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PEDIATRIC HOSPICE CARE: A LITERATURE REVIEW OF HOSPICE CARE, ITS
ROLE IN PEDIATRICS AND RESOURCES IN MAINE

By

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ABSTRACT

Hospice care allows individuals to die in the most comfortable way possible, with the most support possible. These services are meant for anyone of any age, including children, who are predicted to die within a few months. Although these services are meant to be utilized by any age group, Maine unfortunately does not have any sort of strictly pediatric-specific hospice resources available. I conducted a literature review to distinguish the differences of pediatric hospice services versus adult hospice services in order to support the reason for a pediatric-specific hospice care service in Maine. I also spoke with pediatric nurses who have worked with terminally ill children to get their perspectives of hospice care for children, as well as found an exemplar program that could be utilized in Maine

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INTRODUCTION

Hospice care is holistic care that focuses on the emotional and spiritual well-being of terminally or chronically ill patients and facilitates a peaceful end-of-life experience (National Hospice and Palliative Care Organization (NHPCO), 2019). When hearing the word hospice, the general public often thinks about older adults such as those with terminal cancers, dementia, or other chronic, life-limiting diseases. Many people may not associate hospice care with children or young adults, but this younger population has the potential to benefit from these services as well. Hospice care is intended for individuals, regardless of age, who have six months or less to live. Although the need for pediatric hospice care has increased, the services may not be readily available (NHPCO, 2019).

The focus of this thesis is to (1) provide a broad overview of hospice, (2) provide an overview of pediatric hospice care, (3) describe the benefits of pediatric-specific hospice care, (4) address barriers to access and quality of pediatric hospice (5) review pediatric hospice care resources available in the state of Maine, (6) include accounts from people who work with terminally ill children and their knowledge of hospice care options, and (7) include an exemplar pediatric hospice care program that could be replicated in Maine. This was accomplished by completed a review of the literature on pediatric hospice care, contacting various agencies within the state to determine pediatric hospice services that were available, interviewing pediatric nurses in Maine who care for hospice patients and identifying an exemplar pediatric hospice program in the New England area.

METHODS

A literature review was conducted using the following databases: CINAHL, Nursing Reference Center, PubMed, and Google Scholar with the following search terms: hospice, pediatric hospice, end of life care, hospice benefits, hospice barriers, children, at-home care, and terminal illness. Studies that were included were articles published between 2006-2019. Informal interviews with nurses who have worked with terminally ill children in Maine were also conducted to understand their experiences and garner information regarding the availability of pediatric hospice care resources in Maine. This is not a research study but instead an exploration of pediatric hospice services in Maine. Identifying an exemplar pediatric hospice service serves to inform planning for potential services in Maine.

LITERATURE REVIEW

Broad Overview of Hospice Care

Hospice Care is defined as a multidisciplinary approach to end of life care based on the belief that “each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so” (National Hospice and Palliative Care, 2018, ¶ 1). Those who receive hospice care decline the use of any life-prolonging interventions, and instead choose to receive end-of-life care and support. A multidisciplinary team provide services such as medical care, pain management, and emotional and spiritual support to the patient and their loved ones. Support is provided to the patient and their family before, during, and after the patient’s death. Hospice services aim to treat the patient and their family’s needs holistically, not just their disease.

Hospice care is most often provided to individuals in the comfort of their own home, but can also be delivered in hospice facilities, hospitals, nursing homes, and other long-term care facilities. Each patient has a multidisciplinary team that may include: physicians, nurses, volunteers, spiritual counselors/priests, social workers, bereavement counselors, home health aides, and therapists. Team members meet with the patient and/or family/significant others to fashion a specific plan of care that meets the patient’s needs. Many team members such as nurses, physicians, and chaplains are also on-call 24 hours a day and can care for and/or support their patients whenever they need it the most, such as when they are in the process of dying (NHPCO, 2018).

Pediatric hospice care provides all of these components, but is specially designed for children and their families. The developmental needs of pediatric patients and the hardship of the parents having to be the decision makers encompass just a few of the

many specific needs of children's end-of-life support. An older adult making end-of-life care decisions is vastly different than an adolescent making these decisions or a parent making decisions for their child. The communication and skills needed to comfort and guide a child and their loved ones through such a tough time takes special services and people. Hospice provides resources not only for the child, but to their parents and siblings as well.

