The Critically Ill Child: Palliative Care, Staff Care, and Self Care in the 21st Century

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Drexel University College of Medicine
NO DISCLOSURES
INTRODUCTIONS

- Colette C. Mull MD
- Evan J. Weiner MD
- Sabina Singh MD
- Arun Chopra MD
- Mindy Dickerman MD
- Christopher Haines DO
- Emily Nichols MD
- Ajay Desai MD
WORKSHOP SURVEY

- Complete pre- and post-workshop surveys

- Identifier
  - Conference registration number on ID tag
  - Used to track pre- and post-survey completion
  - Will be discarded & changed to single number

- Uses
  - Self-evaluation
  - Educational research purposes: implied consent
  - Support for need in graduate medical education and maintenance of certification
GIFT TO YOU

WORKSHOP CD-ROM

- Survey answers
- Slide presentations
- References
- Educational tools

- Difficult Conversations
- Family Presence
- Palliative Care
- Care of Self and Staff
LEARNING OBJECTIVES
Learner will be able to...

- Tailor interactions with guardian/family of critically-ill child
  - Culture
  - Spiritual beliefs
  - Level of education
- Introduce concept of palliative care
- Identify ways to support self & medical team caring for critically-ill child
Who are you?
CASE

- 10 year old boy
- Presents to ED
- CPR in progress
- In asystole
- Accompanied by parents
PAST MEDICAL HISTORY

- Hypoxic-ischemic encephalopathy
- Hydrocephalus: VP shunt
- Seizure disorder
- Chronic lung disease
  - Tracheostomy
  - Ventilator-dependent
- Gastroesophageal reflux disease
CASE PROGRESSION

- PALS algorithm-guided resuscitation
- 20 minutes elapse
- Questions:
  - Where are parents during this resuscitation?
  - When do you speak to parents?
  - What do you say to parents?
CASE PROGRESSION

- Sinus rhythm returns
- Poor perfusion
- Low blood pressure
- Questions
  - What do you say to parents?
  - What medical care should this patient receive?
The Difficult Conversation

Evan J. Weiner MD
Director of Operations
Assistant Professor of Pediatrics & Emergency Medicine
Department of Emergency Medicine
BACKGROUND

- Commonly encountered
- Patients with complex medical needs
- Lack of education
  - Pediatric residents care for 35 dying patients
  - Comfort level
    - 13% Resident
    - 56% Fellow
    - 71% Attending Physician

BARRIERS

- Fast-paced dynamic environment
- Limited information available
- Rapid changes in condition
- Decision-makers not immediately available
- Familiarity with patient
- Provider comfort level
- Language discordance - Interpreter utilization\(^1\)

\(^1\)Norris WM. *J Palliat Med* 2005
DELIVERING BAD NEWS

- Setting
- Foundation
- Discussion
- Adapting
- Next step

SETTING

- Privacy
- Family support members
- Multidisciplinary support (e.g. clergy, social work)
- Role definition
- Acknowledge provider feelings
THE FOUNDATION

- Introductions
- Pacing and tone
- Empathy
- Compassion
- Rapport
THE DISCUSSION

- Avoid medical jargon
- Assess what family already knows
- Assess response
- Use silence
- Use touch
- Allow for breaks and questions
- Frank presentation (family preferred)¹

¹Woolley H et al. BMJ 1989
ADAPTING

- Assess how much family desires to know
- Allow for breaks & questions
- Range of responses
- Grief reaction: DABSA

