

The Pediatric Palliative Care Forum

June 14-15, 2007

Minneapolis, MN

The purpose of the Forum is to bring together experienced providers in the field 5 years after the publication of the IOM Report, “When Children Die,” to take stock of the progress, needs, challenges that exist in the field today. We will work together to define next steps for this specialty practice area, develop collaborative strategies for addressing a variety of important issues including advocacy, standards for clinical excellence, funding, research, outcomes and data collection, education, training, and organization of networking in the field into the future.

The Forum’s program will be designed to encourage interaction and the exchange of ideas among participants. Our goal will be to create “products” from the meeting that will include:

- A national registry of existing programs and services in pediatric palliative care that will become web-based and web accessible to providers, families, and others. (In collaboration with the Gems of Care project)
- A report on the State of the Field: models of care, successes and challenges, and directions for future efforts.
- A plan for organizing communication, sharing of knowledge, and a central source for referrals and information related to the field as a resource for those in the field as well as those seeking to access or develop services.
- Other items to be determined by the needs of the assembly.

The field of Pediatric Palliative Care has been growing rapidly in recent years. There are now a number of providers, organizations and agencies that have significant experience in the practice of this care, and have much to share in regard to lessons learned, successful models, and mistakes that others can benefit from. The field seeks to care for children with life –threatening conditions and their families. This is “low frequency, high intensity and high impact” care. It is important that providers collaborate and share expertise to

- Minimize the potential for competition for limited resources needed to advance the field
- Maximize the development of services to kids and families
- Advocate for funding streams and service development that meets the needs of children and families
- Create efficiencies and standards of care that have been tested by practice
- Create data sets and outcome measurement strategies that will encourage benchmarking and strengthen knowledge driven growth of the field
- Develop collaborative strategies for research and advancing clinical excellence

On June 14-15, 2007, pediatric palliative care providers from the US and Canada met in Minneapolis, MN for the first Forum on Pediatric Palliative Care. This event aimed to gather experienced providers in the field of pediatric palliative care to reflect upon the state of the art of this area of practice five years after the publication of the IOM report, “When Children Die.”

The agenda was structured to emphasize discussion amongst participants, with acknowledged leaders in the field engaging the group in that process. (Appendix A) Ninety-nine people representing fifty-one programs took part. (Appendix B) Those who attended cared for over 2000 children in 2006. Programs represented were diverse, ranging from pediatric palliative care services in large, metropolitan medical centers, like Boston Children’s, and CHOP, to rural, decentralized hospice programs like Michigan’s Hospice service, and small community nursing services that provide pediatric palliative care, like Douglas County’s PHN service in Minnesota. Some programs attending have been active for five or more years, while others are in the first stages of development.

Discussion was focused into five topic areas:

1. State of the Art of Clinical Practice
2. Research
3. Models of Care
4. Outcomes and Quality Indicators
5. Education and Training

Conveners for each topic were identified as leaders in the field by consensus of a planning committee. (See Appendix A) Conveners had latitude to develop their presentation and/ or panel discussion in any manner they felt would be most effective and useful for engaging the assembly. The result was a very animated and participatory series of discussion over two days. The content of those discussions and plans that have evolved from them are summarized in this report.

The Conference

Day One: Thursday, June 14 2007

Welcome and Introductory remarks were offered by Alan Goldbloom, MD, CEO of Children’s Hospitals and Clinics of MN, and John McNamara, MD, Medical Director of Home Care and Hospice, Children's Hospitals & Clinics of MN.

Dr McNamara challenged us to consider how we can link our “islands of care” into a community that can share experiences, create sustainable programs, and win the respect of our peers for this specialty field. Also, we need to reflect upon strategies for self-care in this emotionally challenging field.

Chaplain Peter Lund read a parent’s comments about their experience with hospice and palliative care services as they anticipated the death of their daughter:

“Alaina has taught me to believe in miracles, but I’ve had to change my definition of what a miracle is. James and I have made a point of never wishing that she would live a certain amount of time. We didn’t want to define the success of her life by how long it was. Often people would say, ‘Maybe she’ll be a miracle,’ and I always resisted that idea. I guess it’s because I didn’t want to think that she would be a miracle only if she lived a long time. I believed that she was already a miracle.

And then I started to think, well what about all the other babies in the world, aren’t they miracles too? And then, what about adults? And I am left with the realization that we are all miracles, but we just don’t recognize it. And miracles happen all around us, but we just don’t see them. I guess it takes a very special little girl like Alaina to show us that we are all very special, and that miracles are occurring all around us all of the time.”

--- Jill (Alaina’s Mom)

Professor Emeritus Ida Martinson, PhD provided the keynote address. She reviewed advances in the field since her initial home hospice care study in 1974 to the present. She complemented the assembly for taking part in the development of services throughout the US and Canada, and emphasized the importance of this care for children and families. Dr. Martinson referenced studies by Steel and Davies (2006) that identified experiences and objectives set by families as they care for their dying child:

- Entering unfamiliar territory
- Shifting priorities
- Creating meaning
- Holding the fort

She further stated that Steel and Davies identified strategies that families can and do adopt to manage, and therefore gain some control over their lives:

- Seeking and sharing information
- “Slow motion” focus on the child
- Taking one day at a time
- Reframing the experience
- Living by the clock
- Promoting child health including physical, cognitive and emotional aspects

Dr. Martinson’s remarks were followed by an open microphone discussion. Comments from the assembly included:

- From a parent delegate: wished her daughter could have died at home. Families need us to make better bridges between hospitals and home services. Families need advocates and better education for themselves as well as providers they depend upon.
- From another parent delegate: Thanks for all the services offered to families now. How do we get doctors to communicate more honestly? How do we make progress in getting doctors to give more information to families? (She) recognizes it is getting better: witness that there are good physicians here. It is up to parents to ask when to stop (treatment) but physicians have to have the training to say when.

- From a physician new to this area of practice: Identified a human/children's rights issue, asks where are the children in these discussions? How can we include children's wishes? For example, teenagers are good at vocalizing; children know when they are dying.
- A number of participants thanked Dr. Martinson for her pioneering work, and many contributions to the field over her long career.

A selection of the most active programs in the US and Canada, as determined by the data sent in by participants in advance of the conference, shared their program models. (Appendix C)

- **Children's Hospitals and Clinics of MN** presented by Krista Westendorp, RN: The Pain and Palliative Care Programs are a hospital based program, including home care services, acute and chronic pain services, hospice and palliative care services as well as perinatal hospice services. The program began in 1976, and formally organized into a hospice service in 1992. The Karuna Palliative Care program was developed in 1999. The program provides consultations services, as well as direct care through the home based palliative care program. The program sees about 200 children per year, and has an average daily census of 75-80 patients in the palliative care program. Patients' diagnoses are from a wide variety of diagnostic groups, including about 30% hematology-oncology, 30% neuro-degenerative and /or chromosomal abnormalities, and 30% traumatic injuries or congenital abnormalities. The program offers care from the point of diagnosis of a life-threatening condition through bereavement. In addition to the clinical services offered, the program's educational arm, Children's Institute for Palliative Care (CIPC) provides education and consultative support to providers in the 5 state upper Midwest region, actively working to encourage growth of pediatric palliative care services in the area through training, advocacy, and outreach. To date, over 500 providers have been trained, and now form a network of caregivers for children.
- **Children's Hospital of Philadelphia (CHOP)** presented by Tammy Kang, MD: The Pediatric Advanced Care Team began in 2003 as a group of individuals committed to improving care for kids with LLC. Staff includes 8 MDs, 1 SW, 2 RNs, bereavement coordinator, chaplain, and child life staff. Other services are accessed as needed from hospital services. Services can be provided inpatient, or at home. Care for the whole family, including sibling care, spiritual support, is offered. Prenatal consultation is also offered. Inpatient consultation and care is an important focus. The team is actively conducting research. Consultations often focus on points of transitions in care. The Team sees children with a variety of conditions, not just cancer. Partnerships with home-health and hospice, as well as hospital providers ensure a continuum of care options. 45% of patients die at home. The Team strives for active partnerships and open dialogues with families. PACT Team objectives include the development of a consult service that is expert in providing palliative care to children, to educate physicians, psychosocial staff

and other providers about the needs of children and families at end of life, and to develop a research agenda for pediatric palliative care. The Team has seen 400 new consults. Approximately 45% of children they have cared for have died at home. Average LOS for children who have died was 102 days. Average time on service for all patients is 265 days. PACT also supports community hospices and home care agencies that care for children through their Partners in Pediatric Palliative Care Program's education and consultation activities.

- **Hospice of the Florida Suncoast Pediatric Palliative Care Services** presented Stacy Orloff, Ed.D, LCSW: The Hospice was established in 1977, with the children's program following in 1983. The current census in all programs excluding consults and Doula /Perinatal program participants is 105. The staff includes RN's, LPN's, Social Workers, and a medical director. In addition, the Team "shares" chaplaincy services, volunteers, home health aids, and palliative arts staff. Emphasis is on counseling support for any member of the family. These services are provided through community based clinics. Families can self-refer, and counseling support is open-ended. Doulas are a unique component in their perinatal hospice program, which has served 150 families to date. Many services provided through home health, which mimic hospice-like services. The average length of stay for their hospice program is 2 years. The Hospice is a provider for the CHI-PACC program in Florida, which is a state-federal partnership to conduct a demonstration project for a palliative care waiver for children. The Waiver was approved in 2005, and preliminary data is now coming in. The Waiver allows and "overlay" of palliative care services while curative therapies are also being pursued. Services include nursing care, respite care, counseling, spiritual care, and expressive therapies. They also offer bereavement follow up services, including support groups and a camp for siblings. They collaborate with the pediatric hospital there, and share many services with the Hospice, including DME, Infusion, Pharmacy, etc.
- **The PACT Program at Dana Farber Cancer Institute / Boston Children's Hospital** presented by Tamara Vessel, MD: The PACT program at Boston Children's hospital aims to care for children with life-threatening conditions with hope for comfort and meaning, no matter how long the child's life may be. The scope of program services includes inpatient and outpatient consultation, collaboration with home-based community services, bereavement support, education, research and training. The program sponsors fellowships in pediatric palliative care medicine and post-masters social work. They had 65 visiting scholars from diverse professional backgrounds in 2006. The Team is composed of physicians, the medical and social work fellows, a nurse practitioner, a social worker, and a coordinator. They access other specialists and services from other hospital departments as needed. Since 2001, their annual patient census has grown from under 20 to about 150. Program activities include patient consults and care, training and education, developing interventions in practice standards, like a direct admission policy, inpatient order sets for uncontrolled pain, the development of the "comfort corner" and an emergency medication worksheet.

The PACT program is also a leader in the area of pediatric palliative care research.

