis, 1997). The strengths perspective is a Social Work philosophy that encourages Social Work practitioners to use people's strengths as a tool or method for addressing their needs (Robbins et al., 2011). The practitioners that adopt this philosophy search for the strengths in a person's life, rather than the deficits. Similarly, portraiture "begins by searching for what is good and healthy and assumes that the expression of goodness will always be laced with imperfections" (1997, p.9). Moments of weakness and strength are inevitable, especially in the lives of families dealing with life-limiting illnesses. Social Workers and portraitists are less interested in the concrete moments of strength or weakness, but rather seek to understand how families negotiate and survive these two extremes. What are the tools and supports they use and how can those tools help them or others in future moments of discourse or unknowing?

### **Study Design**

In the Social Work discipline it is often thought that local knowledge is the key to understanding the breadth and depth of people's experiences (Shepard, 2015). This knowledge is organic, messy, and reflects the real lived truths of the population Social Workers seek to understand (Shepard, 2015). For the purpose of this study, it was assumed that family members of children with life-limiting illnesses and medical clinicians working with these children hold the local or insider knowledge about their care. These individuals are on the front lines both experiencing and carrying out the methods of care for these children. If we assume that each person is an expert of his or her own life, we can conclude that the expert opinions about the care

for children with life-limiting illnesses lies with the children, family members and medical professionals involved in this type of work. This study hoped to illuminate the voices of these experts to gain a better understanding of the care this population.

As a whole, family members and medical clinicians' perceptions are the unit of analysis that was used to answer the stated research questions. Each participant's experience was identified as a key piece to the overall story. Participants were considered eligible if they were a parent, sibling, grandparent, cousin, aunt, uncle, stepparent or any other family members of a child with a life-limiting illness that received any type of medical or emotional support from a clinical professional. Since this study focused on methods of professional health care, families that did not receive any care from a medical institution were not considered eligible participants. Additionally, participants were eligible if they identified as a nurse, social worker, resident, doctor, physical therapist, psychologist, child-life specialist, or any other medical professional that had a direct role in planning, implementing, supporting, counseling, and coordinating the care of a child with a life-limiting illness.

The participants for this research were recruited through a mixed non-probability sampling method of expert sampling followed by a snowball sampling method. Recruitment started with expert sampling, which is grounded in the belief that the best way to gain a deeper understanding is to elicit views from a person with expertise (Tromchim, 2006). The first parent that was interviewed was identified first by the advisor to this thesis project as an expert. The academic advisor had attended and hosted presentations by this parent on numerous occasions, as well as had read and uses this parent's narrative in her class that focuses upon disability. This led her to conclude that this parent's experience of caring for her daughter with a life-limiting illness would qualify her as an expert, particularly an expert in her own story. Following that interview,

the researcher employed a snowball sampling technique. Snowball sampling is a method in which potential participants are identified through previous participants (Engel & Schutt, 2013). The sample grows over time as the participants continue to identify future participants based on connections and relationships around the research topic (Engel & Schutt, 2013). In this study, the first interviewee identified a professional agency with which her family had had a good experience: "I think you should definitely talk to somebody from Children with Special Health Needs...they do their job really well" ("Participant Interview One for Thesis: Resilience Through Relationship: Understanding Care for Children with Life-Limiting Illnesses," 2014). Following that recommendation the principal investigator reached out to the director of the agency to offer participation in the study for any willing clinicians at the agency. This resulted in an additional interview with two nurses. The final interview was identified again through an expert sampling method. The principal investigator identified a colleague whose brother had passed away from a life-limiting illness as an expert after a presentation given by the colleague in class. The colleague then identified her parents as additional experts and resources for this study. The mix of these two non probability sampling methods, expert and snowball, was a great combination for the purpose of this research because it allowed the researcher to access unique perspectives, insights, and stories in regards to a specific issue (Yedigis & Weinbach, 2009) while also allowing the participants to reflect on their relationship and connection to one another.

While an interview protocol was established, it was developed with the intention to be used only when needed. The protocol, along with the rest of the research methodology, was grounded in a Social Science Portraiture methodology, which seeks to encompass the nuances and complexity of human life (Lawrence-Lightfoot & Davis, 1997). A rigid interview structure is uncommon for research influenced by this philosophy. Interview protocols that allow for many

open-ended questions, additional probing questions, and permit the interviewee to be the dominant voice are better suited for this methodology (H. Anderson, 1997; Lawrence-Lightfoot & Davis, 1997). The importance of the participants' voice cannot be overstated in eliciting their true stories and experiences (H. Anderson, 1997). The principal investigator approached these interviews with an attitude of "unknowing" (H. Anderson, 1997). This unknowing attitude was not a typical unawareness or ignorance, but an intentional stance by the principal investigator to take a back seat in the conversation and let the participant's voice echo the story and define the themes (H. Anderson, 1997). There can be a tendency in social science literature to portray a person's story in a certain way based on the researcher's personal cultural and historical context (Lawrence-Lightfoot & Davis, 1997).

The development of these interview protocols was a deliberate attempt to avoid this type of clouded story. As a result, three individual interview protocols were created for each interview. Protocols were structured in a way that would facilitate the participants telling their complete story from their own perspectives. Furthermore, the researcher provided each participant with the interview protocol beforehand as a potential outline for the discussion. She also mentioned that the real intention of the interviews was to understand the stories of each participant, so setting the protocol aside or "going off-script" was okay and encouraged.

### **Procedures and Data Collection**

Once participants were identified, they were contacted via email or by phone by the principal investigator (PI). Upon agreement of participation by the family members and clinicians, the interviews were scheduled with the principal investigator. Particular attention was given to the location of the interview. The PI made all attempts to conduct the interviews at a place where the interviewees felt most safe. Without the feeling of a safe space, participants

might have encountered some resistance in sharing their stories. As a result of this attention to location, two interviews were conducted in the participants' offices and the final one was conducted at a participant's home. The semi-structured interviews were tape recorded by the PI. Following the interview, the recordings were de-identified and transcribed. Transcription was paid for by an Undergraduate Research Opportunities Program grant. The interviews were conducted by the PI and varied in length. The two interviews with the family members lasted about an hour and a half each and the interview with the two clinicians lasted about forty minutes. As previously mentioned, participants were asked a range of questions from the interview protocol and additional probes that stemmed from ensuing discussions. Each interview had its own unique in protocol, which was tailored to the experience of the participant [See attached Interview Protocol]. The interviewees were given the protocol unique to their interview prior to their scheduled meeting with the PI. The PI offered to omit any questions the participants did not wish to answer. The researcher found that all participants were willing to answer the questions on the interview protocol and more. One family member even asked the researcher to stay and ask more questions: "Are you sure that's it?" (The Family)

The beginning of the interviews started with a review of the research information sheet, which explained there was no foreseeable harm to the participants outside of a breach of confidentiality. Each participant was told that her/his name and information would be left out of the study and any documents containing her/his identity would be destroyed upon completion of the research. From the researcher's perspective, none of the participants seemed concerned with her/his rights to confidentiality. They were happy to share their story. From there, the researcher transitioned into a phase of rapport building. Building rapport is a Social Work skill that is most often thought of as initial relationship building (Counoyer, 2011). This skill is thought to be an

integral component of any working human relationship because it establishes a mutual understanding of the person's background and purpose for the work that the researcher/clinician/social worker can then build upon. Additionally, in research settings rapport building enables researchers to establish trust with the participant in order to ask the more difficult questions (Patton, 1987). Questions about children with life-limiting illnesses are difficult. They require a certain level of trust and emotional security between the researcher and participant, especially when the participant is a direct family member of the child. This rapport-building portion of the interviews included but was not limited to the participants sharing their background, the context of the family, the description of the diagnosis, educational background (in the case of the clinicians), agency background, their position at the agency and more.

During the interviews with the family members, the researcher noticed a tipping point in the building rapport phase in that the family members seemed to feel supported and safe. From there they launched into the telling of their story, from the very first symptom to the hard moments of bereavement after the passing of the child. Each of the family members was articulate and seemingly quite eager to share her/his experiences with the researcher. The researcher encouraged the participants to elaborate on their stories and go deeper throughout this story-telling phase. She finished the interviews by asking the families to give some advice or future recommendations for young professionals who aspire to work with children with life-limiting illnesses. The researcher considered it a privilege to hear the stories of these families. She is thankful that they were willing to share a piece of their narrative with her.