Pediatric patients who may find comfort and support in hospice care are those with childhood cancers, cystic fibrosis, congenital heart anomalies, and many other terminal conditions. It has been reported that 20,000 children in the United States ages 0-19 years old die from serious illnesses annually (Johnston, Rosenburg, & Kamal, 2017). To ensure that these children have access to the end of life care and support that they deserve, the United States needs more pediatric hospice resources and education.

Benefits of pediatric-specific hospice care for the child and family

Benefits of pediatric hospice care extend to the child and the family. The benefits to the child include (1) pain management, (2) emotional preparation for death, (3) familiarity with their environment at the time of death, (4) a sense of normalcy (5) support of family, friends, and the interdisciplinary team, and (6) ability to take part in planning for the end of life ceremony. Benefits to the family include (1) support at home to allow for normality of family activities and routine, (2) support in providing physical care of the dying child, (3) emotional and spiritual support, and (4) help in planning funeral and other ceremonial arrangements to celebrate the child's life.

Benefits for the child

Pain management is an essential component of hospice care to improve the quality of the death experience. Children who qualify for end-of-life care often have complex medical conditions with unique and multifaceted symptoms, including pain. Pain is subjective and can vary depending on the patient, their age, and their disease. An important and primary function of hospice services includes managing patient pain. In a retrospective telephone interview-based study, parents reported that 89% of children dying from cancer suffered “a lot” or “a great deal” from at least one symptom in the last month of life, most commonly pain, dyspnea, or fatigue (Himmelstein, 2006).

Assessing and treating pain in children can be very different than adults depending on the patient. Elements of the pain assessment are similar to that in adults, such as asking what the pain feels like, where it is, its severity, and factors that make it better or worse. However, pain assessments for children must be age and developmentally appropriate. In some cases, depending on age and illness, children may not be able to self-report or verbally address their pain and how intense it is. This leads health providers to use standardized behavioral assessment scales such as the CRIES, Riley infant pain scale, or CHEOPS scale, in which they use physical signs of pain such as crying, body language, and facial expression to assess pain severity. Children between the ages of three to seven can report pain most commonly using the FACES scale that show a progression from happy to very unhappy faces that correlate with the 0-10 pain scale that adults use. For verbal children over the age of seven, the 0-10 pain scale may suffice. Nurses who are not pediatric-trained and who have limited experience assessing

pain in children may fail to provide adequate interventions to treat the child's pain (Himmelstein, 2006).

Pain medication administration and pharmacokinetics in infants and children are also different than adults. Nurses must determine whether the child can or will take oral medication, or administer it liquidly, through an IV, or if possible, mixed in food. Also, pharmacokinetics and pharmacodynamics of medications are different depending on age. For instance, neonates have reduced clearance of many medications because of the incomplete maturation of hepatic enzyme systems, which can lead to an unintended accumulation of medication within the infant's system if not dosed correctly. General guidelines suggest that starting opiate doses in babies should be one third to one half of those in older children. Children two to six years of age have greater opioid clearance than adults, which requires children to have more frequent dosing of extended release opiate products than adults; which is why 24-hour pediatric hospice nursing service is greatly needed (Himmelstein, 2006).

Preparing children for their own death is a complex process. Factors that influence this preparation include the age and level of development of the child and parents' beliefs regarding including their child in this discussion. For example, a three year old does not understand the finality of death, or the concept of forever, while a 10-year-old understands death as final, but does not connect death with younger adults, only older people. These different levels of understanding require different therapeutic approaches (Kroen, 1996). Methods to enhance understanding and emotional preparation for the child's own death requires different approaches than those used for adults. Play is

one technique that may be used to help children understand and cope with their impending death (Van Breeman, 2009).

At-home pediatric hospice care allows the child the opportunity of playing in a comforting, familiar environment. Play is a vital part of children's development and overall acts as their best form of communication. Van Breeman (2009) describes play as the language of children that lets them express themselves and relieve stress and anxiety. Play also serves as a way to develop therapeutic relationships among family members and hospice workers. Receiving care at home makes normalcy of play in a familiar environment possible, with all of their loved ones close by.

