The Integral Role for Pediatric Palliative Care in Our

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Pediatric palliative care has evolved over the past several years into a care delivery model which has proven to be an integral component in the current health care environment. As defined by the World Health Organization, "Pediatric palliative care is the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease." When further exploring its role and defining the care delivery model, Pediatric palliative care is a multifaceted approach of healthcare delivery which emphasizes quality of life of all children with life-limiting or life-altering conditions, as well as their families. Care focuses on the prevention and relief of suffering and addresses the physical, psychosocial, emotional, and spiritual needs of the patient and the family.

Historically, the term "Palliative Care" was thought to be synonymous with "end of life care." In prior traditional care models, after diagnosis was made, efforts were directed at curative care. When and if curative care was exhausted and did not achieve a "cure", care would be transitioned to what medical providers termed "palliative care," "hospice care," or "end of life care." The current care model and practice of Pediatric palliative care varies greatly from this historical delivery model, with the focus on palliative efforts starting at disease diagnosis and occurring in varying amounts in conjunction with disease-directed therapy. As the disease evolves, the role of Palliative Care often increases. In this care delivery model, there is an individualized coordination of care directed at the underlying illness with emphasis on physical, emotional, social, and spiritual needs of the child and the family. Throughout the care continuum, there is continuous reevaluation and adjustment of care based on goals set in a team approach by the multi-disciplinary, multi-specialty medical team and family unit. This helps to delineate the individualized, multi-faceted needs of the patient and his or her family and places emphasis on those needs throughout care planning. While pediatric palliative care includes end-of-life and bereavement care, it is much more broad in its delivery spectrum as care is provided and adjusted throughout a child's life. This care model also emphasizes continuous communication regarding goals of care with the entire multidisciplinary care team spanning all specialties involved.

The patient population who should be considered for this model of care is vast and continually increasing. Any child diagnosed with life-limiting or life-altering disease should be considered a candidate for pediatric palliative care. Patients who have multiple components to their medical care (i.e. multiple subspecialists) or require multiple hospitalizations due to their underlying diagnosis would benefit from Pediatric palliative care. As medicine continues to advance and the role of technology increases in the day-to-day care of our patients, the volume of patients continues to rise as patient complexity increases.

Pediatric palliative care is coordinated and delivered by specialists in the field. Both allopathic and osteopathic licensing boards have designated certifications for Hospice and Palliative Care Medicine and there are several fellowship programs in palliative care across the country. In addition, physicians who had additional clinical training and clinical experience in the field were eligible through 2013 for board certification via a clinical pathway. Once initiated, the components of an inpatient Palliative Care consult are multi-faceted and include chart reviews, interviews with primary and subspecialist physicians, nurses and all other members involved in care, including social workers, child life specialists, and chaplaincy as appropriate. In addition, extensive patient and family interviews are conducted. The patient and family interviews include symptom assessment, psycho-spiritual assessment physical exam, discussion of prognostication, goal setting, and disposition planning. Communication with the primary medical team addresses symptom and pain management, direction of care to meet patient and family-defined goals, and further triage of additional services including pain management, psychological needs, rehabilitation, as well as other outpatient therapies. At the later stages of disease, when encompassing more end-of-life care, the palliative care team facilitates discussion regarding home care, hospice care, DNR orders and planning for possible death, and helps to facilitate the appropriate disposition with the primary team.

The care model of Pediatric palliative care has similar principles to Adult Palliative Care, but care delivery and implementation are altered due to many factors. The cognitive ability and emotional maturity of the patient population may lead to limited communication when assessing patient needs and desires regarding goals of care. Along the same lines, while patient autonomy is a focus of adult medicine, family autonomy is weighed more heavily in the pediatric population, with parents and legal guardians having more inherent "ownership" over care delivery and planning. Furthermore, the diseases in the pediatric population differ from the adult population. When life-limiting or life-altering disease is diagnosed in the pediatric population, there are varied emotional and psychological impacts on the family unit, which ultimately affects the complexity of the parent, child, and sibling relationship. All of these factors must be taken into account for effective delivery of care, both palliative as well as disease-directed.