- **Canuck Place** of Vancouver, BC, Canada was described by Hal Siden, MD: The program was founded in 1995, and was the first freestanding hospice facility for children in North America. The program offers family care and respite, pain and symptom management, support through transitions in treatment, end of life care, and bereavement support for families. Components include the Hospice, outpatient care through the Madison Clinic, inpatient hospital consultation, provincial telehealth, and community teams that coordinate home based care needs. The program has a close affiliation with the local Children's Hospital. Plans to expand the program's offerings in 2007-08 are underway. Program staff includes 15 FTE's nurses, 1.2 MD's, 4.6 PCA/ LPN's, 1 SW, .5 Chaplain, .1 Pharmacist, 1 Volunteer Coordinator, and a .5 Bereavement Coordinator. In 2006, Canuck Place provided clinical care to 209 patients, and provided bereavement support to 97 families. They admitted 56 new patients to their service, and managed 36 deaths. Their annual program budget is \$5.1 Canadian dollars.
- Ross Hayes, MD presented the **Palliative Care Consulting Service of Seattle Children's Hospital**: Following a state wide survey of families and providers caring for children with potentially life-threatening conditions in 1994-95, the Robert Wood Johnson Foundation awarded a three year demonstration grant to the Hospital develop a program. The program grew over its first three years, and was able to demonstrate increased satisfaction re: care from both families and providers. In 2001, Children's Hospital agreed to continue the program as a Consulting Service of the hospital. The program emphasizes clinical care, education and research. The Team's approach is hospital based and transdisciplinary. They work in collaboration with the child's existing health care team. The Team includes a medical director, a nurse manager (who is also a bereaved parent), a social worker, a bereavement coordinator, a program coordinator, and a nurse who is a program development specialist. 62% of their patients have a hematology-oncology diagnosis. The remainder includes a wide variety of diagnostic groups, including genetic and congenital abnormalities, CNS disorders, traumatic injuries, neuromuscular disease, and heart disease. In 2004-05, they received 154 referrals, representing a steady increase from 103 the first year of the consultation program in 2001-02. They have found success with this model encourages earlier referrals. They have not had to change their name. The model is reproducible, and staff have experienced an increased job satisfaction as they found that joining a family's suffering is paradoxically easier than avoiding it.
- Sarah Friebert, MD presented information on the **Akron Children's Hospital's Hasslinger Palliative Care Center**. Their program is an outgrowth of their Ethics Committee, and is a division within the Department of Pediatrics there. Medical residents rotate through the service. Patients can be cared for on an inpatient and outpatient basis. There are direct admission options available to the

service also. There is a system of automatic referrals set up for BMT and ICU patients: families have the “Right of Refusal” for palliative care. According to this protocol, staff will meet with families of ICU patients after 1 week in the PICU. They emphasize intervention when a life-threatening diagnosis occurs. The program offers a Fellowship in Pediatric Palliative Care. Their team emphasizes a trans-disciplinary approach. The program will host a national educational conference on pediatric palliative care in Akron, Oct 4-6, 2007. The program’s staff includes 2 MD’s, 3 APRN’s, a social worker, chaplain, and access to child life, pharmacy and psychology services. They provided care for 230 patients in 2006.

The State of the Art of Pediatric Palliative Care

Stefan Friedrichsdorf, MD, Convener

Dr. Friedrichsdorf provided an overview of the development of care for the dying, spanning 8 centuries and several continents.

- 18th and 19th Centuries: 90% of children in hospitals or orphanages died. Pediatric Palliative Care began because RNs were caring for these children everyday. Practical issues and compassion drove the development of care strategies.
- 1982 : UK opened the 1st hospice for kids, Helen House.
- Today, at least 49 programs for children exist in North America, per statistics submitted for this conference.
- Epidemiology: Most frequent causes of death in childhood are
 1. Birth
 3. Unintentional injury,
 4. Homicideand 2: Life-limiting conditions (LLC)
- LLC by definition offers no reasonable hope of cure. Death is expected to occur before adulthood. In the US:
 - 72,000 children have LLC; 14,000 die each year
 - > 15,000 would benefit from PPC
 - Kids have conditions other than cancer and die from many other things, e.g.: neuro-degenerative conditions, congenital anomalies, etc.
- Symptoms over life span can include pain, loss of appetite, fatigue, nausea/ and vomiting, dyspnea, etc.
- By definition, Pediatric Palliative Care offers a total approach to care
- Different models have been developed around the world:
 - Poland – exclusively home care (9a-3p), then MD/RN on call
 - Free
 - Staff: 3MD, 8RN, 3 SW, 5 Psychosocial
 - Experiences: most sib & children participate in bereavement program
 - UK – symptom care team
 - At time of diagnosis, have team meet w/ parents

- Most parents able to choose and plan wish for home care
- There is a high correlation between the availability of PPC & frequency of children dying at home care
- Australia – inpatient, home health, respite, stationary hospice create a system of care
 - Bear cottage – free charge
 - Not a “bad” place, meant as a place for families to recharge batteries
 - Parents choose between hospital, hospice, home
 - Continuum: Pain → Palliative care → hospice care
 - Not “death and dying squad” because they also do pain management and are known, trusted by family prior to EOL care

For adults, high standards of E O L care exist. Why have we not achieved as good a system for children yet? These questions need to be addressed.

- JCAHO is likely to adopt NQ standards in near future.
- The cutting edge of practice is increasingly focused on getting kids home

Some Thoughts:

We need to ensure EXCELLENT pain & symptom management, including both pharmacologic and & non-pharmacologic modalities.

We need better collaboration to set and achieve our goals in advancing

- Research
- Teaching, fellowships (only 2 in US)
- Standards, benchmarking, outcomes measurement
- Centers of Excellence across the US and Canada

We need to determine a place to meet as a field on an annual basis to continue collaborative efforts and share knowledge and experience.

Discussion Groups/ Exercise:

Domains of care

The group divided into small groups by discipline. Participants were asked to consider the following questions:

- 1) Review the status quo in general and in your field
- 2) What are your aspirations in general and in your field
- 3) How do we advance state of the art in clinical practice of PPC?

Reports from Groups:

Parents: Concerns included

- Limited access or non-existent access to care, e.g.: difficulties in finding a hospice team to care for kids.
- Issues w/ continuum of care. Families prefer no shifting teams, continuity of caregivers
 - Diagnosis should trigger referral to PPC (not necessarily using those terms)
 - Terms, names of services (“hospice,” “palliative care”) may be barriers: might hinder continuum development and/ or operations in practice? (Confusion that Palliative Care equals EOL care?)
- Role of parents & families
 - National IOM report; state-coalitions; institution-specific opportunities, like family members on PC teams; roles in training at med schools, with residents, etc., input into service / program development

The Continuum of care is essential. Families value continuity of caregivers involved from diagnosis through bereavement. Families would like to see evidence of parental involvement on teams, e.g.: parent-to-parent programs, as advisory council members, etc.

Parents would like to be involved in education initiatives, e.g.: training residents about the needs and perspectives of families living with LLC.

Parents would like opportunities to be actively involved in the development of the field

Physicians: Concerns include

- Efforts to operate programs w/ no money,
- Under treatment of pain by anesthesia
- How can we get Peds Palliative Care Fellows trained for certification (currently taking adult test w/ <25% of questions for Peds)
 - Could this be linked to conference for yearly meeting (AHPAM or PAS)
 - Who funds this?
 - Educational resources: We need MORE!!
 - Research priorities: we need more structure & collaboration
 - Pharmacological management of symptom control
 - Indicators are that there will soon be a pediatric palliative care standard in JCAHO requirements. We need to get ready.
 - Challenge exists to develop own PPC standards while conforming more to established adult palliative care standards of care.

- Advocacy is needed for proper reimbursement for services, including Medicaid legislation for uniform standards across states.
- Strategies like State waiver programs and, improvements upon Medicare guidelines may contribute to better funding, collaborative initiatives, improved coordination of services.

MDs: (2nd Group) : Concerns include

- We don't know what we don't know– training/definitional problems
- “Huge advancement despite great variation”
- “When you've seen one PPC program, you've seen ONE!”
- Emerging credibility: progress noted, but efforts to establish credibility continue
- Aspirations: gain credibility & clarify definitions
- Need models for collaboration
- Advocate for a standard of service upon diagnosis/admittance to programs
- Research agenda needs to be developed and pursued
- ESTAL

Where are we now?

- We don't know!?!
- Definitional problems: what exactly is PPC?
- Volunteer fire (people)
- “When you've seen one PPC program, you've seen... one”
- Huge variability despite great advancement
 - Services continuum and expertise
 - Funding
 - Territory
 - More passion than reason so far
 - We are a “Homeless” field across settings (e.g.: academic, institutional, hospice, community)
- Emerging credibility, ex: board certification in progress, more established and successful programs

Aspirations

- Model for collaborations (local, regional, national, JCAHO, AAP, ACGME, LCME, AAP, AAHPM)
- Gain credibility
- Gain definition
- Establish expectations for a National Standard of Care and secure funding\$ streams
- Develop and advance a Collaborative Research Agenda

Getting there from here?

- Research needs to happen: lends legitimacy to our efforts and supports credibility. We need funding for it.
- Establishing standards of care
- AAP section, develop a presence in academic societies
- National meeting: where should the field meet?
- Coalition building needs to continue and expand: needs to include everyone where kids are, across specialty areas, disciplines, programs and regions, etc.
- Need to establish expectations for where we want it to go
- Advocate for the determination that PPC needs to be a standard service, available to all, and a core service with children's' medical care continuum, and raise societal as well as professional expectations
- Funding is needed for a unified research agenda
- AAHPM as a possible organizational "home" for the field? Funding source for training of MD's, others?
- We need an annual national meeting to come together, and to collaborate in order to move the field forward.

Psychosocial Professionals: Concerns included

- More trans-disciplinary emphasis vs. sustaining existing silos: level the traditional hierarchy!
- Focus on **trans-disciplinary** care, programs, models, and interactions around interests so we can learn from each other
- More dedicated teams, less sharing of staff between programs which leads to stress for staff and uneven access for families
- Importance of defining it as specialty practice area
- Contribute psychosocial knowledge to field: participate in research, publications
- Need for specialized training opportunities, including mentorship/ and/or fellowships to help translate / impart the experiences of seasoned workers to those coming up in the field
- Need more funding to be able to meet all patient /family needs, including expressive arts, and integrative therapies.
- Sabbatical to process experiences and reflect upon these to make further contributions to the field, as well as for personal renewal and sustained longevity in the field.
- More national workshops to bring together the professionals who are working in this still relatively small field to share skills, intervention strategies and enhance program development issues, etc. and to foster professional development.

Nursing: Concerns included:

- Status quo: Limited EOL/ PC info in formal nursing education through all levels (LPN, RN, APRN). Need to increase awareness but avoid fragmentation: need better training
- Increase all RNs' skills: raise the bar for nursing practice in all areas to embrace PPC: emphasize interaction; develop capacity for PPC.
- EOL: training, exposure is fragmented/decentralized throughout nursing and various specialties.
- Foster young RNs: support their learning and capacity development
- Need for more funding for staff time, and to allow for the extra time PPC tends to take
- Confusing term : RNs don't know when to start PPC
- Where to go? Formalized training at all levels
- Seamless care: start PPC early
- Nursing burnout is a real problem. Self-reflection can help, also support reaching out to our teams for more support. Need to develop teams' capacities for mutual support.
- Nursing specialties/institutions
- How? Research, transdisciplinary training and practice: demonstrate what works
- Need to foster Centers of Excellence for support at all levels: regional, local, national: support changes in medical culture.
- \$\$\$: Need for more funding for care, for training, and for staffing across the continuum. We need enough staff to do the work.
- Nursing organizations need to work together to promote research, local networks, changes in the culture of how care is provided, and to develop certification for PPC nurses, in both home and hospital settings.
- Limited pediatric EOL expertise in the community settings.
- Awareness of some issues, but confusion about when to start terminal palliative care, terminal chronic care

Where can we go from here?