The interview with the clinicians was structured much in the same way as were the interviews with the family members. The interview started with a building rapport phase in which the researcher asked the clinicians to describe their role at the agency, the role of the

agency in the lives of children with life-limiting illnesses, and a description of the of the multiple programs the agency sponsors. From the researcher's perspective, this interview seemed to remain closer to the intended interview protocol. After the researcher exhausted most of the questions from the interview protocol, she asked the clinicians what could be strengthened about the care for children with life-limiting illnesses from their perspective. Both clinicians displayed a deep understanding of the care for this population in Vermont. The researcher is thankful she had an opportunity to speak with these seasoned and passionate clinicians.

### **Data Analysis**

In coding the data, the researcher employed a cross-case analysis (Johnson & Christensen, 2008). In utilizing this method, the researcher coded the interviews individually and collectively, searching for themes within stories and across them. This technique allowed for common themes among participants to emerge while also honoring the differences and complexity in human experiences (Johnson & Christensen, 2008). In addition, this method allowed the researcher to create portraits that were rich in describing the whole and the unique parts of the whole. The following portraits narrate the presenting themes as both a whole experience of caring for a child with a life-limiting illness, and as separate distinct human perspectives.

After the initial write up of each portrait the research completed a phase of member checking. Member checking involves asking each participant if the findings are accurate and representative of her/his lived experience (Creswell, 2002). The researcher was looking for the accuracy of the description, context, themes, and interpretations of the data (Creswell, 2002). Member checking for this research data was completed after each portrait was completed via

email. The researcher took into account feedback from each of the participants and reviewed and edited each portrait accordingly.

## **Portraits**

### **The Clinician**

As I make my way down the hill to historic downtown Burlington, I am thankful I brought my winter boots. It is a cool snowy day, like many Vermont days in the beginning of January and I am thankful to have the warmth and traction from my boots. As my route begins to flatten out, I come upon Cherry Street, a cross street that lies perpendicular to the well-known pedestrian only Church street. On a summer day Church Street is home to many shoppers exploring the local shops, tourists taking in the beautiful brick architecture, and locals having their favorite Vermont craft beer on the patio. Although on a wintry day like today, the summer crowds have disappeared. What remains is a small array of tough looking youth hanging outside the mall entrance and a few people in weathered clothes sitting under the shop overhangs. It is during this time of year that the homeless population in Burlington is strikingly visible.

Cherry Street takes me past Church Street towards the Cherry Street Bus station. This is another place notoriously known to Burlington dwellers as undesirable. People who don't fit within the Burlington construct of normal tend to gravitate here, most because they rely on the bus system, Chittenden County Transportation Authority, to get around. Just beyond the rather dingy and un-kempt bus stop, you can see the regal State Buildings. In contrast to the bus station just on the other side of the road, these buildings are pristine. The first state office building I stumble upon happens to be the building that is home to the Vermont Department of Health and the Children with Special Health Needs. The large brick building is marked with shiny gold letters that read "John J. Zampieri State Office Building."

Inside the calmness continues. The lobby, which cannot really be considered a waiting room because of the lack of benches or places to sit, is empty besides a security guard. The security guard barely flinches upon my arrival; I am guessing besides the professionals working in the building they don't get many visitors. When I get closer to his desk, which seems like miles away on the huge open white tiled floor, he looks up and asks if he can help me find something. I thank him but deny his request and quickly pull out my phone to text the clinician I had scheduled to meet. I keep the phone out a bit longer to ease my discomfort from the silence that fills the vast lobby. To pass the time I walk over to a wall that would be very bland if it were not for several large black and white photographs hanging in a neat row. The pictures are of Vermont immigrants, all from different nationalities and all wearing similar expressions of hardship and sorrow. Just as I begin to move onto the next wall of photographs, Sarah calls to me from a door across from the security desk. She is about my height and looks comfortable in a traditional Vermont style sweater, khakis and Danskos.

She brings me back into the cluster of offices and cubicles that is the Vermont Department of Health Children with Special Health Needs (CSHN). We pass several cubicles on our left and a few shared offices on our right. Space seems like a real constraint. After a short distance we reach her office at the back right-hand corner. She offers me a smile and I enter the room first. She is the "Interim Palliative Care Nurse," filling in for the Palliative Care Coordinator who is out on maternity leave. Her office is cozy with two large desks, one seemingly vacant. A space heater is standing knee height in the middle of the room, blowing hot air towards Sarah's desk. I stop for a moment at the sight of this object and appreciate all it symbolizes: the harshness of Vermont winters that require space heaters even in large

government buildings, and the severe lack of resources CSHN operates on that I would soon come to understand fully. Sara sits down comfortably in her office chair, legs crossed.

Sara motions for me to sit in any of the three office chairs that are neatly arranged in a circle adjacent to her desk. I choose one close to a cabinet, thinking that would be a good resting place for my recorder rather than holding it during the whole interview. Her eyes quickly flash to the recorder and then she stands up from her chair and leaves the room quickly and comes back with another nurse; suddenly I am feeling nervous. The other clinician had a similar casual style but looked a bit older. She walked in slowly and took the empty seat. She carried herself in a way that let me know she was a seasoned nurse. This look of confidence made me a bit nervous. Up to that point I had been feeling confident. I was a young researcher but I had my handy dandy interview protocol and I had already gotten one interview out of the way, so I was thinking that this one would be a piece of cake, until I realized I would be interviewing two professionals. Suddenly I was acutely aware of my age and inexperience, and I couldn't help but think that they were questioning why this twenty-two year old undergraduate student was here asking them questions. I was feeling incompetent. Thankfully, as soon as the conversation started most of this feeling of incompetence washed away. I realized that my original intention was to go in as the "unknowing" person, who wanted to gather their expert knowledge. What did not wash away was my awareness of my inexperience with this population. Both of these nurses had been working at CSHN for fifteen years or longer. They described how "people have been here years." The staff at CSHN are seasoned experts on the care for children with life-limiting illnesses. Although I felt much like the inexperienced young professional, I was thankful to gain a bit of their vast knowledge when it comes to this population.

The initial contact with Children with Special Health Needs was a curious experience for me. I knew for sometime that I wanted to include the experience of a clinician from this agency in my research. The previous interviewee informed me that they were a great agency with expert knowledge about the care for children with life limiting-illnesses. I soon came to find out how true that assertion was. When I began recruiting them for my research, I started with their website, looking for a direct e-mail address of a clinician. I did not have much luck, besides finding a place for general questions. I submitted a request to speak with a clinician about CSHN in the general questions line. My optimism in getting a response back was low because of previous failed experiences in contacting agencies through a general email. To my surprise, this encounter was very different. Two days later I had an email sitting in my inbox from the Interim Palliative Care Nurse. Sara had contacted me on behalf of the Palliative Care Coordinator who was out on maternity leave. How powerful. A woman who is tasked with doing her job and another person's job, responded to an inquiry from an undergraduate student within two days. Her response was more than welcoming to me in terms of coming in to talk with her about the agency. At the time I was not aware that this was the first of many times when the voices of CHSN's clinicians reflected a deeply-rooted commitment to children and families facing special health needs. This sense of commitment to their work can be felt by anyone who is privileged enough to hear the stories of these clinicians.

In our meeting, Sara opened with a brief description of the agency saying broadly, "So Children with Special Health Needs serves kids 0-12, State of Vermont and we've changed a lot in the last couple of years. It used to be ran clinics... and then the last two to three years we've sort of gotten out of that business and we're doing more sort of care coordination." Because this agency is State run, it changes with changing state policy. As a Social Work researcher I was

familiar with the term “care coordination”, but I was curious what that meant and looked like for this agency. Unfortunately, I did not stop her to clarify what this meant until later in the interview. She continued with her description, “So now we are sort of opening up and we’re seeing more kids with diabetes and asthma. I mean we are just sort of helping them.” Again I wanted to probe, but missed the opportunity. She explained, “Now we’re sort of much more Social Work than nurses.” I smiled at this because of how near and dear the Social Work profession is to my heart. Thinking back, it makes sense that more and more Social Workers are being utilized at the agency because of the shift in the agency’s structure towards care coordination. Social Workers are particularly trained in human relationships and improving communication. These aspects are integral pieces to the care coordination for these families.

Even within this new model CSHN is an umbrella agency for the many programs and clinics funded by this agency. Sara looked proud when she explained that agency Social Workers and nurses are in “University Pediatrics, Timberlane, Hagan, Rinehart and Connolly.” These clinicians go all over the state and meet with families through many roles. These roles include; going to care meetings, going to families’ homes, helping families fill out Medicaid paperwork, providing high tech nursing and support, providing palliative care, approving the grant hours and reading the applications for funding, providing developmental screening, giving families education, and resources, running a cleft palate clinic, referring families to the Visiting Nurses Association and fitting children for wheelchairs. This is by no means a comprehensive list of the extent to which these clinicians help families. The clinicians at this agency take on many professional roles including nurses, social workers, “financial technical person, physical therapist, audiologists, nutritionist, developmental pediatrician, neurodevelopment psychologist,

and nurse practitioners.” They are a diverse team that serves the children and families in the state of Vermont in many ways.

