My New Patient is How Old?!?

Caring for the pediatric patient in an adult hospice world

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Objectives

• Understand the make-up of the pediatric hospice population
• Identify eligibility criteria for the pediatric hospice patient
• Recognize the similarities & differences between pediatric & adult hospice care
• Examine the role of parents in pediatric hospice
• Describe the developmental stages & how they impact a child's concept of death

A VERAGE NUMBER OF PEDIATRIC PATIENTS SERVED BY TYPE OF HOSPICE

The majority of ped hospice patients are care for by hospices that use less than 10 pediatric cases per year.
What about caring for a peds patient makes you nervous?

The parents?
The siblings?
Med dosages?
The patient?
Talking to the patient about death?

What is pediatric palliative & hospice care?

• A philosophy of care
• An organized method for delivering individualized care
• For children with chronic, complex, and/or life-threatening conditions
  – Hospice care requires the 6-month or less determination
• Services are available concurrently with, or independent of, curative or life-prolonging care
  – This includes being on hospice care
• Patients, families, palliative care providers, and non-palliative health care providers collaborate and communicate about care needs

Pediatric Palliative / Hospice Care Philosophy

• Supports goals for the future
  – Including hopes for cure, life prolongation, improvement in quality of life
• Aims to guide & assist child & family in making the best decisions possible
  – Make the best for remaining time together
• Care is planned & delivered through collaboration of interdisciplinary team
  – Includes child, family, & caregivers
• Provides support for family & caregivers without duplication of healthcare services
Who can receive pediatric hospice care?

- Children and their families who face a life-limiting condition, or limited life expectancy
- Some adults over 21 years if developmental delays or conditions are monitored by pediatric specialist
- Families of unborn and newborn babies with life-limiting conditions
  – Hospice may actually start prior to the birth of the baby.

Baby Amanda – Trisomy 18
Causes of Death in Children, Birth – 19 years

<table>
<thead>
<tr>
<th>Causes of Death</th>
<th>All Infants</th>
<th>Infants with CCC</th>
<th>All Children 1-19 years</th>
<th>All Children 1-19 years with CCC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital malformations</td>
<td>Cardiovascular</td>
<td>Accidents</td>
<td>Malignancy</td>
<td></td>
</tr>
<tr>
<td>Short gestation/LBW</td>
<td>Congenital / genetic</td>
<td>Suicide</td>
<td>Neuromuscular</td>
<td></td>
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<tr>
<td>Maternal complications</td>
<td>Respiratory</td>
<td>Assault</td>
<td>Cardiovascular</td>
<td></td>
</tr>
<tr>
<td>SIDS</td>
<td>Neuro muscular</td>
<td>Malignancy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accidents / Unintentional injury</td>
<td></td>
<td>Congenital malformations, deformations &amp; chromosomal abnormalities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complications of placenta, cord, or membranes</td>
<td></td>
<td>Heart disease</td>
<td></td>
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</tbody>
</table>
| * Includes static neurologic and neurodegenerative conditions ** 55% of childhood deaths in 2013 occurred in infancy and approx. 2/3 of infant deaths occurred in the neonatal period.

Friebert & Williams, 2015

Similarities Between Adult & Pediatric Hospice Care

- Focus is on quality of life
- Families in crisis
  - family support is a priority
- Medications
  - Same meds, different doses

Differences Between Adult & Pediatric Hospice Care

- Family will fight for a cure to the end
- Parents want to be in charge and are very involved in care
- May need to consider young siblings
- Pain and symptom tolerances and expressions
- Trajectories of illness
- Ethical concerns
- Staffing ratios
- Research paradigms
The Needs & Roles of the Parents

• Very caring parents may make very different decisions for their children
  – Family values & goals of care
• Parents need to feel that their child's life—and death—"matters" to practitioners.
  – This requires the practitioners to move out of an "expert" posture and into an open and receptive position
• Acknowledge that family views are highly individualized
  – Do not make assumptions about a family's values based on cultural or religious stereotyping

The Role of the Parents

• Parents need to know the likely illness trajectory and set appropriate goals of care in ways that respect their values and preferences.
• Help parents evaluate their treatment preferences in terms of the likely consequences of each choice
  – "What is the likely benefit to the child?"
• When treatment and non-treatment options are all morally permissible, the decision should belong to the parents
  – In the case of mature minors, to the adolescent in consultation with parents.
Strategies for finding a sense of control

Professional Obligations

Professional obligations whether one agrees with the parents' decision or not:

• Work with the parents to establish reasonable goals of care
  – Even if they represent values that differ from one's own

• Anticipate and ensure that the parents fully understand the potential consequences of their decision AND that of all the other options

• Share one's professional recommendation
  – "Many nurses & physicians worry that in order to be ethical, they must present decisions as neutral choices for parents. ... As long as reasonable options are shared and health care professionals are open to parents' views ... recommendations are an essential part of professional practice. Most parents want to hear what their child's doctor recommends and why."

• Work with the parents to make a plan for the final stages of the child's life

IPPC, 2003

Don't Underestimate the Goals and Values of Parents
**Siblings**

- Children can experience conflicting emotions
  - They can feel sad & worried about their sibling, while simultaneously resenting them
  - They can suffer the loss of “innocence,” which can include loss of security in their parents’ ability to protect them from “bad things happening” in the world.