- Improve education in nursing school
- Strive for seamless care models and in practice
- Develop Certification standards and pathways
- Encourage Nursing organizations to pool resources to better provide continuing education

How can we get there?

- Research
- Local/regional COE for nursing
- Develop funding initiatives
- Advocate for culture changes that are more responsive to family needs, and more supportive of nurses doing this challenging work

Nurses can work to

- Increase Self Awareness
- Increase compensation
- Decrease judgmental attitudes

Open Microphone discussion Highlights:

Open Mic:

- Parent commented: PPC MD should have been Primary care physician of her child with a LLC
 - Community Pediatricians and Primary Care Physicians need skills to provide good care on a continuum instead of striving for thousands of Peds Palliative Care MDs
 - Group of subspecialties is a critical issue: how do we prevent formation of silos?
1. A Physician commented: There is a tension between making PPC a specialty vs. a point on a continuum. On a practical note, where would primary MD's receive training for skills needed to provide PPC?
 2. A RN commented: There is a significant disparity between rural and urban populations in terms of access to PPC. We need to develop regional centers of excellence that can support care in their area and partner with rural resources.
 3. A SW commented that she is concerned that we keep talking in terms of medical models. Much palliative care involves aspects beyond the medical-physical.
 4. A MD commented: We are all struggling with definitions. There is even little continuity among disciplines.
 - We need to define the different levels of learning, stages of learning that exist and must be addressed, for example: proficiency vs. competence.
 - Given the current state of medical care systems, MD's need to be the leaders for social change and systems change. To change the culture, we need to advocate for better acceptance of PPC, and interdisciplinary care.
 5. MD Commented: Communication is essential. It ahs to be clear who the "captain of the ship is," and who is coordinating care, and can access additional care as needed.
 - Everyone has responsibility to care for a child even if child will die
 - Community physicians don't like hard patients. There is a lack of ownership. They "don't know what they don't know," and may only see one or two PPC pts in their career.
 - Physicians can be reluctant to delegate to nursing roles
 - Physicians who take ownership of case must follow through

6. A Parent commented: What is PPC? What about families of kids who have died from sudden deaths? Does that fall into PPC?
 - Example from North Carolina: Their Coalition assists families after a child's death, whether from a disease or other cause.
 - What is a "sudden death?": eg, trauma or in a disease context?

Discussion:

Put energy toward getting revenue to get paid

- PPC can save insurance companies dollars
 - Cost differences are hypothesized but not yet demonstrated. We need money to do research, demonstrate cost savings to commercial insurers and encourage them to see returns on their investments into PPC.
7. Comment from a Parent: We have taken action from our loss, but not all parents can accept what has happened or take action
 - We need to change society and culture: look beyond health care to social care and support
 - Families need to be able to have conversations with each other, and with providers. "We are each unique."
 8. From an MD: We need to understand from parents what bodies of services are needed.
 - Parents need care coordination, respite, reimbursement, understanding of their options, changes in legislation, evidence to advance state of the art by providing best possible care.
 - Recommend we pursue something that is not a medical model, but does have a medical component
 - We will need to address/ make social change
 - Every ICU admission deserves a PPC consult.
 - PPC helps families understand their child's situation, and their options, not just prepare for death.
 - Include the concept of uncertainty as a trigger for PPC
 9. From a MD/ Family Practice: Remember the importance of including Family MD's and Neurologists, for example, and others who essentially provide PPC without belonging to the pediatrics community.
 - 10: Question: Where to house the efforts to advance the PPC agenda given the variety of players who may be (or need to be) involved?
 - Ideal would be a combination of clinician w/ administrative hat
 - Field needs to combine clinical & business savvy or won't survive
 1. Comment from Kate Eastman: We need to find some way to advance the business plans for program development.

Stefan Friedrichsdorf, Convener, summarized discussion and asked a question: “What are the most important tasks that need to be addressed to advance the state of the art?” A Survey will be provided for participants to complete on Day 2 of the conference to enable us to identify some priorities among points raised in this discussion. (Appendix D)

Brian Carter, MD made the following comment to the general assembly:
Strive to be open-minded. It is hard work to incorporate new and challenging ideas...
Note both the risks and benefits of the open mic: time is limited. so note the speaker’s best intentions and hear remarks in the spirit of collaboration, and the shared desire to move things forward.

The State of the Art in Pediatric Palliative Care Research

Joanne Wolfe, MD, Convener

See the Powerpoint presentation Dr. Wolfe presented at www.childrensmn.org/hospice

Dr. Wolfe shared her hope that an outcome from this meeting can be that we identify the need for collaborative research forum in this field.

We need studies to let us know if what we are doing works, and helps.

Question to ask our selves:

Why are there so few empiric studies focusing on palliative care for children with life limiting conditions?

1. Ethical barriers:
 - Barriers: patient and family vulnerability, refusal to ask families when there are no alternatives for care
 - Consequence: not randomized, under-enrollment
 - Overcome these barriers through education, creativity in modified designs or non-randomized designs
2. Practical barriers (same as barriers to care)
 - Small numbers of patient populations, developmental concerns, variability in LLC, heterogeneity, uncertainty, individuality / specificity of needs and treatments, no money for research, poor PPC network
 - Consequences and strategies: conduct primary studies in children not adults
 - Standardize nomenclature, data collection and analysis schemes, and pilots which enable us to use funds wisely
 - Advocacy for money for research for PPC as a priority

In summary:

“Don’t know what to study, we have no network, and we have no money.”

Some good news exists. There have been some successful efforts. For example,

Three Instruments to Assess Fatigue:

Scales have been developed to measure experiences.

- Marilyn Hockinberry: Developed instrument to assess fatigue, The Child Fatigue Scale. Pam Hinds worked on this study also. They looked at what questions do we ask kids to get at their experiences? For example: kids can't play because too tired, so generate questions to get at how their ability to play has changed.
- Christina Ullrich and colleagues looked at fatigue as a symptom from which patients suffer, and as a symptom for which they are being treated.

“N of 1” Studies can be a good option. In addition to helping us decide the best course of treatment for a specific child and family, they can contribute to overall research as well. Furthermore, they can allow elements including use of placebo in a trial. Researchers can obtain subjective and objective data during a trial. Double-blind designs can benefit families by enabling them to see, with evidence, which treatments benefited them.

Emerging Themes in Research:

Physician competence:

Hilden et al, 2001, JCO

The Study looked at physician competence as reflected in a self-rating exercise.

- 92% feel they are competent or very competent
 - 92% learned by trial & error, 10% from formal courses
1. Physicians perception of own skills is very high
 2. 92% learned from trial and error ... 10% learned from courses, formal training

One can conclude it is hard to recognize needs for improvement; this is distinct from “doctor bashing.”

Note implications of deep care for patients, and hints of possible altruism in the responses.

Wolfe et al, 2000, JAMA

Note the critical importance of relational aspects of care

- Looked at timing of understanding that no realistic cure existed. Providers understood this about 3.5 months before death, while families grasped that death was likely about 6.9 months before death occurred. How do we account for this gap?
- Study found that the gap in understanding is smaller when a psychosocial staff member is present at time of critical discussions. This was also associated with family later feeling they were better able to meet their goals for care.
- Families hold two goals simultaneously, or hold “blended goals:” treatment should aim to lengthen life, but also to lessen suffering. Parents want life extension, and they want symptom treatment: not *either/or* but *both/and*.

- Parents with more realistic goals were better able to achieve them
- Further study of differences between mothers and fathers is needed.

Edwards et al, AAHPM, 2007. Study asked: “are parents who have more realistic goals more able to accomplish them? Results suggest that yes, they are.

- Parents priorities: honest & complete info, access to staff, communication & coordination, staff compassion, support for the integrity of parent/child relationship, faith
- Realistic sense of prognosis contributes to greater likelihood of meeting goals. Parental were asked about their goals including:
 - To cure (0%)
 - To keep hoping (60%)
 - To extend life without cure (71%)
 - To have done everything (80%)
 - To lessen suffering (88%)

Meyer et al, and Robinson et al, 2006, Pediatrics

Two studies looked at parental priorities in the ICU setting.

- High ratings of care when presented with clear information, observed sensitive communication with child, and were prepared for death
- Parents value complete and honest communication
- Robinson in particular looked at role of spirituality, and existential support for kids
- Care that respects spirit and affirms the transcendent parent-child bond that survives beyond the child’s life

Mack et al, JCO, 2005: Examined parental vs physician goals.

- Higher ratings of care from families associated with clear information, sensitive and caring communication with staff. Note emphasis on relational aspects of care.
- Physicians gave higher ratings of care when there was less pain, and shorter hospitalization at end of life: focus on bio-medical aspects of care.
- Potential benefits of better communication include better agreement on understanding when no cure, agreements regarding the goals of care
- Clear info that is sensitive and caring, communication with child, and preparation for death are highly valued by families
- Need to try and merge these priorities

Wolfe et al, JAMA, 2000: Study shows early PPC involvement is better

- Outcomes related to planning of death is more important than actual LOD (location of death)
- Focus on lessening of suffering
- Relationally focused care important

- Satisfaction better when know staff providing care: importance of continuity
- Alignment of goals between families and staff occurs when communication is improved

Wolfe et al: examined factors related to location of death. (This is as yet unpublished data.)

- Family satisfaction is associated with having the chance to plan, and make choices vs. location, so opportunity to plan is more important indicator of satisfaction with EOL care
- When given choice, most families did opt for, prefer death at home
- Reflects importance of advanced care planning and communication re: EOL needs and care

Kreicbergs et al, JAMA, 2003

Study looked at parents' feelings about talking with their children about death.

- 67% did not talk with their children & 33% of those regretted not talking to them
- 33% did talk about it and of those, 0% regretted it
- Need to teach parents how to talk to kids, and help them identify when, e.g.: Teaching strategies like listening for opportunities, reflecting back to child, etc.

1. Hinds et al, Quality of Life Research, 2004:

This study looked at QOL in children who have cancer

- a. End of life care preferences: thinking about relationships with others
Quality of life as defined by kids w/ cancer
 - Explored the meaning of being ill, spoke with kids directly
- b. EOL discussions showed that 95% think about relationships with others and how those people will be affected (parents, family members) as they make choices
- c. Existential concerns of children facing death were identified

Kreicbergs et al, JCO, 2005: Examined care related distress amongst parents.

Study looked at pain at EOL, and family perceptions of difficult moments.

Experiences still affected parents 4-9 yrs later.

- Quality of life & symptom management
 - Suffering may result even with change in teams, best efforts
 - Preventative focus rather than crisis management
 - Parents still affected by pain and “rough moments” long after
- Note parents' recollections of suffering pointed to a need to “think outside the box” to develop preventative strategies for pain and suffering
- Efforts to minimize suffering help patient, but also long term survivors after the death of their child.