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While this all-encompassing model of care delivery may seem ideal, barriers exist in today's healthcare environment that must be overcome to insure successful implementation. Some of the chief barriers include: lack of exposure and family perception of palliative care, lack of professional training, communication difficulties when discussing difficult topics, population awareness, and limitation of resources. In a national survey of Children's Hospitals in 2012, it was noted that Pediatric palliative care is available at 67% of Children's Hospitals/institutions (up from 58% in 2008).[1] The availability of such services may be workforce and funding related. In an assessment of the current palliative care workforce, a study showed that an acute shortage of Hospice and Palliative Care Medicine physicians exists, with an estimated gap of up to 18,000 individual physicians needed to achieve mature staffing of the existing number of hospice- and hospital-based palliative care programs.[2]

While access to care may be limited, another barrier lies within the burden of diagnosis and prognosis in the pediatric population. In a study of barriers to palliative care for children published in *Pediatrics*, nurses and physicians surveyed cited that the most frequent barriers were the patient's uncertain prognosis as well as the family's unwillingness to accept the diagnosis of an incurable condition.[3] In addition to family resistance to accepting such diagnoses, the pediatric community has demonstrated difficulty in discussing such diagnoses with families in an appropriate manner, which may limit palliative discussions regarding goals of care. A study published in *Pediatrics* examining the delivery of care and effective communication reported that medical staff felt inexperienced in communication with patients and families. In this study, families reported distress about the way bad news was delivered to them by healthcare professions. Ultimately, 54% of medical staff surveyed reported that adequate care was not delivered secondary to these communication issues.[4] Deficiencies in the ability to deliver bad news and conduct difficult discussions spanned all levels of training. In a study of pediatric residents, attendings, and fellows, when asked to provide self-assessment of ability to effectively deliver bad news, one half of all attending physicians and two thirds of fellows did not feel sufficiently knowledgeable or comfortable in their ability to deliver bad news. More strikingly, all pediatric residents felt insufficiently knowledgeable for independent practice of this skill.[5] Given that effective communication, often occurring in times of family duress, is critical to effective delivery of pediatric palliative care, our skill set as pediatricians may create an additional barrier.

Even though many barriers exist, there is still a great need to forge ahead and promote the effective delivery of pediatric palliative care. In a randomized control trial studying the impact of an inpatient palliative care team, patients who had palliative care involvement reported greater satisfaction with their care experience and with their providers' communication. These patients had fewer ICU admissions on readmission, as well as lower total healthcare costs.[6] Regarding quality of care, a prior study found that palliative care patients had improvement in care quality and also reported that a higher percentage of their emotional and spiritual needs had been met.[7]

Cost should not be a leading factor in determining a patient's care delivery, however, the principle of social justice and the current medical and economic climate in the United States do promote a need for cost effective medical care. In a comprehensive study, US hospital palliative care consultation programs have been shown to significantly decrease cost in both subsets of patients alive at time of hospital discharge as well as decreasing costs in those patients who had died during hospitalization. A decrease was noted in both direct costs per admission as well as in indirect costs per day, with significant reductions in pharmacy, laboratory, and intensive care unit costs. In further assessment, decrease in cost of care was directly related to timing of consultation; early consultations were associated with earlier reduction in costs.[8]

With its positive effect on patient satisfaction, quality of care, and decreased total cost of medical care, Palliative Care should be seen as one of many key components in the restructuring of our current medical system. While barriers do exist, the promotion of this care delivery model will aid in overcoming barriers and will facilitate improved care delivery as a whole to our pediatric patients.

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Biography:

Colin O'Reilly, D.O., F.A.A.P, F.A.C.O.P., F.C.C.M. is the Assistant Vice President of Inpatient Medical Affairs at Children's Specialized Hospital, where he oversees the inpatient medical programs as well as serves as Medical Director for two Pediatric Long Term Care facilities. Dr. O'Reilly was previously the Medical Director of the Pediatric palliative care service at the Goryeb Children's Hospital of Atlantic Health in Morristown N.J., where he also was a Pediatric ICU Attending. He is board certified in General Pediatrics by both the American Board of Pediatrics and the American Osteopathic Board of Pediatrics, board certified in Pediatric Critical Care Medicine by the American Board of Pediatrics, and is board certified in Hospice and Palliative Care Medicine. He was trained in Palliative Care at the Harvard Medical School Center for Palliative Care and completed the Program in Palliative Care Education and Practice Program. He is also active in Bioethics, with additional training at the Kennedy Institute of Bioethics at Georgetown University. He is active in local government and serves on the Board of Health for Morris Plains, New Jersey. He has served on the Board of Directors of the alumni association of the University of New England College of Osteopathic Medicine. Dr. O'Reilly is a fellow of multiple medical societies and has published in numerous medical journals. He has received multiple awards for compassion and for excellence in the care of pediatric patients.