Along with providing normalcy, play therapy is used as a way for children to express their emotions, feelings, and concerns. Storytelling is a great tool that play therapists use. Stories can provide the child with some distance from difficult, scary topics such as death. Children's storytelling may occur during most types of play, such as while using a sand tray, painting, dress-up, and drawing. Storytelling allows the patient to have a place and person in which they can express feelings about their family, how they view their illness, what they need to feel supported, how they want to live and who they need in their dying journey (Van Breeman, 2009).

Adolescents also benefit from the discussion of death and dying provided by hospice. Although young adults understand death and may have had experience with it in their lives, adolescents try not to think of the finality of their own life, and may refrain from discussing their feelings (Nielson, 2012). It was reported that adolescents with progressive neuromuscular illness who participated in a support group at Canuck Place

Children's Hospice in Vancouver expressed anger at their physical body and guilt over the increasing burden of care they were on their parents. They described how these discussions of their thoughts and experiences were difficult to have with their parents. They defined conversations of fears and hopes as being 'off limits' because the topics are too emotionally charged and/or they did not feel they had the words to make their parents understand (Van Breeman, 2009). Hospice services can give adolescents a place in which they can comfortably express their feelings, and develop the skills to discuss them with their parents.

Children's understanding and connection to death is an essential component of pediatric hospice services. Art therapy is one method to facilitate children's understanding and coping with death. In a study conducted by Yang and Park (2017), 82 children between the ages of five and six years were given blank sheets of paper along with coloring utensils such as crayons and markers. Researchers encouraged the children to illustrate their concepts or knowledge of death and dying by asking them to draw "whatever the word death brought to mind." After completing their drawing, they were asked to describe it. This information was then used to determine children's perceptions of death and loss.

Common depictions of death through their artwork included similar causes of death such as accidents, crimes, and war. None of the children associated death as an event involving children or young adults, but rather as an event that affected adults and older people such as grandparents. Beliefs that medical treatments would make the dead person alive again is another theme that emerged through the artwork. Children in the study did not seem to completely comprehend the irreversibility of death. These common

themes emphasize the importance of hospice care services being able to developmentally describe death and dying to younger patients. Young children have a disconnect to young children dying from biological reasons, and this disconnect should be addressed, and their definition of death redesigned so that anxiety, fear, and confusion are prevented (Yang and Park, 2017)

Pediatric hospice services can also provide patients with the unique and valuable opportunity to plan their own funeral/death ceremony. The extent to which children can participate in planning their own funeral arrangements and celebration of their life depends on the age and development of the child. Parents are also active participants in this process such that their beliefs regarding the child's participation in this planning is important. Frith (2018) explains that planning a funeral can be truly difficult for a family because of the instant grief felt after death. Making just small plans such as what the child wants to be done for a ceremony, how they want it to go, any sort of specific things they want to include (special song played, a poem read, etc.) can help the family have an easier time planning the ceremony and allow the child add in their own personal touches.

Benefits for the family

Pediatric hospice care can provide support at home to allow normalcy of family activities and routine and has been reported to be beneficial to families who are caring for a dying child. In a qualitative study intended to illicit the perceptions of parents whose children received in-home hospice care, three main themes emerged that supported the benefits of in-home hospice: (1) availability of expert care, (2) emotional support for the child and family, and (3) consistency of care (Brenner et al., 2016).

Home pediatric hospice care has been the focus of many studies. Kassam, Skiadaresis, Alexander, and Wolfe (2013) set out to discover parents' and clinicians' preferred location for end-of-life care and death for children with terminal illness. In this study, most parents and clinicians said that home was their first choice for end-of-life care (70.2% and 87%) and death (70.8% and 87%). This supports the need for in-home pediatric hospice care. Availability of in-home pediatric hospice care allows the child the choice as to where they would like their care and death take place. Receiving care in the most comfortable atmosphere for the child allows for a more personal, relaxed experience during a scary time of their life.

However, caring for a terminally ill child in the home can be a full-time job for parents and can be emotionally, physically, and mentally draining. Parents reported that 24-hour availability of care providers was very comforting. Children may have unpredictable trajectories, especially those with rare/unique conditions, and parents appreciated that hospice staff understood the importance of immediate expert care and support for both the child and family. Parents also valued the holistic care provided to them and their child by the team of multidisciplinary hospice providers in which the child's voice was recognized and included in establishing a plan of care (Brenner et al., 2016).