1Kubler-Ross E, *On Death and Dying* 1969
NEXT STEPS

- Concrete
- Be available
- Enlist help
  - Clergy
  - Social Worker
  - Consultants
  - Primary physician
<table>
<thead>
<tr>
<th><strong>DO</strong></th>
<th><strong>DON’T</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Choose private setting</td>
<td>Forget introductions</td>
</tr>
<tr>
<td>Enlist support</td>
<td>Do it alone</td>
</tr>
<tr>
<td>Acknowledge your feelings</td>
<td>Shirk responsibility</td>
</tr>
<tr>
<td>Show empathy</td>
<td>Use medical jargon</td>
</tr>
<tr>
<td>Build rapport</td>
<td>Use family to translate</td>
</tr>
<tr>
<td>Pace yourself</td>
<td>Rush</td>
</tr>
<tr>
<td>Allow for pauses and questions</td>
<td>Avoid silence</td>
</tr>
<tr>
<td>Be adaptable</td>
<td>Be rigid</td>
</tr>
<tr>
<td>Be frank</td>
<td>Use euphemisms</td>
</tr>
<tr>
<td>Be concrete</td>
<td>Forget to utilize support staff</td>
</tr>
</tbody>
</table>
ADVANCED DIRECTIVES

- Life preservation vs. suffering prolongation
- Tailored to family/patient desires
- Involvement of primary physicians
- Not “all or nothing”
- Focus on palliative care
# ADVANCED DIRECTIVES

<table>
<thead>
<tr>
<th><strong>Do Not Resuscitate (DNR)</strong></th>
<th><strong>Living Will</strong></th>
<th><strong>Durable Power of Attorney (DPA)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician order</td>
<td>Legal document</td>
<td>Legal order</td>
</tr>
<tr>
<td>Menu of specific desires</td>
<td>Categorical statements</td>
<td>More for adults</td>
</tr>
</tbody>
</table>

DEBRIEFING

- Takes place in minority of cases

- Attitudes
  - Helpless
  - Innocent
  - Not natural
  - Didn’t experience full life

- Emotional responses

- Self-care

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1 Serwint JR. J Pediatr 2004
2 Wolfram W, Bradshaw JE. Emedicine 2011
SUMMARY

- Commonly encountered
- Have a plan
- Coordinate palliative care & advanced directives
- Pay attention to your own feelings
Family Presence During Resuscitation

Sabina Singh MD
Physician Leader, Family Presence Program
Assistant Professor of Pediatrics & Emergency Medicine
Department of Emergency Medicine
Sterile Cockpit Rule

- Aviation accidents attributed to
  - Interruptions
  - Distractions
  - Preoccupation with one task
- Enacted in 1981 by the FAA
- Prohibits non-essential activities
- Tracked by Aviation Safety

*Title 14 Code of Federal Regulations* 121.542, 135.100
Family Presence in 1960s

- Frankl et al. 1962
  - Maternal presence in dental procedures

- Schulman et al. 1967
  - Parental presence during anesthesia induction
History of Family Presence

- 1992 Foote Hospital reports positive experience \(^1\)
- 1993 ENA resolution supports FP \(^2\)
- 2000 PALS & AHA support FP \(^3,4\)
- 2003 Survey of ED/ Critical Care Units nurses \(^5\)
  - Family Presence  45%
  - Written Policy  5%

\(^1\) Hanson C, Strawser D. *J Emerg Nurs* 1992
\(^2\) Position Statement, Emergency Nurses Association 1995
\(^3\) Hazinski M et al. PALS Provider Manual 2002
\(^5\) MacLean SL et al. *J Emerg Nurs* 2003
Family Presence Myths

- Traumatic experience
- Negative behavior in kids
- Susceptibility to infection
- Resuscitation time
- Stress & distraction for staff
- Misinterpretation of staff actions
- Malpractice
Reality: Interference/ Distraction

- Bauchner et al.
- Two separate studies
- Conclusion: no interference with healthcare providers’ efforts when family present

Bauchner H et al. *Pediatrics* 1989
Reality: Stress/Anxiety

No difference in anxiety level

- **Healthcare provider**
  - Parents present or absent during their child’s lumbar puncture\(^1\)

- **Parents**
  - Parents present or absent during their child’s CPR\(^2\)

\(^1\)Haimi-Cohen Y et al. *Clin Pediatr*, 1999

The Healthcare Provider’s Opinion

- Prospective survey
- NJ ENA members, n=208
- “If your family member was ill or injured, would you want the option to be present for…?”

