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Review Article

# Policy Advocacy to Advance Pediatric Palliative Care; A Call for Action

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**Abstract**

Approximately 55,000 pediatric deaths occur annually in the United States. Estimates suggest that more than half of all pediatric deaths occur in a hospital. Within hospitals most of those deaths happen in a critical care unit, such as the pediatric intensive care unit or the neonatal intensive care unit. The death of a child will never be easy to accept or manage. Healthcare professionals, policy makers and all advocates for children can and must do more to integrate palliative care for any child living with a life limiting illness.

**Keywords:** Pediatrics; Palliative care; Policy; Children living with life limiting illness; Pediatric critical care

## Introduction

According to the Centers for Disease Control and Prevention there are approximately more than 2 million children living with a life threatening illness in the United States (www.cdc.gov). The medical care of terminally ill and incurable children creates tremendous stress and financial burden, on an already taxed system [1]. The goal of improving pediatric palliative care services is to increase funding to educate and support pediatric palliative care services for any child with a life threatening illness thus ensuring that pediatric patients and their family's healthcare needs are given the attention and priority they deserve.

In the United States, key stakeholders, including state and federal policy makers have an obligation to make fiscally prudent decisions regarding healthcare spending and be committed to the imperative to spend our dollars wisely. Many times the attention and allocation of resources does not reach our most vulnerable and smallest of patients, our children. Enhancing and increasing pediatric palliative care services can serve a dual role of providing compassionate care and improving quality of life for children with an incurable illness, honoring their childhood while relieving an overtaxed healthcare system redirecting resource allocation.

Pediatric patients living with a life limiting or terminal illness, who would benefit from palliative care services die a prolonged death in hospital settings or more specifically in intensive care settings [2,3]. Daily costs of intensive care approximately ranges from $2,000-$3,000 per patient per day in the United States (www.cms.gov/). The average pediatric intensive care unit contains 25 beds, what's more, pediatric intensive care units are expensive to build and staff, so adding extra intensive care unit beds represents an enormous cost burden for the consumer of healthcare and the public. Because bed shortages jeopardize both quality patient care and access to intensive care it is essential that we examine methods to foster both quality patient care and development of pediatric palliative care programs.

The Affordable Care Act and other policy changes have created an environment of rapidly evolving models of healthcare. As palliative care responds to these changes, research and funding must be directed to enhance the care environment to support our pediatric patients living with a life limiting illness in need of palliative care. The Children's Project on Palliative / Hospice Services (Chipps) defines pediatric palliative care as a philosophy of care delivery to children living with life-threatening illness or life limiting conditions and their families. Improving pediatric palliative care services and access to care remains an elusive legislative goal and surprisingly the past several years have been lacking in enacting legislation to support pediatric palliative care. There is a growing need to change the restrictive Medicaid hospice regulations in order to open access to hospice and palliative care services for children. Furthermore, Pediatric palliative care legislation has been absorbed within Maternal Child Health services thus reducing the exposure and minimizing the publicity of the issue.

## Scope and Severity

The current healthcare system tends to fail pediatric palliative care patients and the experience of pediatric patients and their families can be variable. This vulnerable population, children and their families are left to make meaning of their experience in a system that is designed to cure [4]. This is especially true for terminally ill children who have an incurable disease and for whom no cure is possible.

Approximately 22,000 incurably ill children are not well-served by a system intended to cure as opposed to improve the quality of life of these children. The lack of adequate provision for incurably ill children harms them, their families, and society. Evidence widely indicates that incurably ill pediatric patients are not dying at home or in the comfort of a hospice setting; rather they are more likely to die in the high tech arena of an intensive care unit or an inpatient hospital unit [5]. More than 2.4 million deaths are recorded yearly in the United States. Most of these deaths, close to 80% occur in hospital settings, where one-fifth of Intensive Care Unit (ICU) patients die [6]. Incurably ill children dying at home or in a palliative care setting may alleviate the issue of intensive care bed shortages that many hospitals have. The availability of intensive care beds would benefit the public health, safety and well-being of communities who can at times be forced to travel in emergent situations for symptom management to distant locales for lack of intensive care availability.

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**Table 1**: Steps to improve quality pediatric palliative care.