Parents in the study often addressed how hospice care benefitted not only their child, but the entire family. One of the most appreciated aspects of receiving this specialized pediatric hospice care was that the care team, especially the nurses, provided the family with respite. During nursing visits, parents were able to attend to their own needs or the needs of their other children. This time allowed parents to take a physical

and emotional break and pay some much-needed attention and care for their other children as well. This sort of self-care time was immensely appreciated by the parents involved (Brenner et al., 2016).

Parents also valued the consistency of care provided to their child. They reported value in having a consistent nurse (and people on their hospice team) who was continually involved in their child's care. It allowed the nurse to truly get to know and form a relationship with the child and family and ensured continuity of the care provided. With each visit the connection between nurse, patient, and family grew stronger and follow-up care was more tailored to the needs of the child and family (Brenner et al., 2016).

The loss of a child is something no parent wants to think about or can even fathom. Bereavement for parents is often more profound and prolonged than grief experienced by loss in other circumstances. It is associated with an increased risk for long-term psychosocial and physical morbidities, and negatively affects interpersonal relationships and societal functioning. This may lead to strains in marriages, financial hardship, and feelings of anguish and isolation. Parents who have experienced the death of a child express the great importance of having institutional bereavement services available to aid them in their healing and functioning (Snaman, 2017).

The death of a child also has negative repercussions on siblings as well. It is important to consider the siblings age when trying to understand their grief. Children between 5 to 10 years of age and younger are thought to have limited understanding of this concept, whereas children older than 10 years are thought to have gained full understanding of this concept (Barrera, 2013). The loss of a sibling can have emotional

(feeling sadness, depression, excessive crying, anxiety, feelings of guilt), behavioral (acting out, sleep disturbances), and social (loneliness, withdrawal) repercussions, and has been linked to a deterioration in school performance.

Pediatric hospice services may continue after the child's death to provide parents and family with bereavement services and grief support. Therapy, support groups, grief counselors, and other resources are provided to help the family get through this difficult time. Hospice care is unique in the way that its' services are available before, during, and after death, both to the child and the family (Care Dimensions, 2019).

Barriers to access and quality of pediatric hospice

The barriers to access of pediatric hospice care include (1) the challenge of establishing a definitive diagnosis for terminal illness in children due to unknown disease trajectories, (2) providers who may feel uncomfortable or reluctant to refer and diagnosis a child as terminal, (3) lack of available pediatric-focused services for those who can qualify, and (4) difficulty securing insurance coverage for pediatric hospice care provided in any setting.

To qualify for hospice care, an individual must be determined to be terminally ill by a physician and have a prognosis of six months or less to live if the disease runs its normal course (NHPCO, 2019). Lindley (2017) conducted research to examine how pediatric primary care is involved in hospice and home health care referral/use for terminally ill children and adolescents at the end of life. The researcher reported that primary care involvement was associated with hospice use only in patients ages 15-20 years-old. This evidence suggests that pediatricians may be less likely to engage in conversations with younger children and their families about adjusting treatment to focus

on end-of-life, than with older children. Lindley (2017) suggested that this may be because pediatricians have limited experience conducting end-of-life conversations with younger patients and their families, the possible mindset of curing instead of comforting, or lack of knowledge about end-of-life resources in their community.

A significant barrier for children in need of hospice care is lack of insurance coverage and reimbursement. Medicare coverage for hospice for adults and children requires a trajectory of six months left to live, which can be very difficult to predict in pediatric patients. For those who died during hospice care, the average length was longer for pediatric patients, being 62 days versus 53 days for adults. This could be because of the difficulty of determining the outcome for certain pediatric conditions (Dingfield et al., 2015). However, there are advances that have been made in insurance coverage when a child meets the criteria of six months left to live. Section 2302 of the Patient Protection and Affordable Care Act (2010) titled the Concurrent Care for Children Requirement, allows patients under the age of 21 who qualify for hospice care to also receive all Medicare services related to their disease (including medical intervention and possible life-prolonging treatments). Services such as transfusion support, respiratory treatments, and chemotherapy that were once not covered with hospice care, are now available options. If not covered under Medicare because of diagnose criteria difficulties, private insurances can cause multiple issues. Some burdens include high copayments for medications and/or services, caps on services that are covered, preauthorization requirements, or medication formulary restrictions (Hinson & Rosoff, 2015).