Li et al, Lancet, 2003: Looked at mortality in parents after the loss of their child. The study concluded that losing a child impacts life expectancy of parents.

- 21,000 bereaved parents in Denmark were surveyed. Researchers looked at increased mortality from natural & unnatural causes in mothers and fathers.
- In mothers, during 10-18th years after the death, they found increased mortality from natural causes, and increased rates from unnatural causes throughout the time period studied.
- In fathers, they found increased deaths from unnatural causes during the earlier phases of bereavement.

Kreicbergs et al, JCO, In Press: Study looked at factors associated with parents working through their grief.

These factors were associated with associated with more positive bereavement outcomes:

- Professional support in helping parents
- Psychosocial support in last year prior to child's death
- Counseling in last month
- Closure session /counseling after the death

Dr Wolfe shared the experiences of their palliative care service, the PACT Program: They focused on certain target areas to try and achieve improvements in care. Their strategies included efforts to decrease the number of hospital deaths, decrease suffering from pain, anxiety, and dyspnea, and prepare families more effectively for their children's death and end of life issues.

- Overtime, they have achieved a decrease in the number of patients dying in hospital, and in the ICU
- While they observe essentially the same symptom prevalence, they also note a decrease in reported suffering from pain, dyspnea, and anxiety
- They report an increase preparedness of parents for impending deaths: parents report they have felt "very prepared."

Currently, the PACT research team is engaged in the PediQuest Study, designed to measure quality of life and symptoms experienced by children with life-threatening conditions. The objectives for the study are to

- 1) Conduct a *feasibility* study on the possibilities of doing a randomized controlled supportive care study on children with cancer
- 2) Conduct a *descriptive* study explore the determinants of a child's suffering, and parent-physician discordance
- 3) Conduct a preliminary *evaluation* study looking at the effects of giving providers and families with QOL feedback data, to see if that has positive benefits to the child's and family's experience.

PediQUEST Study is gathering some preliminary data:

- Parents have little stress as a result of the study, and kids find the survey easy
- The study aims to be prospective (look forward) and introspective
- Feedback to team and family with symptom information creates opportunities to try and improve care
- One difficulty with accrual of subjects is that some died before participation. Otherwise, there has been a low attrition rate
- Some providers have been unwilling to refer patients for participation
- Data so far indicates a wide variety of symptoms that patients are experiencing.

Discussion

- 1) Key priorities for research?
- 2) Challenges to implementing a research agenda?
- 3) Strategies used to move forward in PPC Research?

Small groups met and discussed the questions posed by Joanne Wolfe, and then reported back to the large group. Certain themes emerged and are listed below:

(Note: **Bolded items were emphasized by all groups**)

Key Priorities for research:

- Talk to children themselves, and engage their perspective
- Impact on the family as the unit of care: a unique feature of PPC
- Role of Fathers
- Needs and experiences of siblings
- **Psychosocial aspects of care**
- **Pain and symptom management: how do we learn what works best? Needs to be based upon science, theory, proven formulas**
- **How to teach effective communication**
- Development of models that include families
- Patient/ family satisfaction
- Contributions of other members (psychosocial) of the PPC team
- Research that reflects the voices of all providers
- Decision making strategies and models
- Develop skills in research
- Pain and symptom **assessment** & management (need assessment tools)
- Children with conditions other than cancer
- Epidemiologic data (not EOL, mortal) instead compile info re: kids living with life-threatening conditions
- Policy, advocacy & marketing: what is our societal, family and staff expectations for care

- Self care for providers: how can support be sustained for PPC providers? What contributes to longevity in the field?
- Children themselves as participants in research
- Impact of *living with* LTC, not just focusing on death from LTC
- What do families want?
- Impact of PPC provision on decision-making
- Cost-benefit analyses
- Bereavement: long term impact of PPC services, longitudinal studies
- Impact of timely referrals

Challenges:

- Human resources are limited
- **Funding is very limited Education/ knowledge re: research is limited within this practice area**
- **Physicians as gatekeepers to research participation for their pt families**
- **IRBs' reluctance to authorize research on vulnerable populations**
- Need criteria for enrollment to create a threshold for participation vs. permission, with full disclosure.
- **Lack of research experience, competency**
- **No academic organization identified to bring us together as a network yet**
- Places of treatment vary: clinics, teaching and private institutions, community
- Concerns re: (over) protection of vulnerable participants (children)
- Lack of common, standardized practices, benchmarks
- **Funding**
- Associations with “The ‘D’ Word, being the “Death Squad”
- Subjective subject identification
- **Lack of resources**
- **Reluctance to approach families due to their extreme vulnerability**
- Lack of dedicated time to pursue research
- Question of Altruism
- Need for collaboration to maximize resources, expertise, and money
- Need to collaborate to achieve significant “N” of subjects
- This area is not a priority for funders: need a national “outcry” to access NIH funds
- What does QOL mean in this LTC context?

Strategies:

- Cost avoidance funding: demonstrate cost savings to funders, insurers
- Surcharges on peds interventions to provide a pool of funds (Ex: vaccines)
- **Identify an Organization to be an academic sponsor, “home” for this group: AAHPM? AAP? NHPCO? Other?**
- Start a fund for research
- **Develop a research collaborative / consortium / network**
- **Develop a national center to coordinate activities, pool/ share resources**

- Organize annual meeting to coordinate activities and share expertise, etc
- Establish benchmarks
- **Mentorship to help expand research expertise and competency**
- Integrate research into care activities: bring it into everyone's work life
- Identify what are the unanswered questions in your day to day routine?
- Have current research as an item on agendas of national meetings
- **Research networking**
- Encourage practitioners to ask what the unanswered questions are
- Integrate research into care so that the idea is not strange to families
- Highlight published data on altruism and subjects' interests in participation in research to IRBs
- Develop guidelines / education re: how to invite participation: how to ask, and allow that to shape the process, vs simply assent.
- Address hesitancy to approach families because of their extreme vulnerability
- Develop pathways to research so physicians' permission is not the only point of entry (do away with gate keeping)
- **Collaboration:** mixed methodologies, parent advisory groups, standardized database, outside-of-hospitals research, creativity around funding, derive protocols that can be used by multiple sites
- **Research aimed at accessing children's voices**
- Develop research networks across institutions
- Identify new and likely funders
- Use parent and investigator partnerships to plan studies and approach IRBs
- Recommend parent advisory role for NIH
- Clinical guidelines for PPC can be developed: these exist in the adult world, and would likely contribute to standardization of practice and credibility in peds?
- Develop protocols for research: "cookie cutter" methods for evidence based research
- Build coalitions at the national level for advocacy
- Target philanthropy for funding: research has good, important outcomes
- Partner with payers as results will improve care, create efficiencies, etc
- Link research so that it is not duplicative, or reinventing, and we can change practice based on research outcomes that are disseminated in a timely way
- Challenge other (psychosocial) disciplines to participate in research
- Research educational models for PPC
- Conduct more research on psychosocial issues as much as medicine: follow the way kids and families live their lives

Joanne Wolfe reconvened large group discussion and made the following observations:

Note the common themes:

- We need to build an academic infrastructure to support research and dissemination of knowledge to help advance practice. Build the academic

infrastructure so high quality studies can be designed. This requires money and protected time in order to be productive.

- There is a need for basic science research to understand mechanisms of suffering, and then apply that knowledge to our practice.
- We need to establish a cohort of investigators who are competent and can share strategies, protocols, and results. This exists in the Pain world, but not yet in PPC.

Feedback and Open Microphone discussion: Stacy Orloff, Gary Wilco, and Kate Eastman facilitated

Major themes that emerged from the discussion included:

- There is a consensus that more research is needed so that we can base practice on good science, and discovery about what really works for kids and families.
- There is need for more research on psychosocial topics and themes
- The mechanisms of suffering need to be better understood: meanings, cultural differences, distinguishing between symptoms and suffering, family dynamics around suffering, etc.
- We need to further study the results to date for better understanding of dynamics, e.g.: what will lessen differences between providers vs parental understanding of impending death?
- Qualitative research has limitations. It is hard for us to do quantitative analysis on this population for a number of reasons. There is a drive to do prospective studies, based on hard science and based on theory.
- There is interest in identifying, agreeing upon, some standard measures to children's QOL. St. Jude's is working on some projects that seek to examine how well we understand the child's experience. PedsQOL (Varney et al), John Collins' Cancer QOL measures and Hines instruments are possible tools cited.
- How do we measure the effectiveness of the interdisciplinary team?
- Accrual issues identified. Physician reluctance to refer patients to studies, and IRB reluctance to authorize studies needs to be addressed in a comprehensive way.
- It is important to develop clinical trials with both PPC and sub-specialties; Phase 1 trials need to have PPC sub-hypotheses. Phase 1 and 2 studies need to include some kind of QoFL questions too. This should become mandatory. This has been attempted, but not successfully done so far
- PPC needs to develop our own collaborative agenda because other sub-specialties have different agendas.
- PPC needs to agree on a meeting place so research initiatives, collaborations, and results can be shared and expanded upon. Where should we meet on a regular basis to collaborate?
- Meetings should allow access to wisdom across the developmental spectrum for expanding ideas, etc: AAHPM, HPNA, Other? Ask these organizations to help us structure a day for PPC as part of the annual meeting.

- As a community we should be together with like-minded individuals across development, adult provides infrastructure and grants. Consider AAHPM, HPNA. Downsides are that there are not social work or chaplaincy components to those meetings, but should share ideas across the developmental spectrum. Advocate for inclusion of other disciplines: there does seem to be a growing interdisciplinary feeling at those meetings. Include parents as co-presenters?
- APS Pain Society model may be a good one to look at: develop a Special Interest Group (SIG) for PPC that meets day prior to general conference.
- Proposal: AAHPM alternating (Tampa in January, 2008) with bi-annual Montreal Congress on Palliative and End of Life Care (next in 2008), which is transdisciplinary, crosses developmental spectrum, and is truly international.
- Plan for a multi-center research collaborative/ center. Put more pressure on funders by demonstrating the efficacy of a multi-center collaborative network.
- Note the critical importance of theory: ground outcomes studies in theory / hypotheses. We need a shared “Theory Toolbox.”
- Test theory with hypothesis: gives framework to use over time
- Need a theory (small treatment theory), then gather data to test it
- We need prospective studies as well as retrospective studies.
- We need a structure for research, beyond just annual meetings
- Parents agree want to participate in research. Some IRB’s pose difficulties because this population is vulnerable. Suggestion: refer to published articles identifying how subjects value participation, e.g.: Michelson and Steinberg: Journal of Palliative Medicine, Kreicsberg: Lancet. We can add to literature the methodology, etc. to create some context for IRB’s as they evaluate studies.
- Can we create a centralized clearinghouse or database of kids being cared for?
- See appendix for more resources shared by participants: Canadian Network, ChiPPS-NHPCO, etc.

As the group adjourned, a parent delegate, Rob Loverich, posed the following question:

How do we explain the difference between parent and physician recognition of impending death? Why does it exist? Is this gap a good thing or a bad thing?

