



**Challenges and Opportunities to Improve Pediatric Palliative Care
in Maryland**

Report of the Maryland Pediatric Palliative Care Summit

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On Behalf of the participants of the Summit

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Executive Summary

Overview

Nearly 1,000 of the more than 40,000 people who die each year in Maryland are children under 18. With each of those deaths, a pediatric palliative care program can offer support to the child and to the family through the dying process and beyond. The purpose of such care is to help children live well, to give them and their families as normal a life as possible and to support families when their child dies.

Description

In fall 2004, more than 40 knowledgeable parents and healthcare professionals attended the Maryland Pediatric Palliative Care Summit to discuss challenges and opportunities for pediatric palliative care in the State. Hosted by the Johns Hopkins Children's Center's Harriet Lane Compassionate Care Program, the summit chronicled the state of pediatric palliative care in Maryland, identified gaps in the clinical care, financing, and policy that affect the care of dying children and their families, and created a model of parent-professional cooperation.

Findings

The summit findings focused around five central themes: denial of death, compassionate communication, continuity of care, public education, overcoming barriers, and current programs and services.

Recommendations

At the summit, the participants agreed upon eight recommendations to improve pediatric palliative care in Maryland:

1. Make palliative care services family-centered.
2. Integrate palliative care with curative care.
3. Educate families, healthcare professionals, and the public.
4. Develop innovative models of care delivery.
5. Improve facilities and space within hospitals to provide palliative and end-of-life-care.
6. Develop pediatric-focused policies and practices.
7. Develop interdisciplinary, state-wide models for the provision of pediatric palliative care from pre-natal through adolescence.
8. Establish resource networks for professionals and parents.

Next Steps

The release of this report, "Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland," documents the summit and identifies the participants' findings and recommendations. These same advocates have since established the Pediatric Palliative Care Coalition of Maryland (PPCCM), which is now refining action steps to accomplish the recommendations and is exploring other opportunities for collaboration and education.

Background

“When Children Die”

In 2003, the Institute of Medicine released its report “When Children Die” and fueled national interest in pediatric palliative care. This came very late in the national agenda, more than a decade after initiatives like “Last Acts” brought death and dying to national prominence. In the years since, a wide range of efforts have defined palliative and end-of-life care, developed models, and created resources for adults facing the dying process.

The focus on children came late for a host of reasons. First of all, denial of death in childhood is strong. Children are not supposed to die. When a child becomes seriously ill, the outcome is often uncertain and the disease trajectory unpredictable. Adults, usually the child’s parents, must determine what is in the child’s best interest in a complicated process that involves deeply held values and beliefs. Finally, the drive to give the child a chance at life can create a cure orientation that sets high thresholds for the burdens of treatment and uses technology close to the time of death.

What Is Pediatric Palliative Care?

What is pediatric palliative care? According to the Institute of Medicine (2003), it supports and comforts children with life-threatening illnesses or injuries. Family-centered, it offers a philosophy of care and an organized model of care that brings all the professions together in an interdisciplinary team to support the child and family.

The purpose of pediatric palliative care is to help children live well, to give them and their families as normal a life as possible. This means offering children and families—especially parents, brothers, sisters, and grandparents—the emotional and spiritual support they need. It means helping families make decisions, by giving them timely and truthful information and by respecting the families’ choices, values, and cultural traditions. Preventing or relieving pain and other physical, emotional, and spiritual distress is fundamental. Based on a model of shared decision-making, children, their parents and health care professionals engage in an evolving process of advance care planning, goal setting, and bereavement support.

Pediatric palliative care works with—not instead of—other treatments. Ideally, it can start as soon as the family knows the child is ill and continue through bereavement. Above all, it does not mean “giving up.” Letting go of our dreams for cure does not mean that we are abandoning caring for the needs of the child and family throughout the disease trajectory. It can help all seriously ill or injured children, not only those who are dying, to live well.

For children who are nearing death, the continuum of palliative care includes end-of-life and hospice care. At this time, the goal is to help each family ease their child’s pain and other symptoms, keep their child calm and comfortable, make decisions about the use of life support, talk about last wishes, and, finally, grieve the death of the child.