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|---|---|
| 1 | Funding is needed in New York to ensure that every child who is living with a life threatening illness has access to palliative care services, in their communities, surrounded by family and friends. These services would most obviously benefit children and their families. What's more, hospitals would benefit appropriately as these children would be cared for in their homes within their communities therefore reducing costs and reducing bed shortages in acute care settings. |
| 2 | Providing support for training and education for clinicians in effective communication skills; this would augment all healthcare patient related quality service as well as safety, including but not limited to end-of-life. |
| 3 | Support mandating clinicians in inpatient and outpatient settings to discuss goals of treatment and values and beliefs regarding end-of-life care with patients and their families and document these discussions to allow for transparency and seamless care across all disciplines and providers. |
| 4 | Developing incentive programs to support these aforementioned issues. |

**Table 2**: Process of action.

| S.no | Action Plan | Low | Medium | High |
|---|---|---|---|---|
| 1 | Increase population of children served by palliative care programs. | Raise public awareness of pediatric palliative care programs that are available. | Conduct research to examine efficacy of pediatric palliative care programs | Mandate healthcare professionals (i.e.: physicians, nurses, social workers) to communicate and initiate open dialogue to all families with a new diagnosis or have children living with a life limiting illness regarding pediatric palliative care |
| 2 | Increase palliative care services for pediatric patients across the continuum. | Enhance communication across the continuum of care to allow for earlier referrals to palliative care. | Interdisciplinary healthcare providers joining forces to educate public policy makers of the cost savings and humanistic value of advancing pediatric palliative care. | Support the reintroduction of S. 1150: Advance Planning and Compassionate Care Act of 2009 |
| 3 | Increase education across the spectrum on pediatric palliative care. | Create organizational cultural competencies for all members of the healthcare team in relationship to pediatric palliative care | Support programs and create P&P's to sustain pediatric palliative care providers. | Enact procedures of education including in all curriculum of healthcare professionals (i.e.: physicians, nurses, social workers) pediatric palliative care. |

A process of action, with details is described and defined in (Table 2).

Many times the healthcare system fails many of these vulnerable patients and families leaving them feeling isolated and overwhelmed and at times the repercussions of their child's illness affect the family for many years. In a recent article in Pediatric Annals the mention of support for these families at the onset of a diagnosis of a life threatening disease, medical crisis, or after the death of a child is inadequate; furthermore the healthcare professionals who do this sacred work have minimal or no support [7]. Conflicting treatment goals, challenging conversations and ongoing exposure to a family in crisis in tandem while honoring families' wishes can be daunting.

## Problem Statement

The American Academy of Pediatrics has a published policy statement on Palliative care for Children. In 2008 three states passed the ChiPACC Act (H.R. 6931), The Children's Project on Palliative Care / Hospice, Massachusetts, Colorado and Florida. Towards the end of 2008, California passed the pediatric palliative care waiver that ensures children with life threatening illness have access to comprehensive palliative care. Unfortunately over the course of the past several years there have been multiple attempts at proposing legislation related to improving pediatric palliative care however they have not been passed nor reintroduced at this time. Federal support is needed to improve access to palliative care service to children who may benefit from these important programs. Pediatric palliative care legislation has been absorbed within Maternal Child Health services thus reducing the exposure and minimizing the publicity of the issue. Understandably in the current economic climate where budgetary issues are paramount to the fiscal success of our nation, the need to cut costs is justifiable. This proposal of enhancing the palliative care services of pediatric patients is an opportunity to support quality patient care outcomes while correlating a positive financial impact.

Some of the model legislation that the above mentioned three states have passed has addressed access to pediatric palliative care issues as well as increasing public awareness to palliative care and its available pediatric programs. For example, Florida currently has in place a section 1915(b) waiver covering children's hospice services. Colorado's section 1915(c) waiver was recently approved by the Centers for Medicare and Medicaid (CMS). Massachusetts Health Reform Law of 2006 included a pediatric initiative with a one-time $800,000 appropriation to pay for hospice services to children. Furthermore, the Department of Public Health of Massachusetts recently selected ten hospices to receive $55,000 in funding to train develop and implement integrated palliative care programs. Most recently New York State has passes a mandate that allows children with a life threatening incurable illness with a prognosis of mortality within the year to be accepted into a palliative care program. This is a paradigm shift from the previous prognosis of less than six months of years past. This is wonderful news for these children and their families; however we still have a ways to go to move this agenda for our most vulnerable children forward.

In a 2005 press release, Health and Human Services Secretary Mr. Leavitt expressed commitment to assist states interested in waiving hospice regulations. The federal regulations in place at times prevent families from accessing palliative care services for their children with incurable illness, including hardships for families, by unnecessary admissions to emergency rooms or intensive care units leading to duplicity of medical tests and services.

Additional support is needed from federal legislators to facilitate concurrent reimbursement for integrated palliative care programs would allow for better coordination and continuity of care, reducing emergency room visits, shorten or decrease intensive care unit visits and prevent duplicative tests and exams. It is time to capitalize on the growing momentum to change restrictive Medicaid hospice regulations.