The meeting adjourned for Day 1.

Pediatric Palliative Care Forum

Day 2: June 15, 2007

Stefan Friedrichsdorf shared results of his session on Day 1, The State of the Art in Pediatric Palliative Care. He presented a Ranking of Priorities as determined through group discussions and worksheets completed. We as field think these are the most important things. (Appendix F)

Dr. Friedrichsdorf commented that this list is in fact is only a reflection of only the first 2 hours yesterday, so the hope is that by the end of today we will agree on a plan for how to move forward with the collective agenda.

Funding, Advocacy & Communications

Devon Dabbs & Ann Morris, Conveners

Devon Dabbs of Children's Hospice and Palliative Care Coalition opened the session by giving a brief history of the California Coalition. She said it was a "social movement:" comprised of people who have seen the barriers that exist for children with cancer and who needed good palliative care. During this time the Institute of Medicine Report, "When Children Die" came out and the coalition was formed. The group is made up of children's hospitals, hospices, home health care, and most importantly, parents.

Funding is always a concern for people. How should PPC be funded and who should be targeted for philanthropy? The coalition's focus encompasses both the "millionaire on the hill" and also the small but equally important individual donors. Don't underestimate the power of a 5-year-old! The coalition had a donation from a little five year old who suggested that rather than presents for her party, her friends could make a contribution to the coalition. The challenge is often getting the word out. Excellent public relations are an important aspect of the work.

Ann Morris came to the Coalition with excellent experience having been Vice President of Communications for United Way, and prior experiences with the Red Cross. She is now doing work with us to help expand the coalition's growth.

Ann Morris spoke about the importance of building good public relations to improve PPC funding and advocacy. She pointed out the need to develop clear and concise messages that stand out over the other issues that are ever present and demanding in our institutions and society. In short, "We need to know who we are and why we are here." Developing a clear message is important but you also must be clear who your target audience is. Identifying the target audience will help you craft the message.

Tips for crafting the message: Make it

- Economical- short and sweet and complete
- Timely and engaging: something that can capture their interest– abort if eyes glaze over!
- Informative- new things they have not heard
- Sincere- speak from the heart
- Compassionate- personal life, touching stories
- Ethical emphasis
- Tenacious – both personal and professional (keep at them in smart ways – keep them updated on things along the way, even if the items don't seem interesting). “If you don't wish to receive these, please let me know” and they never do.

Tips for developing communication tools:

- “Keep the Brand” so they all look alike,
- Printed materials -Website, e-mail, PowerPoint
- Press releases, donor communiqués, electronic communiqués
 - PowerPoint template: keep consistent, identifiable

Tips for effective messaging

- Know your Audience and use their language,
- Economic and Astute presentations: in all mediums
- Share the message whenever, wherever
- Make sure the audience knows the take away message
- Ensure correct knowledge, check back with them and have a call for action what do you want the audience to do

Identify trusted messengers

- Know how to match personality (delivery style) with opportunity or context (media, etc.)
- Good communications, are concise & compelling, show compassion for child & families

Having children tell their stories

- Have adults tell children's stories: can be very effective
- At times it's appropriate to have children be advocates for the program
- Be aware and be protective. Ask yourself: Are you doing the child and family justice? Are you protecting integrity and dignity of the family? Whose needs are being met?
- Parents are strong advocates. See www.partnershipforparents.org site resource for parents and empowers parents. For parents of children with life threatening conditions. It is now a coalition that brings parents from across the country to promote PPC, like the disabled community that brought together a variety of conditions to work together.

Advocacy

Legislative change often is important and comes in the form of advocacy. In September, 2006, the Nick Snow Palliative Care Act passed in CA. The Act

- Allows children to receive palliative California while undergoing curative therapy
- One of the strong voices was a parent who summed it up by saying “My son was terminal for seven years.”

Although there are states with a variety of ways of providing this sort of coverage, California is one of the first states to extend coverage in this way. It was a difficult process as they worked for 4 years developing the waiver and working with MediCal. It was interrupted by the a recall election for then Governor Davis so the whole process was put on hold. However Governor Schwarzenegger’s administration has been very supportive in the process. The legislation directed the state’s department of health to develop a waiver. The plan is to “infuse” PPC into the department and have individual pilots across the state. It was estimated that 12,000 children with benefit from this integrated service.

Melissa Gilbert has emerged as a strong advocate. She originally got involved when she met an ill child at LA children’s. She presented him with an honorary SAG card so he could appear on TV show. It was this meeting and her own experience of a childhood friend who was a very ill child with an uncertain future that inspired her to get involved.

Funding

The question of funding always comes up in pediatric palliative care.

For the California coalition, 80% of the funds came from foundation, 5% from donors and 20 % from events. But the feeling is that this is too heavily dependant on foundations. The long range plan is to shift to 80% donor based funding. This would provide long-range sustainability. The remaining 20% would come from events and sales of the specialty bracelets that were designed for pediatric hospice and Palliative care.

Possible funding sources were reviewed..

- Grants/foundations- hand outs for more information on writing grants and researching grants
- Local/state government grants
- Federated funds (United Way)
- Unique opportunities (build up individual donors)
- Individual/corporate donors (none too small)
- Reimbursement through public/private partnerships can be done but it does take education and some marketing. Developing a “dog & pony show” to educate many different people who are involved in reimbursement is important. In California a letter was sent out to county offices with specific info about PPC, what it is and how to get it covered. Education to both private and state entities about how to refer to and get reimbursement for pediatric Palliative care was also provided. Encouraged Medicaid dept to continue education re:what services are already available

and how to access them. Many need education of what's already out there.

- Private payers reimbursement is still being worked on. There is an on going dialogue to discuss ways to do this. One option is to follow the example of Washington State where the hospice staff and the private payers work together on individual cases to meet the need of pediatric palliative care.
- Special events can have an important role in fund raising, but you need to evaluate the effectiveness of the event. Events such as dinner dances take time and money and extensive planning. One unique idea was a “non event” which says .. “you are invited not to rent a tux, get dressed up have to attend a dinner, etc ... but rather to write a cheque.”
- The Bracelet campaign is a new and successful project that was started by a the family of Dustin who was a child who died. He had wanted to be an actor. After his death his family wanted his legacy to continue in some way. A jewelry designer created bracelets with children's short quotes on them . Melissa Gilbert became very interested in this and started mailing them out to her friends. One of her friends, Johnny Depp got involved and has been helpful in promoting the sales.

A Reminder of Three Critical Points:

- Importance of raising awareness, inspiring community, developing trusted relationships
- Look for unique opportunities for funding and raising awareness
- Talk about the messaging around PPC at a state and regional and national level

Panel Discussion

Lauren Spiker, a parent, spoke about her experience. She said she wanted 2 things in the care of her daughter, medically competent professionals with personal compassion who care about her. She stated the primary team was the glue, which kept everything together. When curative treatment was no longer an option they refused the hospice team as they felt they did not want a new team at that point. There had been no palliative care team, but the hem-onc team had doubled as this. This meant that the transition from curative treatment went more smoothly for them. She said they received consistent and candid communication from a supportive team. She suggested dropping palliative care as a subspecialty as she felt this would become divisive rather than collaborative.

Kate Eastman, Director of The Jason Program

We can build Inclusion & community as values by telling stories. We need to emphasize building relationships and not mincing words about kids suffering. This takes tenacity.

Open Mic Session Followed

Themes emerged including

- How does a program raise an endowment for the program not specific person?
Some programs suggested ideas like including a percentage of all donations to go

to a sustainability endowment, e.g.: 10% or all donations go to the endowment. Others suggest a community campaign with the establishment of a challenge grant to the community that offers a foundation contribution when the match is achieved.

- Encourage donors to earmark funds for endowments that protect program sustainability without restrictions that may limit program growth and development.
- Some hospital foundations are steering donors away from PPC. We need to advocate for this population and develop leverage to help change this process. One idea is to identify a challenge grant to a hospital for PPC that can't be redirected to demonstrate that funders will support PPC.
- We need to develop fundraising opportunities at the national level
- NACHRI has stated they do not plan PPC initiatives in the near future. We may need to develop arguments to encourage their involvement and participation, at least as a clearinghouse of information for peds hospitals.
- Identify champions on your Boards and lobby for their support.
- PPC Champions are encouraged to
 - find your champions and lobby.
 - talk about what you do from a place of passion and pride
 - plan: donors want to know what you're going to do...
 - develop sound bites to describe what we do, and want: the "elevator ride hit."
 - Remember that success comes from the right person delivering the right message at the right time!

Pediatric Palliative care is a right of children. We need to see it become covered by health plans, and not something that is available only through philanthropy.

Discussion continued to look at

- What is happening at regional/local level to set policy?
- Get children involved: no children here, we need to help them get involved and fully integrated in ways that respect their abilities and vulnerabilities too.
- Involvement of private payers
 1. Coalition involves private payers (insurances) usually follows medical assistance plans
 2. Who will benefit from change? 1 business CEO look at impact on them, then they pressured their insurance company to include a benefit.
 3. Come from bottom up: create public awareness to put pressure on insurances

There is a need for a shared definition of PPC. It is proposed we utilize the ACT definition:

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements.

It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.

Royal College of Paediatrics and Child Health AND Association for Children with Life-threatening Conditions and their families (ACT)

- PPC is aggressive pain and symptom management, holistic care for the child and family, and continuity across care sites. Can we agree on this definition? Review and consider...
- There was discussion that AAP has a medical home emphasis for Primary Care Peds to do PC in community. This may contribute to a model of not turning over patients. So goal becomes that any health care approach is palliative/holistic, which if successful, then we wouldn't need separate silos or systems for PPC?
- There was discussion on the "pay for performance" movement in health care.
 - PPC needs to show sustainability. CAPC is a good resource for this. We need to
 - Gather data, but expand upon requirements and have additional outcomes (for research & endowments)
 - Demonstrate a "return on investment"
 - We all need access to that same information
- There is a need to partner with CAPC: conclusion from Gems of Care research.

At the end of the discussion there was a suggestion by a parent delegate that parents who wanted to could say the names of their children who died to acknowledge that they were represented there.

Models of Care

Sue Huff, MSN, Convener

Sue Huff presented a brief overview and identified four areas consistently identified as critical to the success of model development: Access, Building Community Relationships, Coordination of Care and Communication, and Measurements of Quality and Success. A panel including Suzanne Toce, Shannon Bruggen, Jodi Chrastek, and Stacy Orloff briefly presented different models and highlighted both successes and challenges in these four areas. To summarize, priorities included addressing continuity of care and the challenges of multiple settings. Pain and symptom management,

communication and issues related decision-making, family centered care, respect for parent choices, and the incorporating the voice of the child remain at the forefront regardless of all model delivery.

Challenges continue with funding; reimbursement; defining palliative versus hospice care; and support for research. Strategies agreed upon as successful:

- establishing a local supportive network,
- having a champion,
- mentorship,
- collaboration between pediatric specialists/acute care and community providers,
- and last but not least persistence.