Sara hesitated and looked confused when I asked her for the agency’s mission. She asked me in response, “well, like the health department? Or general special health needs?” I could begin to see that these two could not easily be distinguished from each other like I originally thought. I asked for the CSHN mission and the other clinician declared, “Our mission is to make sure every child that has some kind of chronic illness has at least, is at least known to our agency.” Sara added, “and offering support to families to navigate the system and get the best care for kids and that sort of thing. I mean I don’t know that Children with Special Health Needs doesn’t have a mission statement that I’ve ever seen.” That was enough for me, I did not continue to probe.

To reach their goal, CSHN faces many barriers, as most social services agencies do when partnering with vulnerable populations. Sara and her colleague sunk back into their seats a bit while they described to me the typical barriers families with children with life-limiting illnesses would encounter such as poverty, housing, transportation to the hospitals, having nursing shortages for home care, getting people through Medicaid applications, access to care, and more. Sara and the nurse both put an emphasis on these barriers, but to my surprise were most concerned with a different barrier. The nurse said to me, “I think on barrier, what our priority is might not be the family’s priority. I mean they may have a really sick kid but they don’t have any heat, they don’t have a car, they don’t have any money to pay rent, they don’t have any housing. And so what we think needs to be done for the child might not be what the first priority is and I think we run into that not all the time but often enough where kids, the family has so much going on, so much crisis, so many other things that it’s hard to focus on just the child’s needs.” I was

surprised to have never come across this barrier in the review of the literature. It seems to me that this would come up quite often, especially for families in crisis or from different cultural backgrounds. The insight these clinicians had into this type of problem impressed me. They told me that in order to overcome this problem they have to remind themselves of their guiding philosophy of being family centered. They said, “ We pride ourselves in being family centered and so we’re going to meet the family where they want to be met and do what’s best for them and if they say ‘I cannot deal with this right now’, then we say okay fine.” The family will decide when, how much and in what way they will utilize CSHN’s services. Families are making the decisions, while the CSHN clinicians are giving them, to the best of their abilities, the tools and capacities to those family decisions.

As I sling my backpack over my shoulder and zip my coat up to the very top, I have a smile on my face. I am so grateful to have just spent an hour with these dedicated clinicians who despite being “up to their eyeballs” have shared with me the commitment they have to their work with child with special health needs. They both offer me a big smile as I leave. Sara walks me back to the lobby and wishes me luck on my thesis. She looks confident as she stands in the doorway to the CSHN office. The snow is still falling as I rush back to my house to get my recorder attached to my computer. I know their experiences will add to the depth of my research. I am thankful to have the understanding of an agency so dedicated to the families of Vermont caring for children with life-limiting illnesses and special health needs.

### **The Mother**

As I walk up the hill towards the UVM campus, I appreciate the stillness. Vermont snowstorms of this magnitude always seem to generate an eerie stillness that is uncommon in the typically busy Burlington community. There is no one to be seen as I bury my face deeper into

my scarf in order to shield my face further from the falling snow. The storm I am walking through is the first major storm of the year. It is the kind that closes businesses and schools early and sends the plows out till the late hours of the night. This storm in particular left hundreds in rural Vermont without power and for some it took weeks to restore. Because of this relentless storm, it takes me much longer to get to campus than it normally does. My breath is heavy as I pass the last few houses before I reach the top of the hill.

The campus becomes visible to me as I come to the top of College Street. Just hours earlier, this same sight would have been full of students, professors and staff bustling to their classes and offices. The view is now deserted. I continue my journey across the Green towards the Central and Athletic campuses. Although I have had the pleasure of witnessing the sheer beauty of the historical Central Campus academic buildings for the past four years, I still am in awe of their attractiveness. The buildings are mostly brick and stand at the very top of the hill that the city of Burlington sits on. From the top floors of the academic buildings you can see right over the city to Lake Champlain and the high peaks of upstate New York. The snow continues to fall at a steady rate as it coats the buildings and lawns with thick white powder. I make my way further up the hill towards the newest dormitory building that is home to the UVM Honors College.

The Honors College is housed in the University Heights North complex, which is part of a two building complex on the Athletic Campus. With their fresh coat of paint and their modern chic style, they stick out like a sore thumb in contrast to the old brick buildings that make up the rest of the Athletic Campus. These buildings are home to student dorms and some academic classrooms. Additionally, they are home to the UVM Greenhouse, an environmentally sustainable housing option for students, and the UVM Honors College, a college that provides “a

rigorous, multi-disciplinary academic challenge that complements and enriches the entire undergraduate experience” (“The Honors College,” 2015) according to its website. When the University Heights (UHeights) buildings are in sight, my pace becomes faster. I am interested in getting out of this storm as soon as possible. On this part of campus there are a few more people in sight. Several students are briskly walking about, bundled head to toe in snow gear.

I enter the UHeights North building with a sigh of relief. I look down at my watch and realize that I am very early for my scheduled interview with Lauren. I decided to wait a few minutes in the lobby. The lobby is large with high dramatic ceilings and crisp white walls. There are a few students milling around, along with a professor chatting with one student in the back corner. The Resident Assistant of the dorm sits at the glass-encased desk just to my left. When a few minutes pass, my anxiousness takes over and I decide to go to Lauren’s office early. I walk several feet to the entrance of the Honors College office suite. This is where Lauren’s office is, as she is the Interim Dean of the UVM Honors College. Because this is my first interview, my nervousness from the anticipation has begun to set in.

I walk past several offices on my left. Each office has large glass windows facing out into the office suite, allowing outsiders to have a view in. It has become late in the day, so many of the other staff members are no longer here. I can see right through most of the offices and out the windows on the opposite walls. It is dark outside, but I can still see the snowflakes falling steadily. I find Lauren’s office in the back left-hand corner of the suite. I knock lightly and she calls me right in with an inviting smile.

Lauren’s office feels warm and friendly. She is wearing what looks like a comfortable sweater and pants. Her dark stained desk sits grandly in the back left corner. Next to her desk is an enormous bookcase stained the same color as the desk. The bookcase wraps around two walls

and is filled with books. Right away I know she is a reader. Before we sit down together she leaves the room to make some tea. When she returns, she motions for me to sit on the couch, and she takes a comfortable seat in the chair next to the couch. The window behind her head displays a view of the storm. She looks comfortable and confident. I soon find out just how articulate and transparent she is in telling her story. Her insider knowledge left me speechless many times through the interview. It was a privilege to listen to the triumphs and challenges her family faced with her second child of three. I took my recorder out, set it on the coffee table and listened.

She takes a breath and starts with her second pregnancy with her daughter Casey, “So the second pregnancy was a desired pregnancy. It wasn’t like I had any ambivalence about being pregnant but it felt weird.” She was holding her steaming mug of tea that filled the room with inviting aromas. She peers at me through her glasses and continues on with describing the “weirdness” of her second pregnancy. “I just thought it was sort of an anxiety about having a second child, and sort of manifesting itself in an anxiety about a pregnancy, although at the time I was just not somebody, anybody thought of, and I certainly didn’t think of myself as being an anxious person.” I was already impressed with her insight into her experiences. She informed me that the pregnancy was pretty quiet and no one had worried much about Casey’s low measurements because they always seemed to catch back up, so the baby was growing steadily. Eventually, “we went to term, and was a little bit overdue. Casey was born at the end of November. It was a pretty normal birth. She looked normal. She looked fine. She looked a lot like her sister.” She takes a sip of her tea, pauses, and then continues. I didn’t interrupt her as her story was gripping.

Casey was a serene baby. Rarely did she cry or fidget, which most people thought was a blessing. Lauren's voice was picking up speed and I could tell she did not agree with the people in her story who thought that Casey's serenity meant she was healthy. "But she also didn't eat well. She couldn't latch on," Lauren told me. Her voice was steady. They decided to take Casey to the doctor's when she was about a week old on Thanksgiving Day. Lauren said, "the only place we could go was to the main pediatrics office at [the local hospital] and to whoever was on call. And it turned out on Thanksgiving Day the doctor that was on call was the head of the whole pediatrics practice... he's famous." She explained to me that this experience was a key moment in her story that she will never forget. I sat closer to the edge of my seat and hoped my recorder was working properly. She described a power difference between her and the doctor that felt incredible patronizing, "he was like you're just a nervous mom, she's fine. She's just quiet." Lauren knew there was something more to be done than the unhelpful suggestions he offered: "Maybe you could get a syringe and pump and use a syringe to get the milk in her mouth." Lauren had a very different interpretation of her daughter's situation. She began using hand motions and I could tell this was a particularly emotional part of her story. She said, "I was so angry because there's something wrong and you're treating it, me like I'm the one who has something wrong with me. It was like he's not listening to me." I could feel her anger as her hands clenched into fists. Despite being on a very different page than the doctor, and with much reluctance, she and her husband brought Casey home with no better understanding of Casey's health.