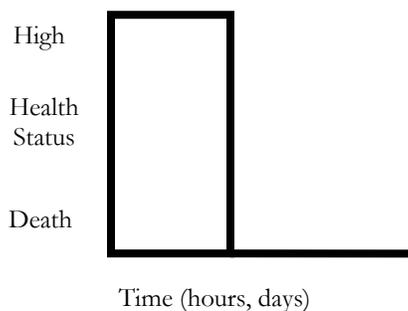
Pediatric palliative care encompasses providing pain and symptom management, psychosocial, spiritual and bereavement support, advance care planning, and coordinated services in the hospital, home and community for children who live with an array of life-threatening conditions. These conditions include but may not be limited to prematurity, genetic syndromes, cancer, AIDS, heart, lung, kidney and neurodegenerative disorders, as well as conditions that arise from traumatic injuries. The continuum of palliative care includes hospital, long term care, home care and hospice. Expanded models of palliative care advocate for integration of palliative and end-of-life services from the time of diagnosis throughout the course of the illness or death, followed by bereavement support (IOM, 2003).

Who Can Benefit?

Who can benefit from pediatric palliative care? Dying children have unique needs. And children do die. Worldwide there are an estimated seven million children and their families who could benefit from hospice services, and even more who could use the support offered by palliative care programs. In the United States, an estimated one million children are very seriously ill. Of the 55,000 children and youth who die annually in the US, one third of them die from life-threatening conditions, while nearly one-fourth succumb to sudden injuries (IOM, 2003). Since most children with life threatening illnesses receive aggressive care until death, the majority of children die in institutions-acute care hospitals, long term care facilities or rehabilitation centers. Of those who die in hospitals, the majority die in critical care units reflecting the aggressive use of life sustaining technologies close to death (IOM, 2003). In contrast to older adults, less than 1% of children needing hospice receive it (Children’s Hospice International, 2005).

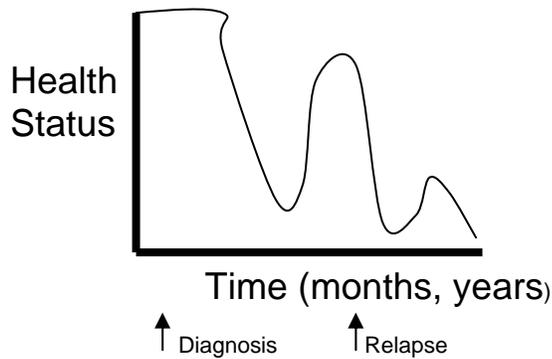
Death in childhood follows several common trajectories. About half occur during infancy, most of them soon after birth, and some later as a result of sudden infant death syndrome. For older children, sudden death results from injuries, intentional and unintentional, which account for about 30% of child deaths. For both of these groups, death occurs suddenly from unexpected causes (Figure 1). For other children, death is expected. It may come from a progressive disease such as cancer with a terminal phase and gradual decline toward death (Figure 2). More frequently, it comes as the child experiences an advanced illness, a slow decline, periodic crises, and then “sudden death” (Figure 3) (Institute of Medicine, 2002).

Figure 1



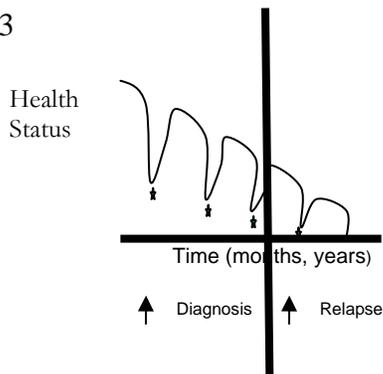
Sudden, unexpected death (IOM, 2002)

Figure 2



Death from potentially curable disease (e.g., brain cancer) (IOM, 2002)

Figure 3



Death from progressive condition with intermittent crises (e.g., muscular dystrophy) (IOM, 2002)

Children in the second two groups, who live with chronic, life threatening conditions, pose special challenges in designing models of care. A study done in the state of Washington of deaths of 8893 children and young adults aged 0-24 measured the depth of this problem. One in four, or 25%, had complex chronic conditions. Of infants with these conditions, 84% died in hospital and 50% were mechanically ventilated during terminal admission. For these infants, from 41% to 92% of all days of life were spent in hospital. Of the older children and young adults with complex chronic conditions, 55% died in hospital. Prior to death, their conditions were expected to last at least 12 months (unless death intervened); either several organ systems were involved or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center (Feudtner, DiGiuseppe, Neff, 2003). Clearly, grief is prolonged and has lifelong consequences, for the family and the entire community.