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CME Quiz

1. According to a study of hospitals enrolled in the Children's Oncology Group, pediatric palliative care was available in what percent of the participating hospitals?
   a. 17%
   b. 25%
   c. 67%
   d. 75%
   e. 85%

2. Pediatric palliative care is a multifaceted approach of health-care delivery that emphasizes:
   a. The quality of life of all children with life-limiting or life-altering conditions.
   b. Addressing the physical, psychosocial, emotional and spiritual needs of the patient and family
   c. Focus on the prevention and relief of suffering.
   d. All the above.

3. The World Health Organization defines pediatric palliative care as the active total care of the child's body, mind and spirit and also involves giving support to the family.
   a. True b. False

4. Components of a multi-faceted Palliative Care consult include:
   a. Chart reviews.
   b. Extensive patient and family interviews that include symptom assessment, psycho-spiritual assessment, physical exam, discussion of prognostication, goal setting and disposition planning.
   c. Interviews with primary physicians, subspecialists, nurses, and all other members involved in care.
   d. All of the above

5. Any child diagnosed with life-limiting or life-altering disease should be considered a candidate for pediatric palliative care.
   a. True b. False

6. At the later stages of disease, the Palliative Care team should facilitate discussion regarding home care, hospice care, DNR orders and planning for possible death.
   a. True b. False

7. Barriers to overcoming for ensuring the successful implementation of Pediatric palliative care include all of the following, except:
   a. Family perceptions of Palliative care.
   b. Lack of training and communication difficulties when discussing difficult topics.
   c. Abundance of resources.
   d. Population awareness.

8. A 2010 article that appeared in the Journal of Pain and Symptom Management reported an estimated gap of up to 18,000 physicians needed to achieve mature staffing of existing number of hospice and hospital-based palliative care programs.
   a. True b. False

9. Nurses and physicians cited that the most frequent barriers were a patient's uncertain prognosis and the family's unwillingness to accept the diagnosis of an incurable condition.
   a. True b. False

10. In a randomized control trial studying the impact of an inpatient palliative care team, patients reported all the following except:
    a. Greater satisfaction with their care experience.
    b. Increased healthcare costs.
    c. Fewer ICU admissions and readmissions.
    d. Greater success in meeting emotional and spiritual needs.

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CME Activity

Improving the Quality of Life in Children through

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There are over 50,000 deaths among children less than 19 years old in the U.S. each year. More than one million infants and children are living with chronic, complex and/or life-limiting conditions (Wang, Burns-McGrath and Watts, 2010). Patients with conditions that were once considered fatal are surviving longer, but oftentimes with much discomfort and suffering. These patients often have complex illnesses that require care from multiple specialties, each with a limited focus. As a result, the uncoordinated, fragmented care that they receive negatively impact their quality of life (Edlynn, Derrington, Morgan, et al, 2013).

Research conducted among children with cancer has shown that those children who die undergo significant suffering before death (Wolfe, Grier, et al 2000). Furthermore, of the over 50,000 children who die each year, only about 5,000 receive hospice services, which mean that the vast majority of children who might benefit from palliative care and hospice services are not being reached (National Hospice and Palliative Care Organization, 2001). As a result of increased survivability and life-threatening diagnoses, there is a greater need for services ranging from symptom control to psychosocial management. Accessing such services can be challenging, however, because of the reluctance or fear to confront death/dying openly with children and their families, and because of the misunderstanding about the philosophy of palliative care and hospice being synonymous with each other.

Palliative care as defined by the World Health Organization (WHO), is "an approach that improves the quality of life for patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychological, social, and spiritual" (WHO, 2008). The goal of palliative care is to prevent and relieve suffering so that patients and their families can have the best possible quality of life, irrespective of the stage of their disease or the need for therapy. Palliative care is provided throughout the continuum of care for patients who have a chronic, complex, or life-limiting condition and their families.

The importance of palliative care has been endorsed by multiple medical groups (AAP, 2000; Field & Burman, 2003). The American Academy of Pediatrics (AAP) supports an integrated model "in which the components of palliative care are offered at diagnosis and are continued throughout the course of illness whether the outcome ends in cure or death." (AAP, 2000) This model ensures that children and their families benefit from pediatric palliative care services throughout the trajectory of their illness, instead of just at end of life, as is in the case of hospice care. The Center to Advance Palliative Care (CAPC) has established referral guidelines for pediatric palliative care. This guide suggests which diagnoses should be referred automatically for palliative care consults and provides suggestions for additional medical conditions that could benefit from a palliative care consult. Some conditions include, but should not be limited to, children with high-risk malignancies, pulmonary disease, cardiac conditions, genetic anomalies, neurological/neuromuscular conditions and metabolic diseases (CAPC, 2014).