Following this first encounter, Lauren described a series of visits to Casey's pediatrician for similar concerns. She chuckled a bit when she explained, "our own pediatrician was great and she was at her wits end with me though." I laughed along with her, but also appreciated the

commitment to her daughter. She was determined to be heard in her concerns for Casey's development. Finally, "she [pediatrician] was like, look, we'll schedule some other appointments for you with a neurologist because Casey had a twitch and she's like but we need to get some help for you because you're so anxious and I wasn't sleeping and I wasn't eating. So she was great." This experience was much different from the first one with the pediatrician. Lauren felt her concerns were heard a little bit and knew Casey's pediatrician was concerned for her well being as well as for Casey's. Lauren said with a much warmer expression on her face, "she was kind and she was great. She didn't patronize me."

Casey was six weeks old when she had her first seizure in her grandmother's arms. Lauren threw her arms up in achievement when she said, "my mom was like okay I totally get it and it was the first time my husband and my mom had seen anything like that." Her voice filled with frustration when she was telling me that she had known there was something wrong long before then. "I knew," she said. She added, "I'd seen versions of it but it never happened when we were at the doctor's office. That's why nobody believed me." I could not imagine the pain and suffering she endured those first six weeks. The experience knowing deep down that something is wrong with your child and not being validated in those concerns, was an experience I could not fathom. Her motherly strength was almost visible in that moment as she sat confidently in her chair.

After six long weeks of knowing something was wrong, Lauren and her husband were told that Casey had Lissencephaly, a disease that affects brain development. In the simplest terms, the brain is smooth and is unable to develop ridges and waves. This impacts all areas of functioning for the child. After inquiring about what the experience of being told what the diagnosis was like, Lauren responded, "it was terrible. The people were so great though." She

further emphasized this point of how incredibly sensitive and empathetic the clinicians were during that time. She told me how their pediatrician was the one who was called into speak with the family first. This resulted in a personal connection that would have been missing with anyone else delivering the diagnosis. Lauren looked directly at me as to make sure I fully understood and said, “She came to the hospital [the pediatrician]. She was pregnant herself and she came in with the resident to give us the diagnosis and they were really sensitive about it. So that was as good as it could be.”

She added that another person that stuck out from the pool of people supporting her family during the diagnosis was the Social Worker on the pediatric floor. Lauren told me, “she was terrific. I don’t know what we would have done if there hadn’t been somebody like Mary there at that moment. Like we needed somebody to tell us that yes it was a nightmare but there were people who would help us. There were all kinds of support services for us, that we were not going to be alone in any of this, all those things that you’re not really taking in but you need to hear that. Like as much as you can’t hear anything else, and were not really taking anything in. Somebody needs to be saying that in the background so you have a sense of okay, I’m about to walk out the door of this hospital with this child who’s going to die soon, but in the meantime it’s going to be hard. There is no good thing besides the people. So when you have someone like that Social Worker, you’re not alone.” She emphasized this point of how important it was that she didn’t feel alone. The clinicians, especially her daughter’s pediatrician and the pediatric Social Worker ensured that she and her family were connected and supported during this time. She took another sip from her tea, which gave me an opportunity to ask another question.

Understanding Lissencephaly was difficult for all involved in Casey’s care. Lauren explained to me, “The doctors did describe the diagnosis as best they could. It was a pretty rare

diagnosis so they didn't really even know." Because of the rare nature of the disease, "the first six months were medically focused in terms of just trying to get information." Lauren looked proud when she said, "we were educating ourselves. I spent a ton of time reading medical literature." Once again I appreciated the fiery passion in her voice. She further solidified this feeling by telling me, "I needed to know every single thing. I'm an academic, so I did my homework. I learned it as best as I could." She told me that her husband had a different mentality during this time. She explains, "My husband was very much of kind of, what can we do about this? I'm just going to take care of her." Her body language remained calm as she described the balance her husband provided in caring for Casey.

Casey's prognosis was not hopeful. She still wore an expression of calmness. Lauren explained to me that because of this terrible prognosis, what they needed for medical care was very different than what most children with life-limiting illnesses need. Her voice did not shake when she said, "there was nothing to be done. Other than control the seizures, there was nothing that he [the neurologist] could do that could make her better." She explained to me that a doctor who was focused on prolonging Casey's life, was not helpful, "it was not the kind of doctor we needed." She had a soft expression when she told me, "What we needed was a great pediatrician, which we had, who could set up the kind of care that we needed for when things came up. We needed a great physical therapist... and then we had our medical Social Worker." I appreciated her insight in that moment. I could hear in her voice just how passionate she and her husband were for caring for Casey. They decided to care for Casey by making the rest of her life comfortable and surrounded by family.

One of the most difficult parts of Casey's story was getting approved for the Medicaid Katie Beckett hours. Lauren explained to me that this Medicaid waiver would "fund things like a

personal care attendant for a child who has a really severe disability and the idea is that it's supposed to kind of provide respite for the parents." The program would give money to Lauren and her husband to pay part of the hourly wage for a personal care attendant. Their medical Social Worker from a state agency helped them fill out this application. Lauren recalled, "I wasn't specific about her needs because she had this horrible diagnosis and I just signed a waiver so that they could pull her medical files and I just wrote down the name of the diagnosis." Her hands clenched as she said angrily, "they denied us." She recounted the long battle she had following that Medicaid decision to fight for this waiver. With a lot of strength and support she had to talk to the Vermont Medicaid worker who makes these decisions and convince him that Casey's needs were far beyond that of a normal four month old child. He told her that they would not be eligible for the funding until Casey was two years old. I am not sure how she managed to tell him, "do you have any idea how that sounds like to someone whose child seizes 50 times a day? And I went on, and [said] anyway, she's not going to live to be two." The strength in her voice was incredible. She sighed and told me their only option was to go through an appeal process and have Casey fully screened. She told me, "it [the screening] was awful. The people were so great, but basically it was like two full days of [learning] all the things Casey cannot do." I let her continue on as I continued to be amazed at the strength she and her husband possessed in order to go through that process. She explained how helpful it was that the clinicians doing the screening were "empathetic and sensitive." After a few more battles with the Medicaid representative and some powerful advocacy from their medical Social Worker, Casey was approved for Medicaid and eventually PCA hours.

Right around Casey's first birthday was a turning point in her development. Lauren had a calm expression on her face when she told me, "Probably the January after her first birthday, she

started getting sick and she'd been pretty healthy to that point. She really started going downhill. She grew enough and her brain just could not keep up, it just didn't grow, and she couldn't keep up with swallowing." Lauren explained to me that they had made the decision before leaving the hospital after the diagnosis how "interventionist" they would be. She took a breath and told me, "we decided not to be." I appreciated her honesty. She explained, "we decided that the quality of her life would not be measured by its length. Prolonging her life would just be prolonging her death." I appreciate how deep she could get into the meaning of her story without me even asking. I had a feeling they must have revisited this decision when Casey's health and development started to decline, but being the strong and passionate family they were, they continued to stick to the decision and make Casey's life as comfortable as possible. Casey never went back to the hospital after her diagnosis.

I was surprised to find out that this decision to be non-interventionist in Casey's care was respected by the medical professionals at the local hospital. Lauren paused, as to let that idea sink into my head and explained, "I think sometimes people are surprised by this and I think knowing what I know now about the medical profession, I am not surprised by it at all in retrospect. We were one hundred percent supported in that decision by the medical establishment." I must have had a surprised look on my face because she nodded with a smile and continued to reiterate this point. "Nobody questioned it. Nobody tried to talk us out of it," she told me. She laughed softly at my amazement. She spoke softly and fluidly. I could still see the snow falling behind her head.

I wanted to ask more questions about the decisions Lauren and her family made about Casey's care, but I hesitated. She was doing such a great in telling me her story without my questions; I doubted I even needed to be asking some of them. Without pausing, she told me,

“the hospice decision was a big one. That was huge. In some ways it felt [bigger] because you don’t call hospice in until you think that the person only has six months left to live.” I could hear the appreciation in her voice for her pediatrician, who was honest. She explained, “it was hard for her to say at that point, look I don’t know, nobody can, but it doesn’t look good and she’s getting weaker... I just don’t see this getting better and I think it’s time.” Lauren and her husband “hemmed and hawed” over this decision for a few weeks. Unlike the intervention decision, which was made within a few minutes, this decision took time. I wondered if having their pediatrician, with whom they had developed a strong relationship, offer this choice, helped them to make the decision about hospice.