A second study documented the depth of suffering through interviews of 103 parents of children who died of cancer and who were cared for at two hospitals in Boston, where they received aggressive treatment at the end of life. Eighty-nine percent of the parents reported that their child suffered substantially from one to three symptoms during last month of life, most commonly pain, fatigue, or breathing difficulties (dyspnea). Attempts to control these symptoms were largely unsuccessful. Suffering from pain was more likely in children whose parents reported that the physician was not actively involved in providing end-of-life care (Wolfe et al. 2000).

A more recent study evaluated the circumstances surrounding the deaths of 105 hospitalized children at Vanderbilt Children's Hospital underscores the opportunities for palliative care. Most (87%) were in an intensive care setting at the time of death, either pediatric critical care (56%) or neonatal intensive care (31%). Almost 90% of the children received pain medication in the last 72 hours of life, and 55% received additional comfort care measures. Averaging seven days, these final stays offered sufficient time to provide interdisciplinary palliative care. Yet other symptoms, specific interventions, and family support were infrequently documented. For example, healthcare professionals documented discussion of the child's situation with the family in only 23% of the records, a do-no-resuscitate decision in only 42% (Carter et al. 2004).

The findings of these three studies and the situations in the states Washington, Massachusetts, and Tennessee are not atypical. Sadly, as the Institute of Medicine made clear in "When Children Die," they are representative of the situation across the nation and at home in Maryland.

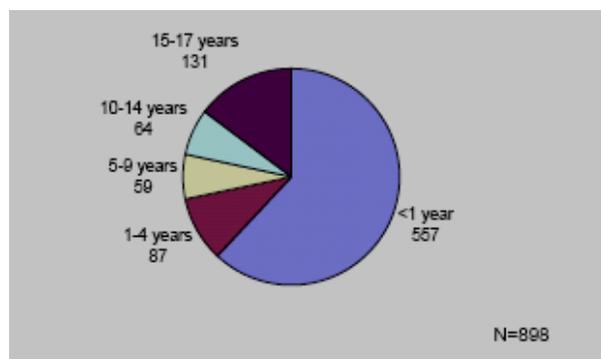
Childhood Deaths in Maryland

The Center for Maternal and Child Health in the Maryland Department of Health and Mental Hygiene published the *Child Death Report* (2003). (Retrieved April 4, 2005, from the <http://www.fha.state.md.us/mch/pdf/ChildDeathReport2003.pdf>.) This analysis of mortality data from the Vital Statistics Administration provides a foundation for assessing the needs of children and families facing life-threatening conditions in Maryland.

Of the almost 44,000 people who die each year in the State of Maryland, fewer than 1000 are children under the age of 18 years. (Maryland Department of Health and Mental Hygiene (2002). *Maryland Vital Statistics Annual Report 2002*. Retrieved April 4, 2005, from the <http://mdpublichealth.org/vsa/doc/02annual.pdf>.) In 2002, 898 children died, 62% of them under one year of age. (Figure 4) Infants under one month of age accounted for 45% of all childhood deaths, infants between 1 month and 1 year accounted for 17%, and older adolescents (ages 15-17 years) made up the next largest age group, accounting for 15% of deaths under age 18 years. This pattern of deaths aggregating in the very youngest and the oldest pediatric age groups indicates that palliative care programs must be designed to care for children at very different levels of physical and cognitive development.