Hospice is a philosophy of care that focuses on providing a natural and comforting environment at the end of life for individuals with a terminal illness. The goal is to manage symptoms and provide comfort when there is no longer the possibility for a cure. There is a distinct difference between palliative care and hospice in terms of timing: hospice is purely at end of life and it incorporates palliative care, whereas, palliative care is appropriate care aimed at relieving symptoms and enhancing quality of life throughout the continuum of the diagnosis.

One of the most challenging aspects of pediatric palliative care and hospice care is helping patients and their families transition their goals of care as they move from a course of curative therapy to end of life. Particularly challenging is when to initiate discussions that center around this transition. In a model where patients are cared for in a continuum from the point of diagnosis through the trajectory of the treatment these discussions can occur more frequently and comfortably. Relationships between the interdisciplinary medical team and family are created naturally and forged throughout the continuum of treatment (Hospice and Palliative Medicine, 2013). The term DNR, do not resuscitate, is very hard for patients, parents and families to hear. No parent or caregiver wants to discuss withholding treatment from their child. Most families perceive withholding care as giving up. On the other side, medical providers may have the sense of loss and/or failure that the therapy agreed upon did not provide the child a positive outcome. The agonizing nature of these discussions from both the medical team and family can often create a barrier that may prevent necessary discussions that would provide the child with a more comfortable manner of death while meeting the unique needs of that child and family's goals at end of life.

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Medical ethicists discovered that in many cases patients' preferences for end-of-life care were not being met (Meier and Beresford, 2009). Additionally, advance directives were often inadequate for patients with serious illness or frailty and are not designed for use in pediatric populations. In 1991 the POLST (practitioner orders for life-sustaining treatment) Paradigm began (National POLST, 2012). Although the POLST Paradigm began in Oregon, many states began to follow and adopt their own programs to fit their unique legal, medical and cultural contexts within their states. New York, Pennsylvania, Washington, West Virginia and Wisconsin were among the first group of states to develop these types of programs. In September 2004, the National POLST Paradigm Task Force (NPPTF) convened to set quality standards for POLST Paradigm forms and programs. Presently, the National POLST Office resides in the Oregon Health & Science University Center for Ethics in Health Care (OSHU CFE) and is completely supported through private philanthropy (National POLST, 2012).

On December 21, 2011, New Jersey signed legislation that enabled patients to indicate their preferences regarding life-sustaining treatment (The National Law Review, 2011). That law called for the creation of a standardized POLST form that would be signed by a patient's attending physician or advanced practice nurse and would provide instruction for health care personnel to follow for a range of life-sustaining interventions. The form was made available in February 2013.

POLST is an actionable set of medical orders, recommended for persons with advanced, chronic, or progressive illnesses that have a life expectancy of less than one year. The POLST helps to define the patients' end of life goals of care and can limit medical interventions, clarify medical treatment, provide explicit direction about resuscitation, and/or include direction on such decisions as intubation, dialysis, antibiotics, tube feeding. POLST is a medical order that travels through any setting, which may include hospital, home, outpatient clinics, or school settings (National POLST, 2012).

POLST focuses on a continuation of care and not the absence of care. It is appropriate for pediatric and adult patient populations and allows for the pursuit of different medical interventions for the patient and/or parents to choose. The POLST form is a tool that provides structure to the most difficult conversation most medical professionals will have and provides guidance to the medical professional for assisting the patient and family in their transition to end of life. The POLST is not a static document; as a patient's illness progresses, their goals of care and decisions about life sustaining interventions may change and the POLST may be modified at any time to meet these changes.

Case Study

A healthy 30 year-old pregnant woman with 4 children, ages 1 to 7, presents with a normal pregnancy until her 20 week ultrasound where it was noted that the infant had severe anomalies consistent with Trisomy 13. The Maternal Fetal Medicine group (MFM) performed a diagnostic amniocentesis and the diagnosis of Trisomy 13 was confirmed. Parents were offered to terminate the pregnancy, but declined. The parents were referred to the high-risk obstetric clinic (HROB). The HROB clinical team reviewed with the parents that a diagnosis of Trisomy 13 is considered to be a lethal anomaly with no known interventions to significantly alter the natural course of the pregnancy.

Discussions with the HROB and MFM helped to bring about a shift in perspective of the parents understanding that certain medical interventions could prolong, cause pain and/or suffering, and would not affect the ultimate outcome for this infant.