Hospice came into their home in late March. This was a very smooth transition for the family. Lauren described how helpful they were with a soft expression, “at that point we had Casey on a suction machine...it was just to get rid of secretions because she had a lot of trouble because of the seizure medication so we had that for awhile but when she needed oxygen and they [hospice nurses] kind of knew and were really good about just sort of, without too much disruption, bringing that into the house and getting us set up with that and normalizing it.” I didn’t have to inquire further about what normalizing meant to Lauren, as she explained, “There was so much through those two months in particular that was so not normal, but hospice managed to normalize it for us. It’s just like how could these people possibly be living through this, but it was bizarrely normal to our lives at that time and I think we owe that almost entirely to the hospice folks.” With the support and grace of dedicated clinicians, this family lived through a tragedy as if it were an everyday encounter. She later described to me that the clinicians normalized this process by sitting with her and her family and really listening to their needs. They offered respite services, they connected her daughter with services for her grief

counseling, and they came to the house long after Casey passed to check in with how the family was doing.

Lauren still looked as comfortable in her chair as she was when we started the interview. By this point in the story we had been sitting together for almost an hour. I could tell she had told her story before. As she neared the end, I sat up a bit straighter. “So Casey died at home. She died in our bed. We were present when she died. I mean I was aware of the moment that she died and it was really peaceful and it was really meaningful,” Lauren told me. She described the meaning and power in that moment she shared with her daughter, husband, family and friends. She continued, “I would say that everybody who was part of that, and there were a lot of people who were a part of that, especially for the last couple of weeks, were totally changed by the experience, for the good. It was really transformative.” Casey’s life and story touched others in a deeply meaningful way. Her life, which was guided by comfort and quality over length, seemed to touch people in a way that cannot be said with words. She brought out love, passion, commitment, resilience, and strength in her family, friends, and clinicians working with her. I took a moment to pause and let all that all soak in.

Lauren caught me off guard when she inquired about any questions on my interview protocol she had missed. She told me she had appreciated having the protocol beforehand in order to decide what parts of her story were relevant to my research and which ones were not. I smiled at this and thought, there is no part of her story that would not be relevant to my research, I didn’t tell her this, though, and quickly looked for a question on my protocol we had not discussed. There was one, spiritual needs. “Were your spiritual needs met?” I asked her. Yet again she had a very deep understanding of her needs in this capacity during her daughter’s care. She told me, “I mean that’s a whole other part of the story is how you take care of yourself

during something like that if you're a parent and so yea, that's complicated. Yes, my spiritual needs was met and the short answer to that question is yes." She went on to describe that her spiritual needs included two dimensions for her: her religion and her profession. Both were equally as meaningful to her and both were something she held on to for support while caring for Casey. She took a breath and I looked down at my recorder once more to make sure it was still working. I wanted to tell her in that moment how much I appreciated her knowledge and recognition of the needs outside of just the child's needs. There is so much more to the needs of these families than just the direct medical needs of the child with the condition. Perhaps when you live these experiences this becomes more evident to you. However, I think this is something clinicians going into this work can pay more attention to. It sounds like Lauren and her family received this family-centered care, and I am hoping more families will as well.

Our interview wrapped up with a bit of discussion about where to get more insider knowledge. Her face had a soft and hopeful expression on it as she offered me several great suggestions for other potential participants and one even came to fruition. It had gotten dark by now and the window behind her head looked as though a black cloth had been draped over it. I took a few moments to gather my things into my backpack that was still sitting on the floor next to me. Lauren was still holding her mug of tea. Our interview had gone much longer than I had expected, but that was mostly because of the amazing articulation and meaning she offered me. I am so thankful she told me her story of reliance and passion. I know that her family's experiences, even beyond this research, will touch and inform all who hear it.

### **The Family**

I had begun my journey to the Wagner family home in my old but sturdy Toyota Corolla. It was one of those bitterly cold Vermont nights that penetrates your bones and leaves you cold

from inside to out for hours. The heat from my car did not seem to be helping. Nights like those leave me wondering why anyone lives in this state. I had set out at about 5:45 pm in hopes of a 6:00 pm arrival time at the Wagner home. My phone navigation system brought me down VT Route 7 towards South Burlington. Route 7 runs the length of Vermont from North to South, connecting towns from Bennington in the southwest corner of the state to towns like Swanton in the northwest corner of the state. I knew I was close to the Burlington/South Burlington line when I began to pass the several grocery stores and commercial shopping areas on either side of the road. Because of Burlington City ordinances aimed at keeping local businesses in the downtown area of Burlington, the commercial stores have to set up shop on the outskirts of town. I crossed into South Burlington and continued my journey down Route 7. The sun set well before my departure, leaving the roads dark and deserted. It took me a few tries to find the correct turn. When I finally did, I was relieved to be that much closer to warmth.

My navigation system took me up the hill towards a townhouse complex. At the top of the hill, the directions stop, yet their home is nowhere in sight. I did a few loops before I felt defeated and call my classmate, Kelly, who is also one of my participants, for help. She directed me around a bend of townhouses and down to the cul-de-sac where their home is located. The wind and cold didn't seem to faze her while she was waiting for me at the door. When I arrived she eagerly waved and directed me where to park. She looked comfortable in jeans and a sweater. The townhomes were quaint and looked homey from the outside. Several units formed a half circle along the road. I later found out that the Wagner family lived in a ranch-style home in Richmond, Vermont prior to moving to this new location. Kelly informed me that she still very much considers Richmond her home. The ranch home was also where her brother was raised and battled a benign brain tumor at first, and then eventually Glioblastoma. I parked my car and

made my way over a snow bank to the front door. A loving golden retriever greeted me at the door as I walked in.

Their home felt welcoming and comfortable. I walked through the kitchen to the living room area and set down my backpack. I was glad to see a fire in the fireplace already going. The room was filled with pictures of Kelly and her brother in their soccer uniforms and school pictures. In each picture I could see their bright happy smiles. From the sheer number of framed photos throughout the house, I could tell these were parents who were proud of their children. Her dad, Mr. Wagner, was sitting comfortably in a chair facing the fireplace. I could tell from his smile peeking out from under his mustache, that he was glad to see me. I noticed a stack of papers next to him that I later found out were additional resources he had printed out for me about his son's story. Mrs. Wagner was upstairs when I entered. She came rushing down the stairs as soon as she heard me and had a large smile on her face. She looked a lot like Kelly with her blonde hair and petite frame. The energy she gave off helped me wake up a bit from my cold drive over. Kelly offered me a seat wherever I felt comfortable. I chose a white rocking chair that was off to the side of the room. I moved it in front of the large coffee table in the middle of the room. I knew right away that the coffee table would be a good spot for my recorder. I pulled out all my materials, recorder, info sheet, and interview protocol. The family members each took a place on the couch, so we were all formed in a circle.

After a few minutes of getting to know each other and taking care of the procedural tasks, I felt confident. I was careful this time not to start the interview rambling on about my research. I was there for their story. I offered, "If you guys want to just start giving me a little background, pretend that I don't know anything about your family, about the diagnosis." Mrs. Wagner starts with a definitive, "Yes, I can start." From the very beginning I could tell that this wasn't her first

time telling her son Jason's story. She sat up a bit straighter and launched into the telling me about the first symptoms her son had in 6<sup>th</sup> grade. Jason was eleven at the time he started experiencing his first symptoms. He "started getting head aches and it was so weird because they weren't bad headaches, like I'm going to be sick and throw up headaches. It was like, I don't feel good, can I have a Tylenol? Then he'd lay down for awhile then he'd go play." She had a puzzled look on her face as she described how these symptoms went on for "a couple of months." She described how she started marking on a calendar when he had headaches, to try and make sense of these "weird" symptoms. When she noticed that the headaches seemed to be more frequent and got to the point that he was having them every day, she made the call to bring him to the doctor's office.

Unfortunately, nothing came of the first time they took Jason to the doctor. She told me, "basically, no diagnosis." The headaches and the doctor's office visits continued for a few more months. She had a defeated look on her face and described one instance during this time that the school nurse called her and said, "Jason's here and he's sick...he's really sick." This time around the doctors seemed to be more receptive; they wanted to test his eyesight and test for strep. He tested positive for strep, but in hindsight Mrs. Wagner knew that this was just a symptom of the brain tumor they found later. "See the problem with a brain tumor is the symptoms are similar to hundreds of other things so I said, okay it's strep throat." I could hear the disappointment in her voice and wanted to remind her of the patience and strength she had during those first few months, but I bite my lip and let her continue her story. She used her hands to talk. They seemed to be moving as fast as her voice. The headaches Jason was experiencing continued, even after being treated for strep throat.