Figure 4: Number of child deaths by age group, Maryland, 2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene



As shown in Table 1, the causes of death in infancy are prematurity and low birth weight, congenital malformations, sudden infant death syndrome, and perinatal complications. Except for SIDS, these deaths occur primarily in hospital nurseries, mandating the need for palliative care services in these facilities. Although cancer is well known as a cause of death in children, it is second to unintentional injury for children age 1-14 years. Among older adolescents (15-17 years), cancer falls to fourth place after unintentional injury, homicide, and suicide. Homicide is the fourth leading cause of death in children age 1-4 years. Therefore palliative care services are needed in pediatric trauma centers, including rapid response bereavement care for the loved ones of critically injured children, including parents who intentionally injure a child, causing his or her death. Of the chronic conditions that cause child death, congenital malformations persist as an important category into the early adolescent years, indicating that many children born with life-limiting conditions live for many years prior to death. Palliative care programs must respond to the long-term needs of children and families for continuous, comprehensive, coordinated care and support.

Table 1: Leading Causes of Death by Age Group, Maryland 2000-2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

<1 year of age	1-4 years	5-9 years	10-14 years	15-17 years
Low birth weight, short gestation	Unintentional Injury	Unintentional Injury	Unintentional Injury	Unintentional Injury
Congenital malformation	Cancer	Cancer	Cancer	Homicide
Sudden infant death syndrome	Congenital malformation	Heart disease	Homicide and suicide	Suicide
Complication, mother	Homicide	Congenital malformation	Heart disease	Cancer
Complication placenta, cord	Heart disease	Septicemia	Congenital malformation	Heart disease

Pediatric palliative care services must be culturally sensitive and respect the diversity of ethnic, religious and cultural values, beliefs and practices. In 2002, African-Americans infants died at 2.4 times the rate of white infants in Maryland. This ratio remained elevated at 2.0 for older children 1-17 years of age (Table 2). These health disparities must be addressed to reduce the death rate among African-American children. For children whose deaths cannot be prevented, respectful and competent palliative care services must be provided.

Table 2: Deaths, 1-17 years, by race, Maryland, 2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

2002	Deaths (1-17 years)	Death rate
African-American	166	38.0 per 100,000 population
White	155	19.4 per 100,000 population

Most child deaths occur within the state’s major metropolitan areas (Table 3). Nearly half occur in the Baltimore Metro region, which includes Baltimore City and Baltimore, Anne Arundel, Carroll, Howard, and Harford Counties. Clearly palliative care services must be available in Central Maryland. Importantly, a significant minority of deaths occur outside metro areas, with equivalent numbers in Northwest, Southern, and Eastern Shore Maryland. This geographic spread demands creative solutions to providing access to comprehensive pediatric palliative care services throughout the state.

Table 3: Maryland Child Deaths by Region, 1998-2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

1998-2002	< 1 year of age	1-17 years	Total
Maryland	2908	1698	4606
Northwest	158	123	281
Baltimore Metro	1350	873	2223
National Capital	1058	462	1520
Southern	146	101	247
Eastern Shore	196	139	335

The Summit

On October 14, 2004, a group of more than 40 parents and professionals gathered at the Johns Hopkins University School of Nursing for the **Maryland Pediatric Palliative Care Summit**, hosted by the Johns Hopkins Children’s Center Harriet Lane Compassionate Care Program. The intent of the Summit was to:

- Chronicle what pediatric palliative care programs and services are currently being provided in Maryland.
- Identify the gaps in clinical care, financing, and policy that affect the care of children in need of palliative and end-of-life services.

- Develop recommendations for moving forward to improve the care of children who could benefit from palliative care within Maryland.

The Participants: Involving Parents and Professionals

To succeed in these aims, the Summit brought together representatives who provide care across the care continuum and serve special populations. Professionals attending the meeting represented healthcare professionals from medicine, nursing, social work and chaplaincy, healthcare administration, and other organizations involved in caring for children in need of palliative and end-of-life services. All had been selected by their organizations as knowledgeable about the resources for pediatric palliative care and prepared to discuss the issues that affect clinical areas, financing, or policy. Many were selected as having the influence or authority to propose and act on recommendations within their agency or organization. Participants were invited to contribute information on resources their organizations provide prior to the Summit meeting. Participants and the organizations they represent are listed at the end of this report.