Following this discussion, the audience broke up into four groups addressing the above categories. The goal of the small discussion groups was to identify areas where there may be opportunity for growth, for programs to work in tandem, to define elements of the different models and collect data that would contribute to best practice definitions and benchmarking. Although every group did not reach this goal, there was active participation and discussion of the importance in each area.

I. Access:

Challenges with serving the rural population came to the forefront in this group. Areas for consideration include:

- long distance training,
- create and support a network of providers,
- tele-health options,
- provide support to caregivers,
- create partnerships, and
- explore how to change mindsets of hospitals to work with community providers.

As far as acute care / hospital challenges related to access development, ‘automatic criteria’ for referral into a program was identified as being on the wish list. Education was discussed as being a constant need everywhere.

II. Measures of Success / Quality

This area sparked fervent discussion related to the challenges of defining success: in conclusion: “success varies by whom you ask”; there was no consensus. It was suggested if we agreed on types of models, with each evaluating success; and then we looked at models to analyze similarities and differences, this may lead to better definitions.

There was agreement on the vital importance of taking advantage of existing resources, and having a central database for those resources. Discussion continued related to differences between working with healthy functioning families, and those that are not; looking at family systems and the relationship to services, and outcomes. Measurement of outcomes can be categorized as short term and long term. Acknowledgement of the needs of competing / conflicting stakeholders was also identified as being important to consider when measuring quality. The difficulties associated with using satisfaction surveys as a measure were broached.

Practical issues, for example, how to quantify areas related to this care, variables in geographic areas, research methods, and response rate was also noted as challenges. Comments were also expressed that many of the existing programs are not present in the room. We need more representation in this area. How to engage others in this process was added to the challenges afore mentioned.

III. Care Coordination and Communication

This group was able to agree there are areas of care coordination and communication that can be measured. These two components cross all settings whatever type of model is providing service. The following were considered important to identify:

- Identification of case manager (who is taking the lead with the child and family?)
- Defining 'family',
- Noting a key contact person
- Defining an interdisciplinary team

Other areas included

- Evidence of a comprehensive assessment
- Participation in care conferences
- Written care plan with parent and child input
- Written goals of care.

Also packaging of information to families and referral sources, and established methods of communication were discussed. Identifying every transition in care between settings and or units of care; sharing information with the identified community providers, whether advance directives were present, and regular review of goals were areas identified.

IV. Community Relations and Collaboration

This group first focused on referral strategies that could be measured: the referral sources, time of referral, time of diagnosis, demographic patient information. There was interest in identifying if the palliative care population in community-based programs was different?

Strategies to put these measures in place were identified and include:

- Identifying your group,
- Meet in small groups, most agree breakfast meetings are best,
- Creativity is key,
- Timing
- Who you bring to the table is vital, never limit referral base, attend rounds on acute care units, look at systemic strategies and the bigger picture, who is serving these children.
- Impact can be made through continued education.

The second phase of discussion revolved around education to improve community relations. Suggested were:

- identify teachable moments,
- presentations in community to increase awareness, tell stories,

- improve national partnerships: AAP.
- Across all settings keep asking “Who cares for these kids?”
- Identify liaisons in Hospitals/ community;
- focus on continuity of care.

Opportunities noted for parents and providers to partner included

- Parent- to –parent advocacy groups in each state,
- Disease based specialty groups,
- Advisory groups with parents on them,
- Decision makers for third party payers.

Also for educational opportunities teach parents good *partnership* skills and communication strategies; Our #1 Partner: Parents. Parent empowerment equals change agent energy.

A key question arose: how do we measure success?

One parents’ definition: “to go thru life from diagnosis to bereavement with complete support w/o guilt or regret as possible”

Standards from Hospice: is hospice as good as we can get?

- Defined & measured from their perspective
- Short-term vs. long-term success
- Palliative vs. hospice success
- Structure before process
- Existence of programs is success

Competing interests of stakeholders, at least potentially competing, (patients, family, staff, payers) are noted.

There are practical issues. How do we quantify these?

- How to contact staff and receive call back!
- Geographic issues
- Pain response
- What is the most practical thing we can do right now?

Note differences in local (program), state/regional, and national outcomes. Measure success could then benchmark.

Open Mic Discussion:

Sarah Friebert, MD: Asked if there is interest in a system like “1-800-COMFORT”: a phone based consult and support system for care givers.

(ex: like 1-800-NOCLOT/poison control in Canada) ??

- MD/Psychosocial expertise
- How might we staff that?
- Is this a doable thing we could enact as a group?

Lauren Spiker advocated parent involvement: Lauren's family was seen as "special case"

- Opportunity to help parents learn to be good partners in care, not just advocates
- Might get better parent feedback this way?

Sharon Brueggeman: Take tips from marketing:

- Bring your "No see physician" (barrier person) on a cruise (or to lunch) idea
- Making cover letter or info/specifics to give to barrier persons.
- Identify: what is it those people are not understanding?

Outcome Measures and Quality Indicators

Chris Feudtner, MD Convener

(See Powerpoint slides)

Dr. Feudtner opened the session with an overview of the issues at hand.

We need a Plan:

- What are we trying to measure?
- What are we trying to accomplish with measurement
- What are our targets for measurement?
- Examples of strategies and measurements
- Research vs. evidence to support program development and growth
- We need a strategic plan: identify steps and FOCUS

Our focus includes Pediatric Palliative Care through End of Life Care and Bereavement

- Goals: think about ends and targets of measurement
- Examples, suggestions and collective problem-solving

All of these questions we will have to re-examine at the local/regional level.

- Strategy: make a plan → break it down → **focus**
 - Can't do everything even if we want to
 - Don't need to all pursue same linear path

We have a daunting task and we have already made a lot of progress. How do we move forward?

1. Survey the lay of the land
2. Develop a strategic plan
3. Break down the plan into steps and /or questions
4. Focus

We want to capture everything that matters in this field, which is both a strength and an Achilles heel! "I wish I could do everything, but this is the next thing I am going to do." True for us, and true for families: how do we make our way through a dark maze and find our way forward?

There are many ways to enter and attack the same goal – we don't need to all pursue the same path necessarily.

A proposed framework:

- What is important? Need a vision here--
- What should we measure?
- What can we measure?
- What is already developed – make an assessment toolkit... What can we measure?
- See Joan Keeno, “EOL Measurement Toolkit”
- Why do we measure or what precipitates change? Who are we trying to convince/ change in their thinking?

Who are our stakeholders and what do they need to know to make better decisions?

Taking a point from Machiavelli: “Measurement is not the key – leadership is the key.”
From TQM founders, Deming and Donabedian: How do we guide people to make the best decisions and make progress that way?

How do I offer advice to make things better, to take away suffering? It is not enough to think of ideals; ideals have to be married with social systems and politics.

In our field, what is important?

- Effective pain and symptom management,
- Avoid time where Q of L is poor
- Communication that prepares and empowers,
- Bereavement support

Think about what is important and then marry that to the framework.

Why? Consider the purpose and criteria of management

- Advocacy: needs to be compelling
- Research: methodological rigor, generalizability
- Quality: feasibility
- Consumer empowerment and accountability: comparability

What are we trying to do? There are purposes and criteria of measurement. How is it helpful to know what happened 2 yrs ago?

Measurement efforts need to support existing services, help them beef up to the challenge so families have choices and are therefore empowered rather than setting up challenges or requirements that burn them and have them drop the service line.

Any successful framework for change will be based network of “change” influences

- What new facts have greatest leverage
- Have meetings w/ key people (who needs to be convinced and what data would be compelling?)
- What precipitates change?

Often what's most important is to get the general descriptive fact clear. We need to accentuate the value of these simple, compelling facts, because they could inset into a value system that would precipitate change. These can vary from one area to another. Focus on local issues and perceptions.

- Meet with your local group and consider what key facts might be able to get things moving
- Who do we need to convince and what data would be persuasive for them?
 - Howard Gardner and his concepts of multiple intelligences: little theories that effectively change minds: *Changing Minds*

Strategies that we can use, as suggested by Gardner:

- Reason
- Research
- Resonance – resonates with some other thing that I already care about
- Re-descriptions – reframing, coming to a new understanding of what situation is
- Resources & rewards – value, fairness, justice, equity, also money but not especially money
- Real world events
- Resistances

Training and re-training: how do we “vaccinate” those who can move change forward from effects of negative power and influences. We need behavior change models for:

- Trainees – teach, and also “vaccinate” against future negative encounters!
- Individual clinicians – physicians are often gatekeepers...
- Individual decision-makers
- Units of care: the ecology of care really matters, e.g., NICU
- Larger organizations
- Political landscape, e.g.: California initiative

We are tying measurement to our practice through quality, safety, **movement**. We can tie into existing paradigms, for example, Quality and Safety.

1. Quality

- a. Structures
- b. Process
 - Outcomes: comfort, satisfaction, costs, family functioning (concurrent with treatment and after death), include structure & process (order sets, staffing, availability, consults, assessments, care usage)
 - Do you have a program?
 - Is it staffed XYZ, etc: Access
- c. Outcomes
 - i. Comfort of patients at Children's Hospital satisfaction
 - ii. Care usage
 - iii. Costs
 - iv. Family function

- Health care should be ... safe, effective, patient-centered, timely (from time zero), efficient, equitable (across groups)
- Quality measures: good/bad events, impact, care that meets pt/family wishes, time interval, cost, group variation (define groups)
- d. Quality measures
 - i. Patient safety = non-occurrence of bad events. “ We prevent badness”. Note that event definition is crucial: almost all our pts die, so what are we preventing?
 - ii. Effective
 - iii. Pt-centered care in accordance with pt/family wishes
 - iv. Timely: straightforward measure if events are defined well
 - v. Cost efficient: this measure is fraught with problems. We need to anticipate reactions to the language that we use, etc.
 - vi. Equitable: define group identification. The ideal of equal access to services across SES & race really does motivate people

2. Safety

In a Safety framework the measured outcome is prevention of harm. Examples might include patient pain, suffering, untimely death, parent dissatisfaction, depression, and staff burnout (failure of support and retention leads to organizational costs)

- a. Structure
- b. Process
- c. Outcome: Note that Wolfe’s study was all about safety: kids in pain and suffering
 - i. Pain
 - ii. Suffering
 - iii. Untimely death
 - iv. Dissatisfaction (does family dissatisfaction lead to complex grief?)
 - v. Depression
 - vi. Staff burnout: it’s unsafe to burn out staff: leads to sub-par care, more errors, etc.)

PPC is quintessentially a patient and family centered service, with strong elements of prevention. We need to define what it is we are preventing.

The adult palliative care world has defined 8 Domains of Care. These can apply to pediatrics too. See the National Consensus Project guidelines for preferred practices.

1. Structure and processes for care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Cultural aspects of care
6. Symptom management and comfort care
7. Spiritual, existential and religious aspects of care
8. Ethical and legal aspects of care

Mularski et al, 2006: Defined ICU domains of care, which may help us to define how we might structure care, and how we might achieve the domains set forth in the NQF list.

