Integration of palliative practices into mainstream pediatric care

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Objectives

• Recognize the need to integrate palliative care into mainstream pediatrics

• Review 7 quality palliative care practices for the general practitioner
Sebastian’s World

Sebastian lay in a tiny bed in the Pediatric ICU, connected to a maze of tubes, and monitors, and a ventilation pump.

He was five months old at the time.
Sebastian’s World

He was born some thirty minutes following the sudden separation of his warm world from his mother’s uterus...a placental abruption.

For those thirty minutes, Sebastian received no oxygen.

For another seventeen minutes after his birth, Sebastian had no heart beat.

The Scream, Edvard Munch
Sebastian’s World

But with the power of today’s technology, Sebastian was brought back to life.

The MRI of his brain later showed the devastation of his traumatic birth.

Sebastian has survived repeated surgeries since his birth day:
Sebastian’s World

A fundoplication to correct his gastric reflux.

The placement of gastrostomy tube to feed him.

A ventricular port to relieve his increased intracranial pressure.

The placement of a ventriculo-peritoneal shunt.

Wojeiech Macherzynski
Sebastian’s World

Emergency abdominal surgery for an obstructed bowel.

The removal of the VP shunt due to a peritoneal infection.

Externalization of the shunt, requiring daily drainage of CNS fluid.

The ultimate placement of a ventriculo-atrial shunt.

Multiple hospitalizations, repeated needle sticks, pain and suffering.
Sebastian’s World

Leaving Sebastian’s three siblings with their grandparents, Sebastian’s mom and dad came to the hospital every afternoon.

They sat by his bed talking quietly, sometimes watching TV.

They touched him often, but could not cradle him, rock him, or nurse him.
Sebastian’s World

A constant stream of “visitors” moved through Sebastian’s room: nurses, respiratory technicians, pediatricians, neurologists, pulmonologists, gastroenterologists, infectious disease experts, critical care specialists, general surgeons, neurosurgeons, physical therapists, nutritionists, medical students, nursing students, pediatric residents, surgery residents, neurosurgery residents...
Sebastian’s World

Even so, Sebastian and his family were lonely, afloat in a tiny raft without rudder or sail in a constantly changing sea.

At five months he had spent the majority of his life in rooms like this, void of sunlight, or the sound of birds chirping. He never complained. He never cried, not even a whimper.

At the age of 8 months, after a prolonged period of intense suffering, Sebastian died in a dark hospital room, alone and in pain.
Sebastian’s Care

What would be an appropriate response to the needs of this seriously ill patient?
## Mortality Rates

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number ‘03</th>
<th>%Change’79-’03</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4 yr.</td>
<td>4,858</td>
<td>-48</td>
</tr>
<tr>
<td>5-9 yr.</td>
<td>3,018</td>
<td>-45</td>
</tr>
<tr>
<td>10-14 yr.</td>
<td>4,138</td>
<td>-32</td>
</tr>
<tr>
<td>15-19 yr.</td>
<td>13,812</td>
<td>-28</td>
</tr>
<tr>
<td>1-19 yr.</td>
<td>25,820</td>
<td>-38</td>
</tr>
</tbody>
</table>

Integration of palliative care?

“The art and science of patient and family-centered care aimed at attending to suffering, promoting healing and improving quality of life”
System-wide Quality Standards

- Individualized.
- Patient and family centered.
- Based on continuous healing relationships.
Practice #1:

Establish a therapeutic alliance
Therapeutic alliance

Together we can form a team to care for your child

Best possible disease treatment

Best possible quality of life

HOPE
Central Issue

The nature of suffering and the goals of medicine
Focus on the investigation, diagnosis and treatment of disease often at the expense of caring for pain and suffering

Fox E. Predominance of the curative model of medical care. A residual problem. JAMA 1997; 278:761-783
Suffering

• The hidden aspect of human illness
• Results from a threat to our:
  – Physical and psychological self
  – Relationship with others
  – Relationship with a transcendent source of meaning
Suffering

• Part of human nature
• Profoundly personal
• Threat to the integrity of personhood
• Endurable when meaningful
• Philosophic stance influenced by one’s educational, religious and cultural backgrounds
Cultural stance towards suffering

“For the wise man of old, the cardinal problem of human life was how to conform the soul to objective reality, and the solution was wisdom, self-discipline, and virtue. For the modern mind, the cardinal problem is how to subdue reality to the wishes of man, and solution is a technique”

CS Lewis
The Abolition of Man
Physician, know thy self!

No man remains quite what he was when he recognizes himself.