The goal of pediatric palliative care legislation is to ensure adequate palliative care services is rendered to pediatric patients while ensuring that appropriate education for clinicians while encouraging service in this specific practice area in order to meet patient care and service demands. More specifically there are several relatively simple steps to take to improve quality of pediatric palliative care while incorporating this into legislation; defined in (Table 1)

Recent data published in the Archives of Internal Medicine suggests that when patients and families have earlier and effective communication about end-of-life care, the result is improved quality end-of-life care thus minimizing life sustaining measures that prove to be ineffective and costly [8]. Consequently by improving communication about end-of-life care allows healthcare providers an ability to improve quality of care while reducing costs.

In the late 20th century and into the 21st century, the palliative care movement gained momentum as a patient centered care approach. In 2003, more than 1,025 hospitals had formal palliative care programs and between 2000 [9] and 2005 the number of existing programs grew to 96 percent. With this rapid diffusion of innovation, hospital-based palliative care programs were beginning to show an impact on clinical and non-clinical outcomes. Unfortunately most of this forward movement has been focused with adult patients and children and their families have been stagnant in their growth of palliative care programs.

The value and evidence based approach of palliative care is synonymous with caring holistically for the patient and their family with a focus on palliation and avoiding all non-essential invasive procedures thus leading to a more patient centric approach that is in alignment with the patient or families goals of care [10]. Palliative care has been shown to improve patient outcomes, quality of life and cost containment and fiscal effectiveness. According to a study by White and Cassel they consistently demonstrated a cost savings of 14-40 percent or more in direct or variable costs per day for the last three to six days of a patients' admission (2009) [11]. What's more, a referral of pediatric patients to palliative care programs and its services may decrease admissions to the intensive care unit thereby eliminating the high number of children who die in the acute care setting.

The *2003 Institute of Medicine (IOM) report when Children Die: Improving Palliative and End-of-Life Care for Children and their Families* [12] discussed the lack of pediatric palliative care education and training for healthcare providers in both nursing and medicine. This report alludes to the argument of the need for pediatric care and points to the lack of available services. The disclosure of these sobering facts highlights attention to this public health problem and is the first step in this process.

Suggestions made by 485 critical care nurses to facilitate a good death included advocating dignity in the dying experience, treating pain, facilitating earlier limitations of life-sustaining treatment or not initiating it, demonstrating presence, gaining information and carrying out wishes, and communicating effectively across the healthcare disciplines [13].

While partnering with the healthcare community to enact legislation that supports palliative care efforts, and utilizing the Framework for Action model through professional associations, we may be able to move legislation forward. There are currently several national initiatives such as ELNEC, The End-of-Life Nursing Education Consortium, CAPC- The Center to Advance Palliative Care, ChiPPS- The Children's Project on Palliative Services are some groups who are working on methods to enact change using national, local and public associations.

A process of action, with details is described and defined in (Table 2).

There is a broad range of key stakeholders, each with vested interests, including, hospitals, academic programs, patients, families, communities and practitioners. Lack of inpatient critical care beds hinder both access and quality care. New influx of funding has the potential to increase availability of critical care beds, improve resource utilization and enhance education of practitioners' thereby increasing patients' access to high quality care. According to CMS (center for Medicare and Medicaid services) Daily ICU costs approximately range from $2,000 - $3,000 per patient per day in the United States. (www.cms.gov/ ). The public would be assured, if providing anticipatory palliative care there is substantial cost savings of healthcare dollars.

## Policy Alternatives

Measures of outcomes of increasing pediatric palliative care services would include the following: more acute care beds available for trauma or lifesaving treatments and utilizing healthcare dollars spending on acute care needs.

Policy alternatives for resolving the issue of increased funding for pediatric palliative care services and education include the following:

1. Do Nothing Option: Continue with current practice
2. Change Option: Funding of pediatric palliative care programs and education of caregivers in this specialty and develop incentive programs to sustain palliative care programs.

Making no change is not a viable alternative as healthcare spending continues to rise and access to care becomes more and more of an issue. Educating and promoting pediatric palliative care can reduce hospital length of stay and improve quality of care [14]. There are more than 2 million children living with a life threatening or incurable illness in the United States, and amongst those children 75% have a chronic complex condition. Approximately 55,000 pediatric deaths occur in the United States annually. Because the pediatric population is not homogenous in nature and includes a wide range of diagnoses, this may result in an already small and vulnerable group scattered across the healthcare delivery system perhaps leading to fragmented and inability to access appropriate care. In 2003, estimates suggest that more than 56% of pediatric deaths occurred in the hospital setting. Currently there are more than 100,000 healthcare professionals serving these critically ill children and their families and the need for improving palliative care serves in pediatrics has never been as important [15].

The current federal hospice eligibility requirements can be a serious obstacle for families who are trying to access these services for their children. In order to receive hospice services, a physician must declare, and parents must sign a written statement that the child has less than six months to live and the family must forego any treatment intended to cure their child's disease or prolong their life (e.g.; chemotherapy, dialysis, radiation, transplant rejection medications).