The youth hunting trip seemed to stick out in her mind. “I forgot about that [trip],” Mr. Wagner says. He looked clam and relaxed as he listened to his wife speak. I could tell he was recalling many memories from that time. Mrs. Wagner paused for a second and then continued, “Jason loved hanging out with my brother-in-law. He would never have said I want to go home unless he was really sick, so I said this isn’t [good]. But then Monday, he got up and said, ‘I want to go to school. Okay.’” She brought him to school, and shortly thereafter received a call from the school nurse. Jason was sick again and not flu sick, “he looked sick sick. He was the color of this paper.” She explained how from there she called the pediatric office and said, “I’m not leaving until you figure this out.” She paused for a second and smiled. She looked at me like I should be shocked, but I wasn’t. I could hear in her voice that at this point she was going to stop at nothing to figure out what was wrong with her son.

So she brought him over to the pediatric wing of the local hospital and said, “I’m just going to sit here. I’m not leaving until you get him over to get his eyes checked. I know my son, he’s sick....he was lying there looking lethargic.” Her ability to have strength in that moment speaks to who she is as a person and family member. Upon arriving at their house I sensed they were a very close-knit family, but this confirmed that suspicion. This family bond is no doubt a strength that is reflected throughout their entire story. Her strength continued when several doctors examined Jason that day, including an ophthalmologist. The ophthalmologist approached her with a seemingly cautious approach, but she had already prepared for the worst, “like I already knew it was bad. Just a gut.” “You can just tell me,” she said to the eye doctor. This is when they were told, “Jason’s optic nerve is swollen which means he does have a brain tumor. We could tell without even looking, doing a CAT scan.” I could see the frustration in her body language begin to build as she recounted this part of the story. It was soon relaxed when she told

me what Jason said to her leaving the hospital, “I said you’ve got a brain tumor. He goes, phewzzzz, good, because I thought I was a hypochondriac. Now I know something’s wrong with me.” Kelly and I chuckled at the irony of this statement.

Following the diagnosis Jason went through a series of tests and procedures to understand fully what was going on. An MRI confirmed that he also had fluid in his brain, so the medical team implanted a shunt to drain the fluid, “and once they did that, he felt a lot better.” A look of relief washed over her. Kelly was still sitting calmly to my left, watching her mother recount their story. Mrs. Wagner explained that the doctors also did a biopsy of the tumor and determined it was benign. They told the Wagner family to “go home and celebrate.” Kelly chimed in, “I remember that.” She sat up a bit taller. I was reminded of the hesitation she had when I first invited her to be a participant in my research. She wasn’t sure how much she remembered, but I think she remembered more than she led on. Kelly looked back at Mrs. Wagner. She continued and told me that the family did exactly what they recommended; they went home and celebrated.

Their first major decision came a few months after the diagnosis. The doctors wanted to be on the “safe side,” so they recommended the family take Jason to Boston for treatment. The treatment they were offering was 3D proton radiation to reduce the size of the tumor. This was not a cut and dry decision for the family. It required moving the entire family down to Boston because “we [parents] didn’t want to leave Kelly home with us three leaving. I didn’t want to leave her out of it.” This was yet another sign of just how close their family was and still is. Mr. and Mrs. Wagner looked proudly at Kelly. Before they moved Mrs. Wagner wondered, “what if we don’t do anything? He’s doing great. Let’s leave him alone. Because they gave us the choice, do you want to do that or leave it be?” But after much consideration, they went. I noticed she

didn't seem to identify any clinicians who helped them make this decision; rather, it was a family decision. Mr. Wagner added later that he didn't remember, "having somebody come up and put their arm on my shoulder." He seemed to like the idea of having a Social Worker help the family make a decision together. Mrs. Wagner continued, "we went [to Boston] for six weeks. When I look back that was, I wish Jason was here, but god we had a good time because we really got to spend quality time." Mr. Wagner told me that the family doesn't regret that decision for a second. He said confidently, "My dad looked at me one day and said, you know it's the right decision because that's the decision you made. So it's helped me in knowing that, I don't ever look at myself in the mirror and say, god I wish was had done something different." This family decision strengthened and bonded them even closer together.

Life seemed to transition back to normal for the family when they returned to Richmond. Jason went back to school in September to start 7<sup>th</sup> grade. About a week in, he asked his mother for help with his homework because he could not see it. Mrs. Wagner grinned as she told me how he immediately took his request back and said he felt fine. Mothers can always see through their children's lies. Her smile faded as she told me, "he begged me not to take him back to the hospital. He didn't want to go back and I believe it's because he knew he was getting really sick." When she took him back, the medical team thought the problem could be fixed with a simple procedure to drain the shunt. They did the surgery and he came out of that surgery seemingly all right, but "within 10 minutes he started freaking out. Having seizures. Screaming. Crying." She pauses for a second but I let the silence continue until she starts again, "and then he had this wicked seizure. They went and did an MRI or CAT scan... the first tumor he had was called a Pilocytic Astrocytoma stage one, like people live their whole life never knowing that even had a brain tumor to a Glioblastoma stage 4, pretty much no survival rate when you get

that.” Following that diagnosis, Jason was in the hospital for another three weeks. Mrs. Wagner told me, “it just happened like that. Everything went downhill. I mean he never went back to school. He lost part of his sight and he couldn’t think clearly. I don’t really remember how he lost motor skills and I guess it was from the couple of seizures that he had. Then we ended up the going to [a rehab facility] ... and basically prepared us to take him home to pass away.”

Mrs. Wagner explained, while Mr. Wagner nodded in agreement that one of the hardest parts of that time was making sure they were caring for Kelly as well. “the hardest part was Kelly and making sure we were with her and that she understood... the hardest part was knowing that she wasn’t going to have him, it was hard.” Although I could hear the pain in her voice as she reflected on this time, I could also hear the pride in her voice. She and her husband were proud, as they should be, that they paid close attention to Kelly throughout this whole process. All too often the sibling’s voice gets lost in the chaos and emotions of caring for a child with a life-limiting illness. This family ensured that the needs of the sister were also met. I was not surprised to hear the sibling program that arose from this family’s experience. Mr. Wagner sat up and told me about the sib shops program at the local hospital that was started right around the time when Jason was there. The program gives attention to the siblings’ needs. He described, “I think we emphasized how important siblings are, it’s not just about the child [it’s about how to] hold the family together.” He looked very proud and gave me a big smile.

“Probably the toughest decision was when we were leaving the hospital, I didn’t want to give up,” Mr. Wagner told me. I appreciated his honesty. Kelly looked at him and seemed surprised. She asked, “you wanted to go somewhere else?” Mr. Wagner said boldly, “oh, I was going to pack him up and go wherever the hell I thought I could go, it didn’t matter to me where. I was going. Tahiti or where. It wasn’t money, it wasn’t time, I was just going to go.” I could

only imagine how difficult it must have been in that moment to decide what to do next when he realized that his son might not get better. It wasn't until he had a conversation with his sister and mother, who each had separate consultations with the doctor, that he finally realized what he needed to do. He realized that it was time to take his son home to be with family and friends for the time he had left. From beginning to end the Wagner family seemed to lean on each other frequently. Looking back, I am wondering how clinicians might transfer this power of the family to children and families who are not as well connected. How can we help families become as connected as this one?

Jason came home to pass. When he did, family, friends and community members were eager to help. Mrs. Wagner was happy to tell me about the support they received from their community members and friends. She said cheerfully, "Our neighbors all built a ramp for when he came home." She added later in the discussion, "when we brought Jason home, we never shut anybody out and that's just the way we are." They had both doors in their ranch house constantly open for neighbors, friends, hospice workers, social workers, and more. Mrs. Wagner took special pride in telling me how great Mr. Wagner was during this time of Jason's story. "I tell you, that guy right there [points to husband], I did the other stuff but what he did, everything else, the wheelchair stuff, and he built a ramp." Mr. Wagner smiled, but still looked as though he was deep in thought. I was happy to hear that each family member seemed to play a role in Jason's care. This family's bond was so tight that their differences in roles did not seem to test their commitment to each other. Mrs. Wagner's voice slowed as she finished her story with, "his brain, the tumor turned nine times the size it was within two weeks so that's why he died. It was too big for his skull but it pushed on the part of his head that just makes you go to sleep." I was surprised not to hear sorrow in her voice. She then explained, "he really wasn't in pain most of

the time. So they say when you have a brain tumor, it's the best cancer, I hate to say this, for your child to have." This seemed to have comforted her, knowing her child wasn't in pain when he died. Jason passed in his home on Thanksgiving Day surrounded by his loving family and friends.