- Invasive procedures 80% YES
- Resuscitations 56% YES

Ellison S. J Emerg Nurs 2003
The Healthcare Provider’s Opinion

- Survey, n=104
- ED attendings, nurses, residents
- Approval higher for less invasive procedures
- Trauma resuscitations:
  - Overall only 31%
  - Attendings 63%
  - Nurses 62%
  - Residents 4%

Fein JA et al. Pediatr Emerg Care 2004
The Resident’s Opinion

- Survey, n=53
- Pediatric residents
  - Level of training
  - Procedures
  - CPR

Bradford KK et al. *Ambul Pediatr* 2005
The Parent’s Opinion

- Survey, n=400
- Parents in a pediatric ED
- Prefer to be present
  - Minor procedures >90%
  - Child unconscious 81%
  - Resuscitation 83% (poor outcome)

Physician Experience

- Prospective mailed survey
  - AAP (Critical Care & Emergency Medicine)
  - ACEP
- FP during CPR
  - Prior participation 83%
  - Participation by specialty
    - Pediatrics 88%
    - Emergency Medicine 75%
    - Surgery 46%
  - Participation pediatric vs. adult provider
    - Pediatric provider 89%
    - Adult provider 73%

Physician Experience

<table>
<thead>
<tr>
<th>Experience</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Good</td>
<td>52%</td>
</tr>
<tr>
<td>Equivocal</td>
<td>33%</td>
</tr>
<tr>
<td>Bad</td>
<td>7%</td>
</tr>
<tr>
<td>Unsure</td>
<td>8%</td>
</tr>
</tbody>
</table>

Physician Experience

- Experience was similar across
  - Provider’s age
  - Gender
  - Pediatric versus adult provider
  - Provider being a parent
  - Provider having witnessed CPR on a family member

- Benefits stated by staff who supported FP
  - Inherent right
  - Facilitates grieving
  - Accept death

Nurse Experience

Nurses Positive Experience

- Team acted with respect
- Encouraged professional conversation
- Better acceptance that all was done
- Family grief facilitated
- Team/ family bonding
- Family voiced appreciation
- Participants would recommend FP again: 82%

Davidson JE. Crit Care Med 2006
Reality:
Psychological Effect on Parents

- Prospective, randomized, controlled trial
- Overwhelming evidence of beneficial psychological effect on parents in trial group

- Study ended prematurely so that the control group could benefit from FP

Reality: Interruptions

- Survey of parents & providers
- FP events: 64 (28 resuscitations)
- Number of participants
  - Parents: 22
  - Providers: 92
- Death in 2 resuscitations
- Results: ZERO patient care interruptions

Mangurten J. J Emerg Nurs 2006
Reality: Treatment Time

- Providers experience of FP
  - No change in treatment 96%
  - Procedure time same 93%
  - Procedure easier 87%
  - Outcome unchanged 92%
  - Performance unaffected 90%
  - Resident training unaffected 88%
  - Provider would repeat FP 90%

- Parents
  - Would do it again 100%
  - No traumatic memories 3 months later

Mangurten J. J Emerg Nurs 2006
What is Family Presence?

- **Family**
  - Parents
  - Grandparents
  - Guardian

- **Presence**
  - Prescreened
  - Option
  - Support person
    - Nurse
    - Social Worker
    - Clergy
    - Child Life Specialist
Factors for Success

- Ability of physician to decide option
- Training for staff
- Presence of family support staff
- Presence of bereavement support staff
- Ability of family member to decline
- Predetermined number of family members

Fein JA et al. Pediatr Emerg Care 2004
Positive Effects of Family Presence

- **Patient**
  - Calmer & more comforted
  - Felt safer & less scared

- **Family**
  - Reduced anxiety
  - Decreased helplessness
  - Increased sense of control
  - Knowledge that everything was done
  - Facilitated grief process

Fein JA. *Pediatr Emerg Care* 2004
Mangurten J. *J Emerg Nurs* 2006
Positive Effects of Family Presence

- **Healthcare Provider**
  - Valuable health information about child
  - Education of parents about condition
  - Reminded of the patient’s “personhood”
  - Improved pain management
  - Might try harder
  - Would consider alternative treatment
  - Would recommend FP

Fein JA. *Pediatr Emerg Care* 2004
Mangurten J. *J Emerg Nurs* 2006
National Consensus Conference

- Representatives from 18 national organizations
  AAP, APS, SAEM, ACEP, ENA, ATS, CLC, NA-EMT, AHA, AHRQ, NASW etc.