These regulations that were developed in the 1970's are based upon adult protocols and have serious implications for adults but are even more problematic for children. Because these federal regulations are implemented by private insurance companies the impact of these seemingly archaic regulations extends to Medicaid and private insurance agencies.

Providing compassionate healthcare to dying children is a rewarding endeavor, but it is also very challenging. The social determinants of health interplay with insurance issues and access to care; at times the ability to provide comprehensive palliative care is inadequate [16]. These aforementioned themes suggest the ability to meet the current and future demands will continue to tax the current healthcare system. Therefore it is urgent for state policymakers to enact the model legislation and provide a budget impact estimate for the good of hospitals, communities, practitioners and most importantly, patients and their families.

Positive externalities are the additional funds spent on palliative care services will save the healthcare system money later. Disparity in healthcare is not bound to race or socioeconomics, but to ethnicity and health status [17]. Often children at the end of life are not provided the social justice deserved and their rights to determine the manner of care at end of life are overlooked by health professionals and family members [18]. Although various cultures approach death different through traditions, processes of grief, or celebrations of lives lived; death can be a unifying event [19,20]. Celebrations of life through palliative care programs can cross intergenerational, ethnic, gender, religious and political boundaries [21].

Negative externalities are the potential for wrongful death suits in relationship to patients and their families who may have not been ready for palliative care services and a patient dies without the family's acceptance of the child's mortality. What's more, differentially the legal judgments for claims affect children and their families with a greater impact because of the years the children may have lost and the loss of potential life. Furthermore if a pediatric palliative care patient lives longer than expected with palliative care services the projected cost savings may not be as substantial.

## Recommendations

The goal of improving pediatric palliative care services is to increase funding to educate and support pediatric palliative care services for any child with a life threatening illness thus ensuring that pediatric patients and their family's healthcare needs are given the attention and priority they deserve. Public policy makers, hospitals, communities, practitioners and patients and their families as well as the public all have vested interest in improving the pediatric palliative care system.

Instead of placing focus primarily on palliative care programs for adults, it is essential to refocus efforts on children and place these vulnerable children's needs as a priority. What's more by addressing and supporting the system needs of the pediatric palliative care patient it will allow for appropriate resource allocation and improve the quality of life for the 2 million children living with a life threatening illness across the United States. This would assist in integrating palliative care services into communities of children with incurable disease in order to provide to the greatest degree continuity of care and if desired, death at home. For example, better coordination and continuity of medical treatment helps to reduce preventable emergency room visits, avoid or shorten hospital stays and prevent duplicative tests and exams. These services would also attend to the needs of dying children and their families, for whom cure is no longer an option, throughout the dying and grieving process.

Research has shown that initiating palliative care early in the trajectory of a life threatening illness improves quality of life, patient's perception of their care and a decrease in patient's dying in the intensive care unit / acute care setting, thus reducing spending and allowing for more availability of an intensive care bed. Furthermore providing patients and their families' accurate and current information on pediatric palliative care is essential [22]. In an article published in the Journal of the American Medical Association the authors discuss how families and individuals make meaning out of a life threatening illness. This poignant article reiterates how imperative it is to maintain skilled methods of communication when families are enmeshed in medical crisis.

Healthcare providers are in a perfect position to educate and advocate for pediatric palliative care patients and their families care. Families who are coping with an incurably ill child need expert support. Caregivers trained to provide this support are in short supply. Increasing the number of caregivers who can support these families with advocacy and education is a priority. The cost of training such caregivers is estimated to be $1,000 - $5,000.

As a nation economically we need to take care of our nation's greatest resource, our children. What better way than to increase pediatric palliative care services and ensuring that every child who is living with a life threatening illness has access to palliative care services, in their communities, surrounded by family and friends. This will allow for more pediatric intensive care unit beds to be utilized in the most efficient and effective manner possible. Only 10% of hospitals with Emergency Rooms have a Pediatric Intensive Care Units (PICU) and the average number of PICU beds is 25. By minimizing the acute care bed shortage, which can cost between $2,000- $3,000 per patient day, has the potential of cost savings to healthcare institutions of 2-3 patient beds per day as well as the healthcare system and its constituents.

More specifically the monitoring and involvement of primary providers with whom patients and their families already have a relationship with will minimize the potential for litigation against healthcare systems for wrongful death suits. Evidence has shown that patients are less apt to bring legal action against a care provider that they have a positive relationship with. Furthermore, in the case of a patient living longer than expected within palliative care thus increasing spending, the cost savings of avoiding an inpatient/ intensive care hospital stay, far outweighs the cost spending of palliative care services.

The care of children with a life threatening or life limiting illness creates tremendous stress and adds to the mounting strain and financial burden on children's families, acute care settings and the community. It is essential that we examine methods to foster high quality patient care, support for families caring for a sick child and development of pediatric palliative care programs and providers.

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