A major barrier to the quality of pediatric hospice care is that nurses who specialize in adult care are unaware of the unique diseases and needs of this population.

Dingfield et al. (2015) reported that pediatric patients most commonly receive hospice services from agencies that are oriented to adults. Although 78% of hospice services care for children, most only care for 1-20 pediatric patients per year, and only 37% of these nurses treating them have formal pediatric training (Johnston et al., 2017). Although there are hospice services and facilities that serve the pediatric population, they are not pediatric specific.

Pediatric patients often have diagnoses that qualify them for hospice care but they are diagnoses that are not seen in the adult population. These unique pediatric diagnoses consist of complex, chronic conditions such as neurological disorders, chromosomal anomalies, congenital malformations, and inherited metabolic disorders. Pediatric patients are more likely to have a diagnosis that adult-oriented hospice workers have never encountered before, making their experience with these patients not as effective as for adult patients.

Quality outcome measures for end-of-life pediatric care are not well defined. Out of the 200 adult-focused end-of-life quality measures endorsed by the National Quality Forum, a non-profit organization that strives to improve in healthcare, none of them are specific to pediatrics. There are existing pediatric quality measures that have been established by the Center for Medicare and Medicaid Services but they do not address pediatric end-of-life. For example, they released a set of pediatric specific quality measures in 2014 for federal payment programs to use. Measures included primary care measures such as immunization status, weight assessment, and counseling, as well as illness management of asthma, mental health, or cavities, but nothing was related to end-of-life care (Johnston et al., 2017).

Differences between pediatric and adult end-of-life care and needs truly exemplify why it is so important to have pediatric-specific hospice care. It is not enough for hospice services to simply assign an adult-oriented hospice nurse to a pediatric patient. Family dynamics, diagnoses, care, and length of stay are among the differences that make pediatric hospice care unique.

PEDIATRIC RESOURCES IN MAINE

Availability of pediatric hospice services was explored by calling hospice services around the state, and by speaking with Greg Burns, a pediatric hospice nurse. Greg Burns travels across Maine to train other hospice nurses to be pediatric-specific and plans to ultimately develop a pediatric-focused hospice service through Northern Lights Home Care and Hospice. There are unfortunately no exclusively pediatric-specific hospice care resources currently available in the state of Maine. There are elements of pediatric hospice care in multiple geographic areas, but no official program. Several agencies provide pediatric palliative care services in York county and Cumberland county, and Maine Health Care at Home has several pediatric nurses who offer home health case management to children, but there are no physicians or social workers involved in their care. Barbara Bush Children's Hospital has an inpatient pediatric palliative care service with physician and social service involvement. These physicians and social service workers have made sporadic visits to some patients in need to support some home care, but there are no exclusively at-home specialized pediatric hospice services (G. Burns, personal communication, March, 2019).

Availability of palliative care is a valuable resource, but palliative care is different from hospice care. Palliative care begins when an illness is diagnosed and is continued whether the patient is receiving life-saving treatments or not. Just like hospice care, palliative care treats the patient holistically and involves a multidisciplinary team that focuses on the patient's physical, psychological, and social distress. However, hospice care focuses on end-of-life care (World Health Organization, 2015).

Some home care nursing agencies such as COR Health, Maxim Healthcare Services, and Home Health and Healing provide block time pediatric nursing support in homes of critically ill children, but not specifically end-of-life care. Block nursing is when in-home nursing care is provided to multiple different families in the same geographic area, however, reimbursement for these services is quite low compared to hospital floor nursing. Northern Light Home Care and Hospice is an agency that covers a very large portion of the state of Maine. There are offices and “home bases” in South Portland, Waterville, Ellsworth, Bangor, Houlton, Presque Isle, and Fort Kent. They have served pediatric patients and their families on an as-needed basis, but do not have a formal pediatric program. Pediatric hospice patients often need much more care and support than what these agencies are able to provide. Many areas of the state have no services at all, such as far north, western Maine and Washington County.