- RAND/UCLA Appropriateness Method
  - Panel of experts
  - Literature review
  - Development of list of issues & definitions
  - Pre-survey
  - Development of second survey
  - Recommendations

Henderson DP, Knapp JF. *Pediatr Emerg Care* 2005
National Consensus Conference Recommendations

- Assess for
  - Possibility of interruption in patient care
  - Disagreement among family members
  - Altered mental status/intoxication
  - Extreme emotional volatility
  - Combative/threatening behavior
  - Threat to safety of health care team

Henderson DP, Knapp JF. *Pediatr Emerg Care* 2005
National Consensus Conference
Recommendations

- Education of all health care providers
- Policy should undergo legal review
  - HIPPA issues & interpretation
- Offer family presence as an option to all
- If not offered, document reasons
- Promote research related to FP

Henderson DP, Knapp JF. *Pediatr Emerg Care* 2005
Palliative Care

Arun Chopra MD
Medical Director, Patient Comfort & Advanced Planning Team
Assistant Professor of Pediatrics
Division of Critical Care
Ethics

- Do families or surrogates have the right to make decisions for incapacitated minors?

- Beneficence vs Non-malfeasance

- Double effect

- Continuum of care is ongoing not withdrawn
When to transition?
You want to do what?!

- Compassionate disclosure
- Assure ongoing commitment to care
- Direct wording, avoid euphemisms
- Allow time to listen
- Minimize agenda
- Optimize the setting
Use your team

- Palliative care specialists
- Pain teams
- Social workers
- Child Life
- Primary care physicians
- Parents
- Family
PALLIATIVE CARE 101

Affirms life

Promotes quality of life

Treats the person

Supports the family
PAIN AND ANXIETY

**PAIN**
- Opioids
  - Morphine
  - Methadone
  - Fentanyl
  - Oxycodone
- NSAIDs
- Acetaminophen
- Bisphosphonates
- Tricyclic antidepressants
- Steroids
- Adjuvants

**ANXIETY**
- Benzodiazepines
- Pain control
- Dyspnea management
- Psychological interventions
- Biofeedback
- Hypnosis
- Titrated to effect, may require higher than normal doses
Dyspnea

- Opioids
- Benzodiazepines
- Combination of opioids and benzodiazepines
- Diuretics
- Inhaled furosemide?
- Oxygen?
- Limit fluid intake

Clemens KE, Klaschik, E. J Pain Symptom Manage 2007
Allard P et al. J of Pain Symptom Manage 1999
Navigante AH et al. J of Pain Symptom Manage 2006
Friedrichsdorf SJ, Collins JJ. Med Princ Pract 2007
Nausea

- **Antiemetics**
  - Ondansetron
  - Metoclopramide
  - Antihistamines

- **Adjuvants**
  - Haloperidol
  - Anticholinergics
  - Benzodiazepines

- **Decrease feeds/volume**

Friedrichsdorf SJ, Collins JJ. *Med Princ Pract* 2007
Constipation

- Prokinetic and softener
- Many options
  - Polyethylene glycol
  - Senna
  - Lactulose
Hydration

- Somewhat controversial
- Use clinical signs
- Unclear benefit at end of life
  - Harm vs benefit of “maintenance fluid”
  - Not demonstrated to decrease delirium
  - May increase work of breathing, edema, discomfort

Suffering

- “The body doesn’t suffer… only the person suffers”
- “To treat suffering you have to treat the person”
- “To treat suffering you have to know the person”

-Eric Cassell 2010
Debriefing

Christopher J. Haines DO
Director, Department of Emergency Medicine
Assistant Professor of Pediatrics & Emergency Medicine
Care of Self and Staff