1. Patient and family centered decision making
2. Communication between the patient, family, and team
3. Continuity of care
4. Emotional and practical support for the patient and family
5. Symptom management and comfort care
6. Spiritual support
7. Support for clinicians

By looking at these areas, we can identify areas for measurement and outcomes analysis. For example, how do we prevent burnout or compassion fatigue? From there, we can begin to design an approach to the question. (See PowerPoint slides)

Analytic design is important. Pay attention to set up and design. Sometimes a univariable design is OK, but it often insufficient, and comparisons can be helpful. Be canny when selecting groups for comparisons. (See Cook and Campbell) Other possibilities include a mixed method of qualitative and quantitative experimental designs. Consider longitudinal comparisons as well. How well is a unit, a group (or groups) of children, a service doing over time?

Creative strategies can include Web-based surveys. See tools that already exist and are already validated, for example Snyder's Hope scale. Simple strategies are now underway in a number of places. A few examples include:

- Question: Do dying patients receive opiates?
Study Example: What fraction of patients receives opiates in last week of life?
(CHOP: 56%)
 - Pair stats w/ stories (eg: teen w/ fears of respiratory distress) to better manage pain, tackle opiate-phobia within the hospital
 - Where are we? Think locally: what happens in our facility? Our network? What can we do locally to improve?
 - Hospitals vs. hospices: volume relationships seem to be evident. The more kids you take care of at EOL, the more likely more kids will get opiates at EOL. Variation does exist: we need to account for these differences
 - These studies don't answer everything, but motivate us to know more

Other Examples:

- Hopefulness of nurses as a motivator of change. Units have their own culture / character re: hopefulness/ hopelessness. Use data as "carrot vs stick," in a canny way to encourage change, make better decisions
- Decision making study: interviewed parents in a prospective study to measure families' distress in the midst of coping with their child's illness
 - PPC Parents are much more depressed & anxious in DPPC study
 - Used standardized instruments, ex: Hospital Anxiety Depression Scale (HADS)

- Positive and Negative Affect Schedule (PANAS): looks at both up and down feelings, PPC parents tend to be much more negatively charged.
- Plea for theory: Both negative & positive affect documented as well, so how to explain or ground with theory?
- Staff need to celebrate the positive: this is part of family experience: families have capacity and creativity to obtain desired goals

As you design your study, consider what data will persuade our target audience? How will you do the pitch? Be prepared to see that sometimes, the data does not support your expectations.

Here are some suggestions for measurement:

- Pay attention to rhetoric: How will you describe or explain the plan?
- Plan carefully *how* the data will be gathered.
- Clarify data, plan analysis, and don't over-measure. Use validated measures, define the process (methodological rigor), enter data, inter-rater reliability (2+ measures), compare to published studies
- What are your Questions in your day-to-day practice? ? Why do want to measure? What is a model to cause change?
- Identify the facts with the greatest leverage in your system. What factors aid or hinder efforts to measure? Buzzwords can add credibility to arguments, for example, "quality", "family-centered care," "Validated, psychometrically sound measure."

Open Mic discussion followed. The following themes were brought up:

- Ask families what they want to know, what outcomes they need. Some have asked family Advisory Councils for input.
- There is a dilemma in that hospitals make money when there are inpatients. Our CFO's want inpatient care. When we look at issues like continuity of care and collaborating with home care and hospices across systems, we need to think about how to advance that cause to our hospital administrators.
- Measurement, CAPC support and funding supports are dysfunctional or non-existent in pediatrics.
- We need a theory about a business model that identifies cost savings and cost prevention. We need to introduce the idea of **cost savers**. Adult PC would lose out by running with the cost savings argument: they do most of their revenue generation in the first 3 days.
- We should define PPC outcomes that don't center around saving dollars.
- We need to advocate for PPC as a subspecialty vs. reliance on a distributive response. How do we study this question, business on the one hand, people embracing skills and subspecialty expertise, while on the other hand PPC should be distributed in the community and available from community physicians. I'm concerned about quality and volume relationships.
- Nurse retention, staff retention, burnout prevention and capacity building are important as cost savings strategies. How can we provide training for emotional management?

- A “Common Curriculum” as has been proposed for PPC training across US and Canada. This could include emotional management training for providers. This would be a long term strategy, with an emphasis on catching people when they are amenable to learning new techniques, puts them on a learning trajectory, and trust as they mature in the field, they will become role models, the helpful attending vs. the “rabid” attending.
- Study services as they relate to quality of experience, and expand on that, vs focus on what’s being taken away from hospitals (losing via system) when kids go to community. E.g., highlight the longer length of care over time, throughout trajectory, loyalty of families for care of siblings, etc. Also, we can attract more care to the system by creating a higher quality system.
- We have to be wary of arguments that motivation for pc is cost. “If I hear you clearly, you say we need to say that, ‘oh by the way, it’s budget neutral.’”
- Can we start to build satellite clinics for PPC in diverse communities? There are real access challenges for families in rural areas, or areas that don’t offer easy access to regional centers. When will satellite clinics be up and running with as high a quality of care offered as in urban areas? What creative, technologic and other strategies can we employ to help kids and families access care in their own communities? Who is not accessing services at all? We are trying to develop services over a very wide geographic area.
- Physicians and parents lead in defining the goals of care. We have to figure out how to train doctors better.
- We need to define the goals of PPC as a field, expected outcomes for pediatrics more tightly. What is the goal that I, personally, have for this field? And as an incentive for being personally engaged in it? How does that inform structure and process?
- A big challenge in all contexts is to define what are the goals and what are the outcomes we are working toward? In the PPC field, I would encourage everyone here to figure out what are the concrete goals for self, and then for our personal departments and programs. A local focus to start with can be helpful. Local improvement in many different areas could yield great progress.
- To give us the kind of data we want is a huge undertaking. We need to develop cooperative strategies for accumulating data, analyzing it, and sharing results so we are not each reinventing the wheel. We need to start small and locally. Next time we can look at which project we should go fwd with to get funding for.

The session adjourned.

Note on the proceedings:

While it was the intent on the part of the planners that the Family Delegates “should have the last word,” the reality of attendees needing to catch flights, etc., caused the group to be concerned that the families’ input not get left to the last hour of the conference. To that end, the order of planned discussions was amended, and the Parent

panel discussion was moved to the first part of the afternoon, and the Education and Training section was held later in the afternoon.

Parent Panel

In the original planning for the Pediatric Palliative Care Forum, it was agreed that the perspective of family members was invaluable. Therefore, the following family members, representing a diversity of personal and health care experiences, participated fully in the Forum:

Rhonda DeBough (Minnesota)	Kim Lovrich (Minnesota)
Deborah Dokken (Maryland)	Rob Lovrich (Minnesota)
Barbara Fermon (Minnesota)	Jill Metz (Oregon)
Michelle Frost (Washington)	Annette O'Brien (Pennsylvania)
Katey Lawson (Pennsylvania)	Beth Page (North Carolina)
Maureen Lilly (Maryland)	Lauren Spiker (New York)

On the last day of the Forum, most of those family members participated in a feedback panel, moderated by Deborah Dokken, Associate Director of the Initiative for Pediatric Palliative Care.

Themes

To highlight the fundamental importance of recognizing and responding to the *uniqueness* of each pediatric patient and his/her family, members of the panel had each prepared an individual statement (see Appendix) addressing ways to advance the field of pediatric palliative care. Although the statements were individual and unique, two broad common themes or needs emerged:

1. Involving and partnering with individual families in defining care for their children with life-threatening conditions

- “Best practices” are as unique as each pediatric patient and his/her family.
- Open and compassionate communication and disclosure of information is key to decision-making about care.

2. Involving and partnering with families to effect change in the health care system, to move the field forward

- Within individual health care institutions by including family members on palliative care committees, other task forces, etc.
- Within broader efforts (regional, national) to change the health care system through research, education, policy development, financing

Resources

Clinicians who are trying to involve and integrate families in expanded ways do not have to do this work alone. Family members themselves can help develop and implement new

initiatives. There are also a number of resources available to serve as models or examples of family involvement, including:

- Many pediatric institutions already have programs and mechanisms for involvement of family members in program development, education, and other activities in pediatric palliative care. Several examples (e.g., Arkansas Children's, Cardinal Glennon, Children's Hospitals and Clinics of MN) were shared during the "open mike" portion of the feedback panel.
- Initiative for Pediatric Palliative Care (IPPC)
Since 2005, IPPC has involved more than 160 family members as co-teachers and co-learners in its educational retreats around the country. Feedback confirms that the participation of parents/families greatly enhances the learning experience of the health care practitioners who attend.
- Partnership for Parents of the Children's Hospice and Palliative Care Coalition (CHPCC)
Partnership for Parents, an on-line support network for families of children with life-threatening conditions, provides information and links to other resources. CHPCC is exploring ways to expand its network and enhance families' role in health care advocacy.
- Publications
Although not focused specifically on bereaved families or families of children with life-threatening, a recent, 6-part, series in *Pediatric Nursing*, "The Many Roles of Families in Family-Centered Care," looks at a spectrum of roles that family members play in health care.

Special concerns

Despite the growing number of programs and initiatives focused on *family-centered* care, the panel and Forum participants expressed concern about "voices" which need to be heard more strongly as the field of pediatric palliative care moves forward:

- Pediatric **patients** themselves
- Bereaved **fathers** and fathers of children with life-threatening conditions
- Bereaved **siblings** and siblings of children with life-threatening conditions
- Families representing greater **diversity**, both ethnic and socio-economic

Education and Training

Jody Chrastek and Stacy Remke, Conveners

Several key challenges for training include questions as to how we identify sub-par practice? How do we establish basic standards for practice? We need training initiatives that can set the bar, that do not reinvent the wheel, and that hold family centered care principals at the heart of their practice standards.

Current activities in education for pediatric palliative care were reviewed. The three main curricula were described:

- The Initiative for Pediatric Palliative Care (IPPC) Program
- The ChiPPS / NHPCO Curriculum
- The ELNEC-Peds Curriculum for nurses

These curricula each emerged about three years ago (2003) and coincided with the publication of the IOM report. It was noted that much development in the field has evolved since that time. NHPCO plans to update their curriculum in the near term.

Models for training include Train the Trainer models (IPPC and ELNEC), Retreat style workshops (IPPC) and Workshop / Seminar format training programs for clinicians (CIPC's Ahlaya Seminars,) and RFP Conferences, like NHPCO's pediatric conference in MI several years ago, and the upcoming OPPEN conference as examples.

Fellowships for physicians also exist (Boston, Akron) and more are currently in development. Bostons' PACT program also offers a MSW Fellowship.

Each has strengths and limitations. The audiences for training vary a great deal, also. For example, clinicians may approach learning with expertise in peds, but none in hospice or palliative care. Alternatively, they may come from adult hospice or home care settings, and need training in peds specific issues. Practitioners may need basic levels of training, or be seeking more advanced and specialized expertise. It is appropriate and helpful that there are a variety of training opportunities, methods, and resources available. The question remains, however, that it is not clear how practitioners can achieve basic skills and move through levels of expertise that might include competent and then expert levels of skill. There is no "certification" or validation of skill sets available on a consistent basis. As the field evolves, it will be important to verify certain basic skills to designate the appropriate provider to consumers and providers.