There is an initiative underway to create a pediatric program that encompasses all the northern offices of Northern Light Home Care and Hospice from Waterville to Presque Isle. They aim to specially train and educate pediatric nurses to provide end of life care at-home to children in need. Once these teams are put in place, the second phase of the initiative is to create pediatric palliative care and hospice programs among the Northern Lights Health System and across the state to create communities of care dedicated to critically ill and dying children. The Hospice House in Presque Isle is planning to convert several of their beds into pediatric beds as well. Hospice care team members across the state will also be trained in pediatric hospice, to further move hospice care away from the idea that it is only utilized by older adults (G. Burns, personal communication, March, 2019).

In my research of pediatric hospice care resources in Maine, I spoke to a pediatric floor nurse, a pediatric oncology nurse, and a nurse who has had past experience with pediatric-specific hospice nursing who is in the process of developing a pediatric hospice care program in Bangor. Maine's lack of hospice resources made me wonder how healthcare providers go about even suggesting pediatric hospice service and about what these individuals know about hospice care for children.

INTERVIEWS

These nurses were interviewed with the hope of understanding their knowledge of hospice care resources for their patient population, get their opinions on what they personally see as benefits and barriers to these programs being implemented in Maine, and learn from their experiences with pediatric end-of-life differences. These interviews occurred in person and over email. I created some basic questions (Appendix A) to ask these nurses, and eventually branch off of into a full comprehensive discussion of this topic.

Pediatric Nurse

When talking to a nurse at Northern Lights Eastern Maine Medical Center who has worked on the pediatric floor for more than 10 years, she admittedly did not know a lot about pediatric-specific hospice care. When asked if she knew any resources in Maine, she said that some adult hospice resources have been called in for pediatric patients and their families to set up at-home care. She mentioned that those who are involved in pediatric care should have pediatric training as well as training related to working with parents/families of dying children.

This pediatric nurse described the lack of a pediatric focus in hospice care being from the fact that Maine is an “old” state. Maine has a large population of older adults that she assumes outweigh the number of pediatric patients seeking hospice. Because of this, facilities may not find it worthwhile to train their staff members in pediatric care.

She also described that the focus of hospital care is different than end-of-life care. Care in hospitals is focused on an attempt to find the cure, offer another treatment, another surgery, or another test. Hospice care supports that death is eminent and cure is not the goal. Hospice care is intended to provide holistic care and support for the dying

child and the family. Employing these services for children who are dying and families who need it can provide guidance to these individuals, and provide a comforting, supportive environment, and make a difficult time less lengthy and more bearable (Barbara Todd, personal communication, March, 2019).

Pediatric Oncology Nurse

I spoke with another nurse who works in pediatric oncology and faces more death in children. She stated how difficult it is to connect pediatric patients to hospice centers because she only knows of two resources locally that are adult specific, but still take some younger patients. It becomes even more difficult when patients are from rural areas of Maine, because there are even fewer agencies/nurses that are comfortable caring for children. The comfort aspect presumably comes from not being emotionally prepared to care for a dying child and not being as familiar with diagnoses that affect the younger population, compared to their more common, older patients. This has been supported in the literature.

She believes that there is definitely a need for pediatric hospice care in Maine but admits that some obstacles to developing this resource would be Maine's geography, patient volume, number of pediatric hospice nurses, and the pay for these specially trained nurses. Geographically, it would be difficult to make care available to most of Maine considering the state's size and winter weather. Trying to establish a "home base", or where the facility would be based out of would be difficult to decide considering there could be children in need from Portland, all the way to Presque Isle. Being able to have a resource that extends to any and all pediatric hospice care needs would be a challenge, for both at-home and facility care. Families want to be close to

their resources, and a multidisciplinary team that is always on-call for their patients could be tricky depending on how far their patients are from them.

Also, the number of pediatric patients who qualify and want hospice care fluctuates significantly, especially in oncology. This could greatly impact income/funding to any possible pediatric hospice care center. Lastly, recruiting nurses for such a specific specialty could be challenging. She stated how experienced pediatric nurses are rare in rural areas, let alone nurses that are experienced in pediatric hospice care. She also mentioned how when she worked outpatient (outside of the hospital), nursing agencies would constantly try to recruit pediatric nurses for block nursing, but block nursing comes with lower pay. The specialty of pediatric and hospice care combined with the lower pay severely narrows the availability of nurses who are proficient in this area and want to participate in such a needed program.