Thomas Mann
How do you solve problems?

- Cancer patient with end-stage disease and malignant pleural effusion in respiratory distress.
- What is the dominant force in your thought process?
Evolution in medical thinking

- Magical
- Dichotomous
- Integrated
Goals of care for medically fragile children

**Disease Theory**
- Investigation
- Diagnosis
- Treatment

**Person-Centered Theory**
- Relationships
- Wholeness
- Integrity

TO CURE  TO HEAL
Primary Outcomes

TO CURE

Disease Directed
Treatment
Cure Rates
Survival Rates
Mortality Rates

TO HEAL

Person-Centered
Care
Quality of Life
Satisfaction with Care
Skillful combination of roles

Dedication to discovery

Commitment to care
Skillful combination of roles

CURE

QUALITY OF LIFE
Practice #2:

Understand the illness experience from the child and family’s perspective
“Dying (suffering) is more than a set of medical problems to be solved. The nature of dying (suffering) is not medical, it is experiential. It is fundamentally, a personal experience”

- Ira Byock, MD
Understand illness experience

- Empathic presence
- Listening skills
- “Willingness to be changed by what we hear” (M. Nepo)
Understand Illness Experience

www.aish.com/graphics/articles/Just_listen_wll_ya
Understand Illness Experience

- Diagnosis, prognosis, treatment options?
- Fears and concerns?
- Beliefs and values?
- Wishes and hopes?
- Child/family preferences?
- Perceptions about pain and suffering?
- Perceptions about quality of life?
- Perceptions about what it means to be a good parent?
## Understand Illness Experience

<table>
<thead>
<tr>
<th>Exploratory Responses</th>
<th>Empathic Responses</th>
<th>Validating Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>“What are you hoping for now?”</td>
<td>“Sit silently, note the suffering, respond with compassion.”</td>
<td>“I believe I would have a similar feeling (thought), too.”</td>
</tr>
<tr>
<td>“I want to listen to you, tell me more about that.”</td>
<td>“I can tell you weren’t expecting to hear this.”</td>
<td>“Yes, what you said makes good sense to me.”</td>
</tr>
<tr>
<td>“What concerns you the most right now?”</td>
<td>“I share your sadness.”</td>
<td>“Your understanding of what I have said is very good.”</td>
</tr>
<tr>
<td>“Could you tell me what has been most difficult for you so far?”</td>
<td>“I can see how upsetting this is to you.”</td>
<td>“Many other patients and families have had similar experiences.”</td>
</tr>
<tr>
<td>“What do you worry about happening next?”</td>
<td>“We are all hoping with you for a better result.”</td>
<td>“I respect what you said.”</td>
</tr>
<tr>
<td>“You mentioned (name emotion), please tell me more about that.”</td>
<td>“I find this to be very, very hard.”</td>
<td>“It appears that you have thought things through very well.”</td>
</tr>
<tr>
<td>“Do you think he is suffering?”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Data from Baile et al
Practice # 3:

Empower patients and families with the information that they need
Sharing relevant information

What determines Quality of Care?

• Parents
  – Giving clear information
  – Communication is sensitive and caring
  – Communicating with child
  – Preparation for death

• Physicians
  – Less pain
  – Shorter hospitalization at the end of life

Mack et al, JCO 2005
Establish & communicate prognosis

- Communicating bad news does not take away hope. (Mack, J. JCO. 2006)

- Families want prognostic information expressed in percentages. (Mack, J. JCO. 2006)

- Prognostic information helps families cope with uncertainty. (Mack, J. JCO. 2006)

- Honest and clear information promotes a realistic sense of hope. (Mack, J. JCO. 2007)
Tell all the Truth but tell it slant
Success in Circuit lies
Too bright for our infirm Delight
The Truth's superb surprise
As Lightening to the Children eased
With explanation kind
The Truth must dazzle gradually
Or every man be blind
-Emily Dickinson
Of 365 doctors and 504 hospice outpatient deaths found that only 20% of prognoses were accurate

Most predictions (63%) were overestimates, and doctors overall overestimated survival by a factor of about five

The tendency of doctors to make prognostic errors was lower among experienced doctors

The better the doctor knew the patient the more likely the doctor was to be incorrect

Predicted versus observed survival in 468 terminally ill hospice patients. Diagonal line represents perfect prediction. Patients above diagonal are those in whom survival was overestimated; patients below line are those in whom survival was underestimated
Recognize clinical decline

• Increased symptom burden
• Progressive loss of function
• More help with activities of daily living
• More frequent ER visits or hospitalizations
• Weight loss and worsening disability
Prognosis