I stayed in the home a few minutes after the official recording and interview had ended. I felt so close to this family and I can tell they enjoyed re-telling their story and having me there. We reminisced over pictures of Jason and Kelly in their youth, while Mr. Wagner asked me more questions about my research. After many more moments of petting their loveable golden retriever and chatting, I left accompanied by several thank you's. I am not sure that they understood how much I appreciated them sharing their story with me. As I was pulling out from their townhouse complex I thought a lot about Jason's legacy, including the foundation his family started to help children in similar situations, the road race held every year on Thanksgiving in his honor and the memories and stories his family and friends hold. This family let me into their story and Jason's story without hesitation. I am proud to be able to share it with others and I am forever grateful to this family. I have no doubt that there is something to learn from them.

## **Analysis**

### **Human Capacity**

These portraits remind us of just how capable people can be when faced with immense challenges. Each of these portraits demonstrated an uncanny level of human capability including an immeasurable level of strength, courage, resilience, knowledge, perseverance, commitment and passion. The participants were all able to make decisions, communicate with others, learn about the disease, advocate for their needs, and access the care they needed. They did this all

while facing the weight of caring for a child with a life-limiting illness. One would think the emotional weight of this task alone would break someone, but not these individuals. The families and clinicians in these portraits tell a collective story. This story is one of innate human capacity that if coupled with the right supports, can be strong enough to face the devastating challenges of caring for a child with a life-limiting illness.

### **Mothers “Gut” Feeling**

The first capability that was strikingly obvious in both portraits of family members was a mothers “gut” feeling. This was the ability of each mother to know something was wrong with her child long before there was any official diagnosis. “I knew it was bad. Just a gut,” Mrs. Wagner told me. For both mothers this feeling started as a concern only they could understand. It took each of them many attempts to get a medical professional to listen to them. Lauren shared with me, “it just doesn’t feel right.” When Lauren brought Casey into the local pediatrics clinics, the head of the pediatric department sent her home without listening to her concerns. Lauren recalled that experience of not being heard as being one of the most difficult throughout Casey’s care. She said, “I was so angry because it was like there is something wrong, there’s something wrong and you’re treating me like I am the one who has something wrong with me.” Both Lauren and Mrs. Wagner showed an incredible amount of strength during this time of knowing, despite so few people sharing their concerns for their children. They were alone in their feelings, yet both were able to ask for help repeatedly, as well as to advocate strongly for their children. Mrs. Wagner was proud to tell me, “I brought him, and I said I’m not leaving until you figure this out.” That was the day when Jason was diagnosed with a brain tumor and Mrs. Wagner wasn’t shocked, “It’s just my gut. Like I wasn’t shocked when they told me.” A mother’s intuition is a powerful thing, especially when it comes to the health and wellbeing of her

children. These mothers' "gut" feelings demonstrate just how capable and accurate family members can be when it comes to understanding their children. By appreciating their capacity early and often, clinicians can build a connection with these families long before the child is diagnosed.

### **Decisions About Life**

Across all three portraits, the theme of decision-making is ever present. The families and clinicians offered important insight into the difficult nature of the decisions they encountered. Decision making is an important piece in the care of any family with a child with a life-limiting illness (Doorenbos et al., 2012) (Barbara Jones & Weisenfluh, 2003) (Michelson et al., 2006). These portraits showed that most of the decisions about intervention, types of care, when to call in hospice and more, all stemmed from a much larger decision the families made. This umbrella decision was how the family would define life. This looked different for each family, which reminds us just how unique these decisions are to the context of the family, their background, culture, history, connection to the community and more.

Lauren and her family decided before bringing Casey home after the diagnosis, "the quality of her life would not be measured by the length... So that was the decision we made and we never changed our minds." Casey's disease had too hard of a grip on her brain development for there to be any hope of her developing cognition, even with fierce interventions. Lauren and her husband decided that Casey's life would have meaning through the quality, comfort and connections she would have with her friends and family.

The Wagner family made a much different decision that made sense for their family. Jason was eleven years old when he was diagnosed with a brain tumor. Having a powerful bond this family was prepared to do whatever was necessary to ensure they did not lose a member of

that family. This decision was made long before Jason came home to pass, but Mr. Wagner explained how he revisited that decision, “I didn’t want to give up. I was going to go wherever I had to go. I didn’t care. Tahiti or where.” The Wagner family made the decision to try everything to keep Jason with them and in the end they never regretted that decision for a second. “It was the right decision because we made it,” Mrs. Wagner told me.

The difference in decisions made by these two families is important to highlight. It reminds clinicians that these decisions about life need to originate from the family. With the variability in culture, background, beliefs and values, a decision about quality of life and the meaning of life can only come from the families. A decision from the family ensures that it is a decision they can live with (Barbara Jones & Weisenfluh, 2003). If we believe in the families’ capacity to make these decisions, we can help them access care that is most suitable for them.

### **Resilience**

According to Webster’s Dictionary resilience is “the ability to become strong, healthy, or successful again after something bad happens” (Merriam-Webster, 2015). This is a human capacity that enables people to overcome hardships and challenges. The Parent and Family portraits in this study reflect an incredible amount of resilience. These families, with support systems in place, were able to overcome the loss of a child. The weight of this experience is unimaginable and each family seemed to handle it with grace and strength. In beating the challenges and barriers they face, these family members came to realize the sheer capacity for resilience and strength they are capable of. They derived a great deal of meaning from their experiences and their self-understanding of their capacity has been a present force in each of their lives since caring for their child.

The families, however, were not the only ones who showed resilience in caring for these children. In addition, the clinicians, especially the ones at Children with Special Health needs, showed a great deal of resilience in their work with these children. These clinicians and others have a very hard job. Many experience suffering and despair when they run into barriers of caring for this population (Contro et al., 2004). Additionally, the clinicians at CSHN are “up to their eyeballs” in work, and yet they are able to overcome these barriers and provide quality care for children around the state of Vermont. It is because of the support they provide that they see families with a child or sometimes two children with special health needs thriving and continuing to fight against the odds. One clinician explained, “Personally, I just don’t know how families do it. These families are the best. Many people say they could do something better but they’re doing the best they can and these kids are surviving and it’s just amazing.” This anecdote shows the reciprocal nature of resilience. The support and strength of the clinicians helps the families survive, while the survival and resilience of the families helps the clinicians to continue their work supporting them. The importance of fostering this reciprocal resilience in the care for children with life-limiting illnesses cannot be overstated. At all costs we must believe in families and clinicians’ ability to be strong and resilient. They are capable of carrying and overcoming the weight of caring for these children.

### **Building Relationships**

In addition to the sheer human capacity that is evident in these portraits, they also tell a story of human relationship. The experiences of these family members and clinicians prove that healthy relationships are vital to the care of children with life-limiting illnesses. Humans are naturally social beings and therefore seek relationship and belonging to others. These human relationships foster connectedness. They remind people that they are not alone in their struggles

and hardship. When we, as humans experience, disconnectedness, our own capacity for strength and life is reduced and thus many experiences of capacity in these portraits are a direct result of feeling connected and supported by others. Support can come from various actors involved in the care of this population, including other family members, clinicians, agencies, support groups, friends, and more. Strong relationships between these actors benefit all involved. These relationships facilitate good communication, meaningful decision-making, alleviate some cultural barriers, and overall improve quality of care. Building relationships is crucial in the care of children with life-limiting illnesses.

### **Agency Relationships**

There are many types of relationships that could be classified as important for this type of care including, parent to parent, child to parent, family to clinicians, clinicians to each other, and so forth. One relationship that proved to be strong in the clinicians portrait was agency relationships. Children with Special Health Needs is an agency that works in the background for these families. Although they are not on the front lines, they do just as much work as the nurses and doctors providing the direct care. This effort includes the relationship they build with other agencies. As Sara stated, “We have a really good working relationship with the different agencies.” This helps them keep track of children who are transitioning from hospital to home or visa versa. “The VNA’s and home health agencies are very good about letting us know” (Sara). Families might not be acutely aware of CSHN relationship with other agencies, but this relationship no doubt helps improve their quality of care. Because of this connection, CSHN can track each family and child’s progress, when they become eligible for additional services or benefits. From there, they can alert the direct care team in order to get those families additional services. This relationship also frees up some of their already busy schedules. If they do not have

to check in with every family individual but rather can get updates from the agencies working directly with the families, they can keep track of more people and hopefully reach their goal of making sure every child that has some kind of chronic illness is known to their agency. CSHN is a dedicated agency. One of the ways they continue that dedication is through the strong relationships they build. These relationships build upon the capacity of families and other agencies to improve the lives of families and children with life-limiting illnesses.