This pediatric oncology nurse explained how she could find great benefits to an in-home hospice program for children compared to a facility. Maintaining a facility would be fiscally challenging primarily because of unpredictable increase/decrease of patients in need. The fluctuating need for services and geographic size of Maine makes an at-home resource more ideal. Home based hospice would also allow the child and their family to stay at home where they are more comfortable, get better pain/symptom management, receive more advocacy from an entire multidisciplinary hospice team, and make it easier for patients to be with friends, siblings, and extended family. She explained how having multiple visitors on the floor can be difficult, especially when hospitals adopt influenza precautions which prevent children younger than 12 from entering the hospital.

This nurse started out working with adults when she first graduated nursing school but has now been working with the pediatric population for around ten years. Some notable differences she sees in treating dying adults versus dying children is the family involvement. She described how difficult it is to lose any loved one of any age, but the loss of a child that you expect to outlive you is one of the worst things a parent can endure. We grow older with our parents, and mentally/emotionally prepare for the day they die, but parents may never give their child's death a true thought. It takes a special nurse to be able to know how to approach the family, know how to be supportive without overstepping boundaries, be flexible in the care provided to meet both the child's and family's needs and wishes, as well as being able to work with and explain care needs to the patient's family members and younger siblings.

Some other differences she has seen have been mementos saved from children as well as building their legacies. They often get footprints/handprints and locks of hair (if they have any left) for the family, something she has never seen for adults. Social work also does workbooks with the patient to recognize the legacy they want to leave, how they want their last days to go, how they want to be remembered, and what they may want their services to look like. She explained that the sort of communication and legacy with children is so different than older adults. Older adults already had decades to establish their legacy, children only have a few years. The therapeutic and age-appropriate language of explaining death and their wishes is drastically different from adults who have had time to experience life and ponder death.

These important differences are why Maine needs more of a specialized multidisciplinary team for children. Children and young adults deserve care aimed at

their age, diagnosis, and development. Putting adult-focused hospice care workers with younger patients is not giving the patients the specialized care and communication that they need (Michelle Graves, personal communication, March, 2019).

Developing pediatric services in Bangor, Maine

I had a great opportunity to speak with someone dedicated to developing a hospice care for children in Bangor, Maine. He has had 25 years working with terminally ill children across the state of Maine and is a wealth of information. He used to drive all across Maine with a pediatric hospice group back in the early 2000s, but its' funding was sadly cut. He works at Northern Light Home Health and Hospice and travels across Maine to train hospice nurses in pediatrics to soon develop a pediatric-specific hospice care resource.

He describes the biggest victims from the lack of hospice resources in the state of Maine are our rural families. Maine has extensive rural areas across the state and often terminally ill children at home are left with minimal services, stressed and strained families, and many unmet needs. Many families cannot afford or have the time to travel great distances to get the services their child needs. Maine also has a lack of educated/specially trained providers in pediatric hospice care as well as a general nursing shortage.

Funding for pediatric hospice home care also poses an issue. The money to develop these sorts of programs is not always readily available in a state like Maine. He explains how many people find it difficult to see how providing funding for what they see will only benefit a very small portion of people is worth the money. However, focusing

attention on providing excellent, evidence-based, cost-effective, patient and family centered care will save money in the long run.

The greatest benefit of pediatric hospice care he described was the fact that this sort of care promotes collaboration and coordination among physicians, disciplines, hospitals, agencies, and systems. This care allows both the patient and their families to develop care that is specific to their situation, location, and needs.

EXEMPLAR PEDIATRIC HOSPICE PROGRAM

Some states across the country have great pediatric hospice care options to choose from. Massachusetts has a great resource for multiple different palliative and hospice care options. Care Dimensions based in Danvers, Massachusetts has specialized services for patients including cardiac, respiratory, dementia, developmentally disabled, veterans, and even pediatric patients. Care Dimensions provides compassionate holistic care for individuals struggling with life-threatening illnesses and their families. This non-profit offer services in more than 90 communities in Eastern Massachusetts. They make their services extremely accessible by placing their phone number on their website and letting anyone, whether it be a patient, family member, or care provider, be able to refer a patient to any of their specialties. Their specialized pediatric team is supported by pediatric hospice and palliative care physicians from the Boston Children's Hospital and provide family-centered services at-home and in different communities (Care Dimensions, 2019).

