Pediatric Palliative Care: Barriers and Solutions

Lonnie K. Zeltzer, M.D.
Director, Pediatric Pain Program
Professor of Pediatrics, Anesthesiology, Psychiatry & Biobehavioral Sciences
David Geffen School of Medicine at UCLA

LZeltzer@mednet.ucla.edu
Talk Outline

1. Status of Pediatric Palliative Care

2. Barriers to Palliative Care
   - Communication
   - Knowledge/Training

3. Solutions: grass roots efforts
WHAT IS PALLIATIVE CARE?
PALLIATIVE CARE: WHO Definition (2002)

• “an approach that improves quality of life of patients and their families facing problems associated with life-threatening illness
  • prevention and relief of suffering by early identification and impeccable assessment & treatment of pain and other problems- physical, psychosocial and spiritual.”
CHANGING THE PARADIGM OF PALLIATIVE CARE

Disease Eradication

Disease Eradication

Palliation

Palliation

Diagnosis

Death

Diagnosis

Death
PALLIATIVE CARE FOR CHILDREN: SPECIAL CONSIDERATIONS

- Cognitive/developmental differences impact child’s decision-making abilities, meaning of QOL, communication
- Family becomes a significant part of the decision-making and reporting of suffering
- Ethnicity, race, cultural background, religion will influence meaning and communication
- More likely to have proxy reporting of pain and other symptoms

National Hospice & Palliative Care Organization, 2000
Symptoms and Suffering in the Last Month of Life

Wolfe et al. NEJM 2000.
NEEDS: Many children with difficult-to-treat congenital conditions die: most die in the ICU

* 154/206 (75%) children with hypoplastic left heart syndrome treated at a pediatric hospital 1983-2004 died
* 62% surgically treated died: 99% died in hospital
* 100% treated without surgery died: 87% died in hospital
* 79-83% died in ICU

Cantwell-Bartl AM et al, J Palliat Care. 2008;24(2):76-84
Cost Barrier?: Costs of care higher without palliative care but resources are needed up front for palliative care team

- case-controlled methodology
- health care costs and distribution of costs compared between children who did and did not receive coordinated palliative care (PC)
- Children receiving PC underwent fewer radiology procedures and received greater assistance from pharmacologic services than those without PC
- Overall hospital costs were greater in those not receiving coordinated palliative care

Ward-Smith P et al, Nurs Econ. 2008 May-Jun;26(3):175-8
Concept Barrier: A vague concept of palliative care may delay the provision of palliative care to children

- Interviews of physicians in a tertiary care pediatric university hospital in Canada
- Physicians limited their concept of palliative care to relief of physical symptoms, *equating palliative care with comfort care*
- Variation regarding the appropriate moment to introduce palliative care for children
- Many physicians not comfortable using the term "palliative care"

Communication: Planning Location of Death

- 63% of 140 parents of children who died from cancer at 2 U.S. hospitals (with ped palliative care) planned child's LOD
- families explained Rx options during child's end of life & had home care: > plan LOD
- Planning LOD vs non-planners:
  - More home deaths (72% vs. 8%)
  - Fewer hospital admissions (54% vs. 98%)
  - More comfortable with LOD (84% vs 40%)
  - Within hosp LOD: More likely to die on ward vs ICU (92% vs 33%)

Dussel V et al, J Pain Symptom Manage. 2008
Communication: Parent Vs MD Recognition of Child’s Likelihood of Dying

- Physicians recognized no realistic chance for cure of child’s CA twice as early before child’s death than did parents (330 vs 150 days)
- Among children who died, earlier recognition by parent/physicians
  - earlier discussion of hospice care
  - better parental ratings of quality of home care
  - Earlier DNR orders
  - less use of cancer-directed RX during last mth of life
  - More likely to have RX goal of reducing suffering
- Earlier recognition by MD & parents: assoc with stronger emphasis on lessening suffering and greater integration of palliative care

Communication: Parents’/Physicians’ Expectations

- 61% parents of children with CA more optimistic about chances of cure than were physicians
- Parents/physicians similar expectations of QOL
- Parents more pessimistic than physicians about intellectual and physical impairments of child
- Predictors of Parent/Physician agreement:
  - Physician confidence in knowledge of prognosis
  - Parents who felt their preferred decision-making role was respected
- Conclusion: Physicians are partly responsible for parents' unrealistic expectations about cure