A new opportunity has arisen in conjunction with EPEC. A benefactor is interested in funding a new curriculum for pediatric palliative care that would be applicable across the US and Canada. This opportunity could be used to develop a "common curriculum" that would be able to offer a standard for training to the competent practitioner level. Representatives from each of the major curricula, the major Peds Palliative Care centers, Fellowship programs, and others are involved in exploring this idea. The first step will be to develop a clearer picture of the needs and conduct a feasibility study for the project. Stefan Friedrichsdorf, MD and the CIPC team will coordinate the project with EPEC staff and the PPC community's steering committee.

Several groups have stepped forward to help coordinate sharing of information and web-based communications so that training opportunities can be well publicized, and information shared across the field. A centralized clearinghouse for information like this is needed. CIPC is interested in adding any interested parties to our e-mail list so that we can share such information with the field and interested others.

- Needs: Interdisciplinary – integrative, team development, intra-disciplinary
 - Clinical intervention – pain & sx management, communication, ethical issues
 - Program development training – system effectiveness (hierarchical), advocacy & collaborative practice
 - Networks for care → building the web/training & support
 - Outreach to practicing professionals → motivated good learners
 - Outreach to rural/semirural areas to advance PC
 - Baseline standards for training
 - Benchmarks for education & training (limited course content)

Conclusions: Action Steps

- Meeting yearly: AAHPM alternating with Montreal in even years; CIPPC to reconvene the Forum in 3 years. Friedrichsdorf and Hutton
- Research collaborative. Wolfe, Feudtner, Friedrichsdorf and Hayes to coordinate
- Web-based directory / database to be established through Gems of Care to support development of care communities for PPC (Kate Eastman)
- MD leaders to work with AAP and AAHPM to establish SIGS in each of those organizations and ask for a peds track / presence in those annual meetings, etc. Friedrichsdorf, Hutton, Lewandowski
- CIPPC will continue to act as a central point for info and referral on what is going on in the field. Remke, Chrastek, Friedrichsdorf, Osenga
- The “Common Curriculum” idea will be explored and developed, utilizing existing resources like IPPC, ELNEC-Peds and ChiPPS curricula, and EPEC materials to be determined and developed as needed. Friedrichsdorf, Remke, and CIPPC Staff
- Recommend membership on PaedsPalCare list serve for international communications and networking. Done.
- Adopt the ACT definitions for PPC and conditions appropriate to refer. Done
- Publish Forum Report and resources on the web (CIPPC).
- Parents to publish a statement re: research advocacy and participation. Dokken

Summary and Conclusions

The Forum proved to be a useful meeting in terms of gathering experienced providers together, and focusing on the needs and challenges of this important and growing field.

Points of discussion emphasized the need for greater coordination and collaboration for benchmarking, quality improvement, research, and education.

It also seems that the sub-specialty practice of pediatric palliative care is rapidly evolving, and at the same time, there is a demand for more education, training and knowledge about palliative care interventions that need to be integrated across the pediatric care curriculum. It seems likely that educational efforts, clinical skills training, and program development initiatives will need to take both these important directions into account.

It will be important to champion family centered care as the field moves forward. There are supportive resources to be tapped among parents who have survived the loss of their children and wish to contribute to the field.

Networking and benchmarking with well established programs can and should continue. These efforts will help establish standards of care and expectations for care delivery that have been lacking to date.

Outcome measures are needed and collaborative strategies aimed at identifying indicators, and comparing outcomes toward the establishment of best practices are needed.

Research into this field is complex and also greatly needed. In spite of having “no time, no money, and no staff” we need to continue to explore creative avenues for developing good data to drive state of the art care.

The group affirmed the importance of these issues and the need to continue the dialog started here. The Field of Pediatric Palliative Care as here assembled is committed to compassionate, effective, and integrative care for children and families, across the care continuum. To that end, we will meet at the AAHPM and / or Montreal Congress meetings, and continue efforts at collaboration using all the tools available to us, and building upon the relationships developed here at the Forum.

Respectfully submitted,

Stacy S. Remke, MSW, LICSW

With special thanks to those who contributed to the Report on the Forum

Deborah Dokken

Susan Huff

Jess Armstrong

Liz Davis

Christine Gibbon

Donna Eull

References:

Appendix A	Forum Rationale and Agenda
Appendix B	Roster of Participating Programs
Appendix C	Program Descriptions / Services
Appendix D	Priorities for Advancing the State of the Art Survey and Collated Responses
Appendix E	Resources shared at the meeting
Appendix F	Ranking of Priorities by the Attendees
Appendix G	Statements from Parent Participants
Appendix H	Parking Lot

The Pediatric Palliative Care Forum

June 14-15, 2007

Minneapolis, MN

The purpose of the Forum is to bring together experienced providers in the field 5 years after the publication of the IOM Report, “When Children Die,” to take stock of the progress, needs, challenges that exist in the field today. We will work together to define next steps for this specialty practice area, develop collaborative strategies for addressing a variety of important issues including advocacy, standards for clinical excellence, funding, research, outcomes and data collection, education, training, and organization of networking in the field into the future.

The Forum’s program will be designed to encourage interaction and the exchange of ideas among participants. Our goal will be to create “products” from the meeting that will include:

- A national registry of existing programs and services in pediatric palliative care that will become web-based and web accessible to providers, families, and others. (In collaboration with the Gems of Care project)
- A report on the State of the Field: models of care, successes and challenges, and directions for future efforts.
- A plan for organizing communication, sharing of knowledge, and a central source for referrals and information related to the field as a resource for those in the field as well as those seeking to access or develop services.
- Other items to be determined by the needs of the assembly.

The field of Pediatric Palliative Care has been growing rapidly in recent years. There are now a number of providers, organizations and agencies that have significant experience in the practice of this care, and have much to share in regard to lessons learned, successful models, and mistakes that others can benefit from. The field seeks to care for children with life –threatening conditions and their families. This is “low frequency, high intensity and high impact” care. It is important that providers collaborate and share expertise to

- Minimize the potential for competition for limited resources needed to advance the field
- Maximize the development of services to kids and families
- Advocate for funding streams and service development that meets the needs of children and families
- Create efficiencies and standards of care that have been tested by practice
- Create data sets and outcome measurement strategies that will encourage benchmarking and strengthen knowledge driven growth of the field
- Develop collaborative strategies for research and advancing clinical excellence

Pediatric Palliative Care Forum

Minneapolis, MN June 14-15, 2007

Objectives:

Participants will:

1. Learn the history and current status of the specialty field of pediatric palliative care.
2. Identify the challenges to research in this field and recommendations for effective research.
3. Learn the core competencies and skill sets necessary for effective provision of pediatric palliative care, and recommendations for future development in the field.
4. Identify funding and advocacy needs and strategies that have proven effective in supporting program development and service provision.
5. Learn three models of care that have proven effective for providing pediatric palliative care, including to diverse and underserved populations.
6. Identify quality indicators that have been successfully demonstrated to document program efficacy and needs for further development.
7. Learn about educational projects and outcomes that indicate best strategies for education of practicing professionals from diverse disciplines to be effective pediatric palliative care providers across settings.
8. Learn about parental / family priorities and concerns as they cope with their children's life-threatening illnesses.

Agenda

Thursday, June 14, 2007

7:45 am	Continental Breakfast and Registration
8:30 am	Welcome from Alan Goldbloom, MD CEO, Children's Hospitals and Clinics of MN Introductions and Announcements from CIPC
8:45 am – 9:15 am	Keynote Address: Where we have been and where we are now: Challenges and Opportunities for Pediatric Palliative Care. Presenter: Ida Martinson, PhD
9:15- 10:15 am	Overview of Some Successful Programs, and Development of the Field of Pediatric Palliative Care: "Snapshots of Care"
10:15-10:30	Break
10:30- 12:30	Advancing the State of the Art in Clinical Practice of Pediatric Palliative Care Convener: Stefan Friedrichsdorf
12:30- 1:45	Lunch break and Program Poster Exhibits
1:45 – 3:45	State of the Art in Pediatric Palliative Care Research Convener: Joanne Wolfe
3:45 – 4:00	Break
4:00- 4:45	Feedback and Facilitated Discussion among Assembly
4:45	Adjourn
5:30- 7:30 pm	Conference Reception at Cue (directions provided upon registration)

Friday, June 15, 2007

7:45 am Continental Breakfast
8:30 – 8:45 Welcomes and Announcements, Comments
8:45- 10:30 Funding and Advocacy
Conveners: Devon Dabbs and Ann Morris
10:30- 10:45 Break
10:45- 12:15 Models of Care
Convener: Sue Huff
12:15 -1:00 Lunch Break
1:00- 2:30 Quality Indicators and Outcome Measures
Convener: Chris Feudtner
2:30- 2:45 Break
2:45- 4:15 Education and Training
Conveners: Stacy Remke and Jody Chrastek
4:15- 4:45 Parent Feedback Panel
4: 45- 5:30 Discussion and wrap up: identification of action steps
5:30 Adjourn

* Total hours of educational content: 14.5

Planning Group

Stefan Friedrichsdorf, MD
David Steinhorn, MD
Michelle Fedderly, Hospice MN
Stacy Orloff, MSW, Ed.D
Lori Butterworth
Gina Santucci, RN, MSN
Kaci Osenga, MD
Marion Taylor, CPNP
Barbara Sourkes, PhD
Deborah Dokken, MPA
Stacy Remke, MSW, LICSW
Jody Chrastek, MSN, CHPN
Annette O'Brien, RN, Grandparent
Katey Lawson, Parent

Snapshots in Care

Ross Hays
Seattle Children's

Stacy Orloff
Hospice of the Florida Suncoast

Krista Westendorp
Children's Hospitals and Clinics of MN

Tamara Vessel
Boston Children's Hospital

Tammy Kang, MD
Children's Hospital of Philadelphia

Hal Siden, MD
Canuck Place

Sarah Freibert, MD
Akron Children's Hospital

Appendix E Resources Shared at the Meeting

- For updates, distributions lists re: publications in PPC, contact www.act.org/uk for pedallit listserv
- E-mail Rita Fountain at PACT Boston for a monthly update: rita.fountain@dfci.harvard.edu
- www.partnershipforparents.org
- For information or resources related to pediatric palliative care education, training, and networking resources: cipc@childrensmn.org
- NHPCO

Appendix G: Individual Statements from Family Member Participants

To advance the “state of the art” in pediatric palliative care, we must . . .

Consider the voice of the parent and child. Who is the parent on your team?

Remember that change starts with each of us; remember to actively care; remember the reason we are here -- the children who need us to care.

Emphasize the importance of open communication, no matter how difficult or how final; it is what made the difference in the decisions we made as a family and in my son's spirit and inner power.

Regard parents as equal partners in the care of their children, requiring candid, complete and compassionate disclosure of all information for optimal decision-making, with the acknowledgement that “best practices” are as unique as each family.

Work as partners, both doctors and parents, because we hold different but equally important information about the care of children.

Formalize the transdisciplinary nature of this Forum, with inclusion of parents, and build upon it.

Identify our allies in positions of power in government and move forward with funding and reimbursement issues.

Create family/clinician partnerships in every area, including advocacy, program development, and education.