A collaborative plan of care was created with interdisciplinary team involvement that included the parents, HROB, MFM, Pediatric Palliative Care and the Neonatal and Pediatric divisions. The plan of care was flexible with clear documentation of the goals and wishes of the parents' pregnancy, labor and delivery, and infant care. The plan focused on the parents wish that the birth as well as the death be as natural as possible. The parents wanted to hold and feed their infant, and give only those measures that would provide comfort and relieve pain and suffering. The family was adamant that they did not want intubation, oxygen, cardio or respiratory monitoring, or intravenous attempts for the infant after the birth. Following multiple discussions, a POLST form was completed for the care of the infant.

In addition, both parents wanted to stay with their infant after birth and during the mother's stay in the hospital. For many reasons, the parents were unsure whether they wanted to take their baby home. It was at this point that the team needed to think out of the box and create an additional plan if the infant were to live past the mother's discharge from the hospital. Hospital protocol would have been to transfer the newborn to the neonatal intensive care unit. This transfer would not have allowed the family to remain with the infant in the way that they wished: holding, feeding, bonding, and caring for the infant in a relaxed, quiet and loving environment. The team's collaborative efforts allowed for the coordination of the infant's care and the ultimate transfer to an inpatient pediatric room with the parents.

The infant lived beyond the mother's stay in the hospital; the infant and parents were transferred to the pediatric inpatient unit supported by the interdisciplinary team. The pediatric palliative care team provided assistance and support to the pediatric team for symptom management, comfort care and psychosocial support for the infant and parents. On the fourth day of life, the infant died peacefully in the arms of the parents with other family members present. In the end, they swaddled and held their infant as they wanted.

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The journey for this family and infant was one of love and comfort. The availability of palliative care services allowed the care team to fulfill the wishes and goals of parents whose infant's health was complicated by lethal anomalies. While the life for this infant was only days, the parents were able to have their goals and wishes for their baby and family respected. In the end, a multidisciplinary approach was achieved and created profound lasting memories for a family that had to deal with the devastation of losing their baby.

Discussion

The goal of pediatric palliative care is to provide comprehensive, multidisciplinary care to the patient and family from the point of diagnosis to the resolution of the condition, whether through cure or death. The palliative care team's responsibilities include managing pain and other uncomfortable symptoms, facilitating communication, supporting decision-making, and helping to coordinate care. This case pulls together all aspects of pediatric palliative care and hospice to provide the best possible care for an unborn infant and family. Palliative care began at the point of diagnosis, in this case, the parents learning their unborn infant had a devastating diagnosis of Trisomy 13, and continued through the rest of the pregnancy, birth, life and death of the infant. The interdisciplinary approach of the team provided the family with the support they needed throughout the trajectory of this infant's short life and death. Contributing to this plan of care was the administration of the POLST, which brought together all of the medical goals of care as well as the parent's goals and wishes for the infant. The POLST brings together an actionable set of orders and becomes a part of a patient's medical record. It ensures that the wishes of that patient are fully accessible to the entire medical care team in one concise location. The POLST is available at https://www.nj.gov/health/advancedirective/polst/.

Care coordination is an important and necessary part of medical care for patients and their families who are faced with complex, chronic and life-threatening conditions. It is critical that timely medical decision planning among members of the interdisciplinary team and the family be executed jointly to prevent suffering and to improve the quality of life for children and their families. Pediatric palliative care services should be an integral part of any medical decision planning for children facing life-threatening conditions.

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CME Quiz on page 17

CME Quiz

1. Palliative care is an approach that improves quality of life in patients with life limiting illness in the last 6 months of life.
   a. True b. False

2. Palliative care goals of treatment include physical, psychological & spiritual treatment.
   a. True b. False

3. The goal of hospice is to manage symptoms & provide comfort when there is no possibility of cure.
   a. True b. False

4. The AAP supports an integrated model in which palliative care is offered to children with chronic conditions:
   a. Last 6 months of life
   b. When they develop more symptoms
   c. At diagnosis of a life-threatening illness

5. Palliative care is only to be offered to children with the following conditions:
   a. Severe neurological conditions
   b. Genetic abnormalities
   c. High-risk malignancies
   d. All of the above

6. In which state was the POLST first initiated:
   a. New Jersey
   b. Oregon
   c. New York

7. POLST stands for:
   a. Pediatric orders for life sustaining treatment
   b. Physician orders for life sustaining treatment
   c. Position on life sustaining therapy
   d. Practitioner orders for life sustaining treatment

8. In which year was legislation signed into law regarding POLST in New Jersey?
   a. 2011
   b. 2004
   c. 2013

9. POLST can only be signed by the patient's attending.
   a. True b. False

10. POLST is valid only in the hospital setting.
    a. True b. False

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