Their multidisciplinary team consists of a multitude of various specialties and services. For medical needs, patients are provided with board-certified pediatric palliative care specialists from Boston Children's Hospital who act as medical directors, pediatric nurse practitioners who coordinates care with the child's primary physicians and specialists, as well as provide clinical care and symptom management, pediatric nurses who provide specialized care, and hospice aides who assist with daily care. For children's own personal needs, each patient has a certified child life specialist who helps the patient and their siblings express their emotions, complementary therapists who get children involved in activities such as art, music, and animal therapy, social workers to help patients and families cope with their situation, and chaplains for their spiritual needs.

Their goal is to allow children and their families to live every day to the fullest and enjoy their time together (Care Dimensions, 2019).

This amazing resource also provides a multidimensional approach to receiving care. They allow pediatric patients to continue receiving curative treatments while receiving hospice care that emphasizes pain and symptom control. Patients can still receive block nursing and home health services from other agencies as well (Care Dimensions, 2019).

Care Dimensions provides individualized care plans that incorporates each specific patients' nursing, medical, psychosocial, and spiritual needs. Some special services they provide include home delivery of medications or medical equipment, education to caregivers, emotional and spiritual support, grief support, guidance in navigating community resources, as well as 24/7 access to nursing visits.

Although their services primarily reach out to families and children at their home or in hospitals, they also have two facility locations. Kaplan House located in Danvers, Massachusetts and Care Dimensions Hospice House located in Lincoln, Massachusetts. These home-like facilities are used by patients of any specialty of hospice care, but each facility have specialized pediatric suites available. They are used for respite care or acute symptom management, and family members are welcomed to stay overnight with their loved ones, and visitors are always welcomed (Care Dimensions, 2019).

Another form of hospice they provide that falls under the umbrella term 'pediatric' is their peri-natal program. This is for parents who are giving birth to an infant with a life-threatening or fatal illness. Their services give the parents support and resources throughout the pregnancy, delivery, parenthood, and bereavement. Care

Dimensions make a plan of care in conjunction with the family and medical-staff in order to facilitate support to the infant's parents and siblings. The pediatric team helps to transition the care provided in the hospital to the home as well as plan memorial services and other arrangements. After the infants' death, the family receives much needed grief support. This is a very unique and incredible resource that I had not seen built into other hospice programs.

Care Dimensions encompasses all that a hospice service should provide. They not only serve the older adult population, but also specialize in the care of all sorts of patients in need. They provide patients and their families guidance, relief, and so many other helpful accommodations from hospitals, facilities, or at home care. Maine could definitely learn from this spectacular non-profit and benefit from all that they have created. They treat the overall human spirit, not just the human.

CONCLUSION

In the final analysis, hospice care for pediatric patients and families can provide holistic care end of life. This review allowed for an overall analysis of pediatric hospice care, its benefits, its barriers, and how we can potentially implement a program in Maine. A stand-alone pediatric hospice care program may not be feasible in the state of Maine due to the wide geographic area and a relatively small pediatric population. However, efforts are underway to expand pediatric hospice services by integrating them in existing adult hospice services. This will require additional training for nurses and other professionals focusing on the unique needs of children and families. The hospice program, Care Dimensions in Danvers, Massachusetts, is an example of an exemplar program that can be potentially implemented in Maine. This program provides diverse hospice care for patients throughout the life span. Programs such as this and the dedication of nurses and other health care providers in the state of Maine can pave the way for pediatric hospice services for children and families in the state of Maine.

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APPENDIX A

Pediatric Hospice Questions

If someone were to ask you about pediatric-specific hospice care, would you know of any resources in Maine?

Do you believe there is enough of a need for pediatric hospice care in Maine?

What are some potential barriers/obstacles you see in developing pediatric hospice care?

What are some potential benefits you see in developing pediatric hospice care in Maine?

What are some unique differences in pediatric vs adult end-of-life experiences (if you have experienced both)?

Where could you see pediatric hospice care being used? (at-home care, a facility, hospitals)

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Rachel Emerich was born and raised in northern New Jersey. She graduated from the University of Maine school of nursing with Honors and magna cum laude. She plans to explore the amazing opportunities of nursing and eventually get her PhD in nursing.