### **Being Heard**

Listening and being heard is a pillar to any good relationship. For the parents and families caring for children with life-limiting illnesses, being heard is important to building relationships with clinicians. Parents and families' opinions and beliefs need to be heard and validated. All three portraits demonstrate the importance of listening, however Lauren's story in particular highlights this idea explicitly. The hospice team working with her family and Casey's pediatrician created a relationship through listening to her family's wishes. By listening to her, they made her feel supported and empowered. She explained, "They ask you how you're doing. They sit with you." Not only were these clinicians a listening ear, but they also actively listened to the wishes of the family. She explained, "they took our cues the whole way." There is no better way to have this care be family centered, or family directed, than to listen and act on the wishes of the family. Lauren, being the insightful woman she is, recognized the importance of listening and further emphasized, "you have to listen, like it goes back to just listen. What does the family need to survive this? If the parents need to work, then let them... just suspend your own sense of what's right and what's wrong and listen to what the family needs."

Lauren raises an interesting barrier to building relationships, which are personal judgments of clinicians. Clinicians in this field will no doubt have certain beliefs and

recommendations for families. We all bring our own personal biases and histories to the work we do, but in order to build a relationship in which families feel heard and empowered, the decision must come from the family. Clinicians in this field must be willing to fully hear families, even families who voice or decide something the clinicians might not agree with. Active listening is an essential part of any relationship; for the relationships surrounding the care for children with life-limiting illnesses, actively listening is even more important.

Moving forward it would be my recommendation to future researchers and medical professionals in this field to focus on these two themes of human capacity and building relationships. These themes are much more general ideas than the methods of care identified in the literature review. They tell a broader story of the resilience, strength and willpower people caring for these children are capable of. If we focus on these broader understandings of improving capacity and building healthy relationships, the concrete methods of care like decision-making, open communication, spiritual considerations and cultural considerations, will all follow suit. If we can focus on the larger picture of human connectedness to care for this vulnerable population, the day-to-day quality of care will improve naturally. This is by no means a limit to the improvements that need to be made, but rather a recommendation to accompany countless other suggestions made by other researchers in this field.

### **Implications for Future Research**

Moving forward, researchers in this area will want to be concerned with understanding the needs of this population further. Much of the research about this population including this research project is exploratory. It seeks to understand the needs and barriers of this population. Going forward, researchers in this field might want to be concerned with how to best address these identified needs. This research offers some suggestions including the fostering of human

capacity and building relationships. However, the methods and structure of care for this population can be further strengthened with the insider knowledge from the actors involved. Clinicians in this field need to be further guided in how they can better facilitate communication, decision-making, alleviate financial burdens, meet cultural and spiritual needs, and utilize palliative care method for these children and families. Addressing the needs of these families is important for the overall wellbeing and quality of care they receive, thus future research should further focus on these needs.

Although the national research spotlight has “flashed” on this population, this attention needs to remain. These families are some of the most vulnerable in our society and should be supported at all costs. The research spotlight needs to remain on this population in order to further understand the total breadth of needs and challenges they face. I would hope this attention could help the research surrounding this topic to continue growing.

### **Limitations**

The most significant limitation of this research was the small sample size. Although each participant provided the researcher with rich description of her/his experiences, additional participants and stories would have added to the ability of the researcher to generalize the findings further. A larger number of interviews would have increased the representativeness of the findings in that other important actors involved in the care for children with life-limiting illnesses would have been represented. These other actors might include: grandparents, aunts and uncles, siblings, social workers, doctors, psychologists, child life specialists, residents, and more. Getting the wide range of knowledge from these actors would be important for understanding the total picture of care for children with life-limiting illnesses. Additional interviews would have also diversified the participant population further. It is well agreed upon that context, culture and

background influences people's experience with this type of care. The participants in this study were all white females, with the exception of the father of the Wagner family who was a white male. Additional interviews might have provided more of a rich cultural take on caring for these children. With the time and space that was provided to the researcher, additional interviews were not feasible. The constraints of undergraduate research are hindering to the undergraduate student who balances school, internships, part-time work and being a researcher. Undergraduate research of this nature is bound by the time and space constraints these students face. Strengthening their research projects would mean supporting and further fostering their capacity to overcome the challenges of conducting undergraduate research.

### **Conclusion**

Caring for a child with a life-limiting illness is a road filled with obstacles and emotional weight. While researchers and clinicians in this field are slowly beginning to understand how to best navigate that road, we must continue to seek the insider knowledge of clinicians and families alike. There is much to learn from the anecdotes and perceptions of these individuals, families, and agencies. This study shows how the rich words of a few can connect to the larger understanding of care for these children. Human capacity and building relationships are no doubt important themes in this type of care. They help families feel supported and empowered. Clinicians and agencies must do all they can to further emphasize these themes in their work with this population. However, this is not to say that this study encompasses the entire scope of needs and challenges among this population. All efforts must be taken to add to these ideas and build upon them. To come back to the initial intention of this study, it is hoped that the portraits of the participants in this study will serve as a reminder to other researchers in this field to listen

to the voices of these families. They hold the true knowledge. Additionally, it is hoped that this study can be a call to action for other families and clinicians who are caring for a child with a life-limiting illness to come forward and tell their stories. The only way we can improve this type of care is with the expert knowledge they hold. Their needs and voices are important. They will be heard.

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## **Interview Protocol**

### **Introductions**

- (1) Info Sheet
- (2) Confidentiality
- (3) Tape Recorder
- (4) Introductions

### **The Clinicians Potential Questions (with additional probes)**

- Tell me a little about the role of VT Department of children with Special Health Needs.
- Who can benefit from these services?
- What is the agencies mission? Have you found this mission aligns with the goals of the families you are working with?
- At what point does the agency intervene? At what point do they no longer work with a family, if ever?
- What are some barriers the agency faces when working with these children?
- How does having an interdisciplinary team of multiple disciplines help in your care of these children and families?
- What is your role in the agency?
- What sort of training did you have to work with children with special health needs?
- What are some ways in which you help families with decision-making? With communication? Or with financial burdens?
- Is there an area of care you believe can be strengthened for this population?
- What is the strongest area of care you think you and your agency can offer?
- Do you face any barrier when working with these children? If so what? And how does that impact you?

### **The Mother Potential Questions (with additional probes)**

- Background- Family, daughter, diagnosis?

- You mentioned in the article, “A mother bears witness” that you felt something was wrong before your daughter even had a diagnosis, what was that like? How did you know?
- What was the experience of being told about the diagnoses like? Who were your supports? What could have been improved upon?
- How was the communication between you and the medical staff at this first encounter of diagnosis?
- You mentions in an article “ we had some really tough decisions” what kinds of decision came shortly after diagnosis? Who made those decisions?
- When your family made decisions, did you feel confident in those decision? Were you given enough education to feel comfortable in those decisions? Did you feel supported?
- What kinds of care did your daughter receive? Palliative? SW? What were those relationships like? Why/in what ways were they supportive/not supportive?
- What was your relationship with your social worker like? Why do you think she was able to make you feel so supported?
- Did you feel like the staff was competent and confident?
- Were your spiritual needs met?
- What were maybe some defining moments you can remember about your daughter’s care? Why were they so meaningful?
- What did the end-of-life process look like? What supports were you given here? Did you feel unsupported during this time? Why?
- Looking back through all the care your family received during your daughters life, what is the one moment or one thing that made you feel most supported? And what is the one area you think could have been improved upon?
- If you could give social workers or medical clinicians any advice for their future work what would that be?
- Tell me a little about your book.

### **The Family Potential Questions (with additional probes)**

- Background- Family, diagnosis?
- What was the experience of being told about the diagnoses? Who were your supports? What could have been improved upon?
- What were the reactions of your family like? How did your other family members handle it?
- How was the communication between you/your family and the medical staff at this first encounter of diagnosis?
- What kinds of decision came shortly after diagnosis? Who made those decisions?
- When your family made decisions, did you feel confident in those decision? Were you given enough education to feel comfortable in those decisions? Did you feel supported?
- What kinds of care did your brother receive? Palliative? SW? What were those relationships like? Why/in what ways were they supportive/not supportive?
- Did your family have a social workers? What was that relationship like? How did they support you and your family or not support you?
- Did you feel like the staff was competent and confident?
- Were your spiritual needs met?

- What were maybe some defining moments you can remember about your brother's care? Why were they so meaningful?
- What did the end-of-life process look like? What supports were you given here? Did you feel unsupported during this time? Why?
- Looking back through all the care your family received what is the one moment or one thing that made you feel most supported? And what is the one area you think could have been improved upon?
- Have there been any people that have supported you after your brother has passed? Who are those people and how do they support you now?