Emily Nichols MD
Fellow, Pediatric Emergency Medicine
Department of Emergency Medicine
The Aftermath

- Often the most challenging aspect of care
- Families grieve… staff grieves too
- Medical training often inadequate
- Most clinicians not prepared
Responses Vary

- Your role in patient’s life
e.g. physician vs. nurse
- Length of your relationship
- Prior experience with death
  - Professional
  - Personal
- Perception of patient’s death
e.g. “good death” vs. “bad death”
### Good Death/Bad Death

<table>
<thead>
<tr>
<th>Good</th>
<th>Unexpected</th>
<th>Overtreated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>Shocking</td>
<td>Full of suffering</td>
</tr>
<tr>
<td>Peaceful</td>
<td>Inadequate</td>
<td>Frustrating</td>
</tr>
<tr>
<td>Natural</td>
<td>Uncertain</td>
<td>Degrading</td>
</tr>
<tr>
<td>Spiritual</td>
<td>Guilty</td>
<td>Isolated</td>
</tr>
<tr>
<td>Moving</td>
<td>Avoidable</td>
<td></td>
</tr>
<tr>
<td>Closure</td>
<td></td>
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</tr>
</tbody>
</table>

Jackson VA et al. *Acad Med* 2005
Emotions Predict Coping

- Increased grief $\rightarrow$ Increased stress
  - Comfort with uncertainty
  - Comfort with level of training
  - Sense of meaning and closure
- Grief-related stress $\rightarrow$ Burnout
- Compassion: Fatigue vs. Satisfaction

Jackson VA et al. Acad Med 2005
Fatigue/Satisfaction Balance

- Emotional exhaustion
- Depersonalization
- Burnout

Kearney MK et al. JAMA 2009
Fatigue/Satisfaction Balance

→ Improved relationships
→ Greater sense of self
→ Post-traumatic growth

Kearney MK et al. JAMA 2009
Short Term Care: Debriefings

- Following any death
- Prompt (24-72 hours)
- Multidisciplinary
  - Mental health professionals
  - Peer support professionals
  - Clergy persons
- Goals
  - Group cohesiveness
  - “Normal” recovery

Spitzer WJ, Burke L. *Health Soc Work* 1993
A Debriefing Guide

- Understand the context
  - What was your experience with patient X?
  - What were the most difficult aspects?
- Review the details
  - What questions do you have about the care?
  - Is there anything you wish had been done differently?
- Explore group & individual feelings
- Assess impact on future care

Jackson VA et al. *Acad Med* 2005
Grief management should precede death
- Maintain your well-being
- Self-assess & reflect
- Use your support resources
  - Individual
  - Institutional
- “Honor my grief”

Redinbaugh EM et al. *BMJ* 2003
Giddings G. *Support Care Cancer* 2010
General Well-Being

- Identify your best destressor
- Keep it healthy
- Have an action plan in place
- Maintain wellness when well

Kearney MK et al. JAMA 2009
Self-Assessment

- Review your experience with death
- Understand your attitudes & perceptions
- RIP Design
  - Me
  - My child
- Define palliative care for you

Rushton CH et al. *Palliat Support Care* 2009
Support Resources

- Personal
- Professional
- Across hierarchies
- Create emote-acceptable environment
  - Receptive
  - Physical space
    - e.g. gardens, spiritual rooms

Redinbaugh EM et al. *BMJ* 2003
Honoring Your Grief

- Evaluate the death medically… briefly
- Find closure – intellectual & emotional
- Denial is okay… for a while
- Grieve with family occasionally
  - Bedside
  - Follow-up call or office visit
  - Funeral

Jackson VA et al. *Acad Med* 2005
Giddings G. *Support Care Cancer* 2010
Klagsburn S. *Am J Psychother* 2010
Please turn-in your post-workshop survey before leaving!
CAST NEW LIGHT

- Conducting difficult conversations
- Incorporating family presence
- Offering & implementing palliative care
- Supporting yourself & your medical team
"One cannot separate the health of the individual from the health of the family, the community, the world, and the health care system itself"

Patch Adams MD & The Gesundheit! Institute