- Siblings may be expected to take on additional responsibilities.
  - The experience of “growing up fast” can be both a positive & a negative

**Helping Siblings Cope...from the Parents**

**Tips For Working With Siblings**

- Encourage open communication from the very beginning
  - Tell the healthy children that it’s their job to let you know when they need something.
  - Explain that it’s safe to share feelings, even sad or angry ones

- Encourage parents to find time to be with their healthy children
  - Even a little time is better than no time.

- Share information that is right for their age
  - Don’t lie!
  - Give short pieces of information
  - Don’t give information they haven’t asked for
  - Find out what the child thinks and already know

- Invite the other children to be helpful
  - This prevents them from feeling left out
Children's Understanding of Death

• Three to Six Years
  – “Magical thinking”
  – Child believes death is reversible or temporary.
  – May believe their thoughts or actions caused the death
  – Death is punishment for bad behavior
  – Significantly impacted by parent's emotional state
  – Difficulty understanding abstract concepts such as heaven
  – May experience regression or somatic symptoms
  – Difficulty verbalizing emotions which may cause "acting out"
  – Only capable of showing sadness for short periods of time
  – Uses play to escape
  – Desires affection and physical contact

• Six to Nine Years
  – Begins to understand finality of death
  – Sees death as a "taker" that comes to get you
  – May fear death is contagious
  – Connects death with violence
  – Asks concrete questions
  – May blame self for death
  – May worry how the deceased can eat, breathe, etc.
  – Continues to have difficulty expressing feelings verbally
  – Increased aggression
  – May have somatic symptoms; develop school phobia
  – May continue to struggle with abstract ideas

• Nine to Thirteen Years
  – Understanding of death is closer to adult understanding
  – More aware of finality of death
  – Concerned about how their world will change
  – May be reluctant to open up
  – May have a delayed reaction
  – Beginning to develop an interest in rituals
  – Increased anger & guilt
  – May develop somatic symptoms or school phobia
  – Self conscious about their fears
Children’s Understanding of Death

- Thirteen to Eighteen Years
  - Has adult understanding about death
  - Death is viewed as an interruption
  - Death is an enemy
  - May intellectualize or romanticize death
  - May show full range of affect or almost no affect
  - May need permission to grieve
  - May question religious/spiritual beliefs
  - Represses sadness but feels anger or depression
  - May act indifferent to death of someone close as a protection against feelings
  - May try to escape by driving fast, using drugs or alcohol, sexually acting out

Frumer-Styron, n.d.

Child Approaching Death

About Watches

First, if they are all set:
A little different.
No one’s ever
Too late, or
Too early, or
Right on time.
They just “are.”

Second, with all these watches on me:
It’s like having
“All the time
In the world!”
And never having
to think about
The end of time
Or about dying.

Mattie Stepanek, 6 years old
Journey Through Heartsongs

Swinging

So high . . .
Wind tickles my tummy
Plays with my feet
Hits my heart a ride
So high . . .
Meditate on being
Touch all my thoughts
Think about friends
And families and
Brothers and sisters.
So high . . .
Leave this world for a bit
Jump into Heaven for a moment
Then, swing back into my life again.
So high . . .
Helping the Child Approaching Death

- Do a self assessment
  - First, process your own feelings about children dying
  - Then leave your personal baggage at the front door!
  - Remember – this isn’t about you, it’s about them.
- Appreciate that each child’s process of understanding and making meaning of their life and death is unique to him/her.
- Use art / coloring / drawing pictures / or “just play”
  - The child’s comments and play will communicate different aspects of awareness at different times during your care
- Encourage and model open communication about death with the child
  - The way illness and death are discussed in the family – and the degree to which parents can be open and honest with the child – are central factors to the child’s experience.
End of Life: Questions and Arrangements

Legacy-Making Activities

Activities can be initiated by staff but completed by family and/or child:

- Hand molds / Handprints
- Lock of hair
- Memory book or journal
- Photography
- Art
- Letters / poetry
- Songwriting / music

Should be offered as part of standard care.
May want to consider doing separate activity with siblings

Advice From the Field

Things Pediatric Hospice Nurses want you to know:

- "Listen and meet the parents."
- "The pediatric family is usually more involved and on top of things."
- "Parents usually want the child awake as much as possible but with good pain/symptom management."
- "Remember that the child is their life – as genetics most usually feel like the patient has lived their life and want them comfortable."
- "Don’t sit the family in the room or living room for a sleep over."
- "Have friends offering options and asking what they think might work best – whether it’s about symptom management or getting away with other family members – is key in the journey."
- "Hospice is about quality of life and enjoyment – there doesn’t have to be an end date."

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Advice From the Field

Things Pediatric Hospice Nurses want you to know:

- Don’t explain the egenome.
- "Show me the plan of care to improve care - outcomes.
- Don’t blame the family who are grieving.
- "If a family’s calls seem unusual, the expert in their child’s care and so they usually only call when they are very stressed and need help ASAP.
- "Don’t just reassure changes in respiratory status is due to actively dying."
- "The needs are usually the same:且 diffrent.
- "Most of us are happy to be a hospice back up.

Professional & Parent Resources

- Courageous Parents Network
  – https://courageousparentsnetwork.org
- NHPCO Pediatric Curriculum
  – https://www.nhpco.org/pediatric
- End-of-Life Nursing Education Consortium (ELNEC)
  – http://www.aacn.nche.edu/elnec
- The Initiative for Pediatric Palliative Care (IPPC)
  – http://www.ippcweb.org/index.htm
- Center to Advance Palliative Care - Pediatric Palliative Care
  – https://www.capc.org/topics/pediatric-palliative-care/

Resources

Resources