Communication: Parents/Physicians

- Parent ratings of child's pain not related to parent perceptions of physician’s care of child
- Physician ratings of care inversely related to parent's ratings of child's pain
- Parent-rated communication factors not related to physician-rated care of child
- No assoc found between parent & physician care ratings
- Par ratings of MD care assoc w/ communication
- MD ratings of MD care depend on biomedical vs relational aspects of care (e.g. disease RX)

Mack JW et al, JCO, 2005 Dec 20;23(36):9155-61
Communication: Between Parent Dyads

- Parents’ goals often concurrent at Dx of cancer
- Parents’ goals often disparate at EOL period
- Parent disagreement on EOL goals:
  - Assoc with parental perceptions of more child suffering at EOL than in parents who agreed on EOL goals

- Conclusion: Need for physicians to help parents to be in agreement at child’s EOL: good parent/physician communication with both parents

Knowledge, Comfort, and Education

- 323/597 docs (children’s hosp) rated confidence level to provide palliative care (4 pt scale) for each item
- Self ratings of "confident" or "very confident"
  - 74% for giving difficult news to families
  - 23% for managing end-of-life symptoms
- Self ratings of "likely" or "very likely"
  - 36% would attend pall care training
  - 86% would refer for pall care consult
  - 91% would refer to home health/hospice
- Summary: few MD’s want more training and would prefer to refer to a palliative care team

Ped Residents’ Knowledge, Comfort, and Education

- 49/75 2nd yr residents reported minimal training, experience, knowledge, comfort & competence in virtually all areas palliative care for children
- no improvement in any of these areas from 1st to 3rd yr residents
- Residents ranked as first the need for more training in pain management
- next 4 educational needs were:
  - communication skills: discussion of prognosis, bad news, code status
  - talking with children about end-of-life care

Ped Residents’ Knowledge, Comfort, and Education

- 40/80 ped residents completed survey
- Residents experienced 4.7 pt deaths (average)
- >50% had discussions of withdrawal/ limitation of life-sustaining therapy, Sx management, completing death certif, seeking personal support
- <50% taught about discussions of withdrawal/ limitation of life-sustaining therapy, declare death, discuss autopsy, complete a death certificate, have f/u with families
- Residents did not feel adequately trained in palliative care

McCabe ME et al, Pediatrics, 2008 Apr;121(4):e731-7
Ped Surgical Trainees’ Knowledge and Education

- 59% of 40 ped surg trainees reported receiving adequate training in bioethics to handle ethical issues re. care of very ill children
- 83%: reg particip in PC discussions
- 30% wanted more discussions on end-of-life issues with staff
- 58% said ethical conflicts not resolved as a result of end-of-life policies
- 31% felt reporting of unethical conduct would result in personal reprisals

Conclusion: Ped surg trainees face ethical/moral conflicts but fear reprisals if concerns reported

UCLA: how did we start with nothing?
Pediatric Residents’ Education: Palliative Care Seminar Series

1. Definitions & Practice: A New Model of Pediatric Palliative Care (PC)
2. Psychological Aspects of PC
3. Psychotropic Medication in PC
4. Pain Management in PC
5. Ethical/Cultural/Religious/Spiritual issues
6. Communication: Giving bad news
7. Communication: DNR
8. Hospice Care
9. Bereavement/Grief
Education <-> Implementation

- UCLA PEDIATRIC PALLIATIVE CARE TASK FORCE
  Multidisciplinary
  Monthly meetings
  Nurses, Faculty, Residents, Fellows, Child Life Specialists, Social Workers, Psychologists, Administrators, Ethicists, Resp Techs, Care Partners, Researchers, Students…

3 working groups: educ, policy, clinical care
*Education <-> Implementation*

**The Children’s Comfort Care Panel**

- Complex pediatric case, child with a life-threatening illness
- Impasse in care
- Multidisciplinary panel of experts
- Provided educ/participation
- Goal: Implement PC Treatment Plan
- One follow-up meeting
- Minutes and Summary for pt chart

**Parents’ Advisory Board**
FUTURE of PEDS PALLIATIVE CARE

• Need for education at all levels of training and for all healthcare providers

• Communication: largest barrier

• Need to change culture of care from acute/save lives/cure to equal importance of maintaining quality of life
I would like to thank

Elana Evan, PhD, UCLA Pediatric PC Director

Shahram Yazdani, MD, Coord of PC Med. Education

Jennifer Richlin, RN, NP, PC Clinical Coordinator

Members of PC Task Force

Parents’ PC Advisory Board

Administration: Mattel Children’s Hospital and UCLA Health Sciences Enterprise