The Summit was unique in that it brought together a wide range of professionals with a small group of parents, each of who had used or was using palliative care services for their child. A key component of pediatric palliative care is a family centered model of care that recognizes the significant role parents play in care for their children. Therefore any recommendations, policies, or outcomes of the Summit would be incomplete without parent involvement. In recognition of this, a parent advocate was involved in creating the agenda for the Summit and the format was designed to facilitate parents and healthcare professionals collaborating on solutions.

In addition to inviting a parent to deliver the keynote, the Summit featured a formal moderated discussion among three healthcare professionals and three parents. Two of the parents had experienced the death of a child, one after a long bout with kidney disease, the other with a rapidly advancing brain tumor. The third parent cares for a child with cystic fibrosis, a life-threatening chronic condition that requires palliative care. The healthcare professionals represented diverse roles and specialties including pediatric oncology, hospice nursing and a bereavement professional. This discussion and other informal interactions provided touchstones and served to validate the group's findings over the course of the Summit. The group quickly coalesced into a collegial atmosphere focused on creative problem-solving and sharing of common concerns and experiences.

The Program: Learning from Existing Efforts

This sharing was enriched by a review of national initiatives in pediatric palliative care, including brief summaries of the recommendation framed by the Institute of Medicine:

- Children should have care that is focused on their needs and the needs of their families
- Health plans should make it easier for children and families to get palliative care
- Healthcare professionals should be trained to give palliative care to children
- Researchers should find out more about what care works best.

Core ideals were identified as central to these recommendations on behalf of dying children and their families. These ideals are:

- Child oriented, family oriented
- Open communication
- Intensive symptom management
- Psychosocial and spiritual support
- Timely access to care
- Flexibility

To help the participants in addressing palliative and end of life issues for Maryland, an overview of initiatives in other states highlighted a number of efforts. The Robert Wood Johnson Foundation has been supporting 22 projects to promote excellence in end of life care, two of them focused on pediatric palliative care. One in the state of Washington is bringing together hospital, health department, insurers, and hospices. The other in Missouri-Illinois involves a regional program, a hospital, and a medical school.

The Children's Hospice International Program for All-Inclusive Care for Children (CHI PACC), part of the Center for Medicare and Medicaid Services, has launched demonstration projects in Colorado, Florida, Kentucky, New York, Virginia, Utah, and New England (including Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, Connecticut). These projects are devising innovative care delivery and financing models to improve the care of children living with life threatening conditions.

The Initiative for Pediatric Palliative Care (IPPC) is a national education, quality improvement and research project led by Education Development Center in Newton, MA. It has designated six IPPC sites, including Children's Hospital and the Dana Farber Cancer Institute in Boston, Children's Mercy Hospital in Kansas City (MO), Children's Hospital of Philadelphia, University of California San Francisco Children's Hospital, Vanderbilt Children's Hospital in Tennessee, and Johns Hopkins Children's Center in Baltimore. These institutions have implemented diverse quality improvement projects and are working with IPPC and other professional organizations to develop curricula for interdisciplinary training.

A representative from Maryland's Attorney General's Office shared recent statewide legislative and policy initiatives that may have impact on the provision of palliative care, with special implications for pediatrics.

Summit Findings

Through the day-long Summit meeting, participants discussed the current state of pediatric palliative care as they identified barriers and formulated recommendations. Five central themes emerged:

Denial of death. Both parents and professionals acknowledged the difficulty in comprehending that some children cannot be cured of their disease and will die. Parents and different members of the healthcare team may arrive at that conclusion at different times creating the potential for conflicts and resistance to efforts to incorporate palliative interventions into the child's care.

Accepting the sudden unexpected death of a child at any age is equally difficult. The lifelong consequences to the families of children who die are profound and largely unaddressed beyond the immediate period after death. Comprehensive programs are needed to raise awareness of the challenges these families and their children face and to provide support for them and for the health care professionals providing care.