- Duration of disease - 32.4 months
- Physician - 6.9 months
- Parent - 3.5 months

- Parent-physician agreement of unrealistic chance of cure 50 days prior to death
  - greater satisfaction with care
  - better symptom control
  - more DNAR days
  - greater use of hospice
  - less chemo in last month
  - greater emphasis on comfort

Wolfe J et al., JAMA 2000
“Something deep and sanctifying takes place when people who belong to each other share the thought that every day, each coming hour, may separate them. In this awareness we always find that the initial anxiety gives way to another deeper question: Have we given each other everything we could? Have we been everything we might have been to one another? Thinking about death in this way produces true love for life.”

Dr. Albert Schweitzer
Practice # 4:
Provide goal-directed care
The “if” conversation

What kind of decisions you might face if the disease comes back?

Goal of Cure

Goal to prolong a life of good quality

Goal to optimize comfort at the end of life

Point in Time

H O P E
Negotiation

• What are you hoping for?

• What is the intent of the treatment/care? (goal)

• What is the possibility that we will achieve our goal? (expectation)
Balance

- Burden vs. benefit

- What you are hoping for vs. what is realistically possible

- What is ideal vs. what is practical
Goals of care

- **Cure**
  - Morbidity: High
  - Psychological attitude: Win
  - Tumor effect: Eradicate

- **Prolong life**
  - Morbidity: Moderate
  - Psychological attitude: Fight
  - Tumor effect: Response

- **Prolong life**
  - Morbidity: Mild
  - Psychological attitude: Live with it
  - Tumor effect: Arrest growth

- **Comfort**
  - Morbidity: Minimal
  - Psychological attitude: Embrace
  - Tumor effect: None
Goals of care

Diagnosis - Science  \( \rightarrow \)  Death - Experience

- Cure
- Life-prolongation
- Comfort
- Bereavement

Physical

Psychosocial

Spiritual

“doing”  \( \rightarrow \)  “being”
Prolong a life of good quality?

• Use of life-sustaining therapies? (DNR)
• Use of life-prolonging therapies? (surgery, transfusion, antibiotics, etc)
• Escalation of comfort care?

How can medical care help the patient and family achieve their personal goals?
Practice # 5:

Identify and respond when a child and family are in distress (physical, emotional, social)
Symptom Control

• Comfort

• Priority area for quality improvement (IOM)
Symptom Control

Wolfe et al. NEJM 2000
Pain assessment

Patients with pain intensity documented every 4 hrs

Oakes L, J Pain Symptom Manage, 2007
Communication and relational skills

- Interpersonal relationships
Emotional support

- Psychological functioning
Social Support

- Sense of Connection

www.co.suffolk.ny.us/images

www.brainblogger.com
Spiritual Support

• Hope, Meaning, Faith

www.cms.edu/graphics

www.dawnjones.us/angel_1.jpg
Distress?

- Ask about and respond to distressful symptoms
- Ask about quality of life
- Explore emotions and experiences
  - Fear, anger, sadness, anxiety, frustration, isolation, hopelessness
- Utilize available resources
Practice # 6:
Coordinate care across settings
Care coordination & continuity

• Priority area for quality improvement (IOM)

• Collaboration
  – Central principle in care coordination
Care coordination & continuity

• Integrate plan of care, share information across disciplines and care settings
  – Multidisciplinary
  – Interdisciplinary
  – Trans-disciplinary

• Communication
  – Interdisciplinary Care Team Meeting
  – Family Conference
Care coordination & continuity

- Continuity
  - Relationships
  - Information

- Barriers
  - Multiple structural, financial, professional, regulatory, institutional and organizational barriers
Care coordination & continuity

- HHH Partnerships!!!
  - Hospital,
  - Home-health
  - Hospice
Practice # 7:

Utilize hospice and palliative care services
Affordable care act

• Hospice amendment for children under the age of 21 years
  – Provision of pediatric hospice care concurrently with disease directed treatment!
  – Scott & White Pediatric Hospice
    • Symptom control
    • Care planning
    • Care coordination
    • End of life care
    • Bereavement care
Is there any hope for patients like Sebastian?

Co-creators of a modern health care system centered around the needs of the person!
Professional sense of meaning

• We discover meaning in medicine by:
  – the advancement of science and technology
  – caring for the human being as a whole person
  – addressing the mysteries of suffering and death
Questions?

“Knowing is not enough; we must apply. Willing is not enough; we must do”

Goethe