Compassionate communication between professionals and families. Navigating discussions about diagnosis, treatment, and prognosis can be fraught with confusion and conflict. Parents struggle with accepting the limits of medicine and technology, hoping that their child will beat the often miniscule odds for survival and recovery. Often when cure is no longer possible, professionals may inadvertently convey messages that may be perceived by parents as threats of abandonment. Participants stressed that families need reassurance that their child is being cared for regardless of the outcome, that the professionals are not “giving up” when they speak of palliative care. Care of the child must be family-centered and consistent with the family’s belief systems. Professionals cannot assume that their values and the family’s are the same; they must be sensitive to the family’s needs and reactions, exercising compassion in their comments and actions. Education and continuity of care are both key to improved communication.

Continuity of care from diagnosis, through treatment, and into bereavement. Parents stressed the difficulties posed by changes in the staff caring for their children. In the curative setting, for example, new teams would take over just as the parents had become comfortable with the old one, or staff unfamiliar to the parents would initiate probing conversations. When care transitioned from curative to palliative and the location of care itself changed, problems of continuity intensified. Together parent and professionals at the Summit agreed that a stronger focus on the interdisciplinary nature of the care team could improve continuity and help to bridge the gap between curative and palliative care. Expanding the therapeutic team to include a wider array of professionals and formally introducing parents to the full team early in their child’s illness could strengthen continuity and ease decision making. Including clergy, social work, child life and hospice workers in the team, for example, could support the family in choosing whether their child would die at home, in the hospital, or in a hospice.

Education across a broad range of audiences and issues. Participants agreed that healthcare professionals and members of the public need a better understanding of pediatric palliative care and the impact of a child’s illness and death on the family. Education is central to changing the attitudes and culture of pediatric palliative care, and to improving communication between families and staff. It is likewise important to community understanding as well, regarding decisions as to whether do not resuscitate orders and hospice placement are, or are not, best for an individual child. The models developed for caring for adults at the end of life are not appropriate for pediatric palliative care and therefore new models will be necessary. Children and their families have special needs, as do the healthcare professionals who care for them. Understanding pediatric palliative care models is critical to addressing these needs and lightening the burdens they impose.

Legal, regulatory, and financial barriers. The burdens borne by dying children and their families are frequently exacerbated by regulatory hurdles and financial difficulties. Some parents must choose between the need to continue work in order to maintain health insurance and he

need to be present at the child's side throughout a lengthy illness. Often parents are faced with choosing between the provision of skilled nursing care in the home and comprehensive hospice services. In reality children and families needs would be better served by financing models that allow flexibility in services based on child and family needs. The arbitrary regulatory requirement that death is expected within 6 months, significantly limits access for some children whose death is expected but predicting the exact timing is imprecise.

Current Programs/Initiatives

Based on data supplied by summit participants, there is one pediatric palliative care program in Maryland at the Johns Hopkins Children's Center (JHCC) and a newly formed program in the nearby District of Columbia at Children's National Medical Center. The Harriet Lane Compassionate Care Program, the pediatric palliative care program of the JHCC, was created in 2000 to achieve the best possible quality of life for the child living with a life threatening illness or injury and their family and when death is inevitable, to support the child and family through the dying process and beyond. The program includes clinical support, education, bereavement support, research and advocacy. In addition to this program there are bereavement programs at the University of Maryland Hospital and selected hospice programs that provide care for children. A perinatal bereavement program at Howard County General Hospital provides services to families before and after death. Maryland Community Hospice has the largest pediatric home hospice program in the state with an average census of 2-5 patients/month. Montgomery Hospice has initiated a pediatric hospice program and Joseph Ritchey Hospice is planning to develop an inpatient pediatric hospice unit. Other hospice programs within the state occasionally provide palliative care and hospice care to children.

Several public and private health care funders were also represented. Maryland Medicaid Program's hospice care program assists family and children with meeting the special needs at the end of life. Children's Medical Services (CMS) serves Maryland's children from birth to 22 years with special health care needs who are either underinsured or who can not meet insurance qualifications can assist in securing resources for children who need palliative care services. Although Carefirst Blue Cross/Blue Shield of Maryland care management program currently only serves adults, there was interest in opportunities to expand to children. Johns Hopkins HealthCare/Priority Partners has no formal palliative care program but has a contract with a hospice agency to provide end of life services for children birth to 18 years.

Participants concluded that there are numerous opportunities for program expansion across the care continuum.

Summit Recommendations

Make pediatric palliative care services family-centered. The cornerstone of pediatric palliative care is the recognition of and respect for the central role parents and families play in the lives of children. Programs and systems of care should be designed to enhance the collaboration of parents, professionals, and policy makers in creating flexible, integrated programs.

Integrate palliative care with curative care. Both advance care planning using a goal-of-care framework for decision making and enhanced opportunities for developing relationships and effective communication between patient, families and healthcare providers are essential. Integrating palliative care from the time of diagnosis and extinguishing barriers that interfere with implementing comprehensive plans of care are foundational to new models of care delivery.

Provide education for families, healthcare professionals, and the public. Educational initiatives for families and healthcare professionals should be undertaken to communicate an integrated model of care. A standard interdisciplinary curriculum should be disseminated to institutions across the care continuum. Public education should highlight options for caring for children living with life threatening conditions and ways to support families throughout the decision making process. This would include creating new partnerships between communities and health care organizations.

Develop innovative models of care delivery. New models for creating a seamless system of care are needed for children in different disease trajectories. Collaboration should extend across all care settings, from inpatient settings to long term care and on to hospice and home care. New funding models should be created, as in other states, within current structures, bringing state agencies, state Medicaid, private insurers, healthcare institutions, and healthcare professionals together to address legal, regulatory, and policy barriers. Such models should guide the development of pediatric inpatient hospice care and expansion of resources for pain and symptom management across the continuum. In any model, continuity in implementing the plan of care among caregivers and across institutions would enhance the quality of palliative and end-of-life care.

Improve facilities and space within hospitals to provide palliative and end-of-life care. Healthcare institutions are not traditionally designed to meet the special needs of children who are dying. The lack of personal space and of sleeping space in inpatient areas, together with inflexible visiting policies, all undermine the provision of services for dying children and their families. Inpatient beds allocated specifically for palliative and end-of-life care and designated to provide aggressive pain and symptom management could ease the transition to home or other facilities and respite care.

Develop pediatric-focused policies and practices. Doing so could allow the focus to be on the philosophy of care, clarify policies regarding Do Not Resuscitate (DNR) orders, abolish the six month timeframe for expected death for hospice eligibility, and clarify issues regarding access and funding for pediatric hospice care at home. Moreover, specific family-centered palliative care policies and practices would need to be developed and implemented. Maryland's Council on Quality Care at the End of Life is an ideal mechanism to review, evaluate, and recommend policies to the Maryland General Assembly.

Develop an interdisciplinary, state-wide model for the provision of pediatric palliative care across the age continuum (pre-natal through adolescence). Using the model waiver program, state agencies and health care organizations caring for children living with life threatening conditions have an opportunity to develop a system of care and financing that is flexible, and responsive to the unique needs of children and their families.

Establish resource networks for professionals and parents. Develop a variety of resources regarding key aspects of pediatric palliative care including bereavement. A directory of existing resources, programs, and services should be made available online, including educational resources, speakers, healthcare professionals with expertise in pediatric palliative care, and parents offering support to other parents.

Next Steps

The group agreed to continue to come together periodically to advance their agenda to integrate palliative and end of life care throughout Maryland. Participants indicated a wide variety of areas where there was interest in working together in areas such as education, clinical care, collaboration with other institutions and agencies, and addressing policy and regulatory barriers. Baltimore Sun Reporter, Diana Sugg, chronicled the experience of a dying child and his family and explored issues related to pediatric palliative care in a 4-part series “If I Die” in December 2004. The current state of pediatric palliative care in Maryland and nationally was highlighted.

In May of 2005, participants re-convened to refine action steps and explore other opportunities for collaboration and education. At this meeting the participants agreed to establish the Pediatric Palliative Care Coalition of Maryland.

Summit Participants

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