

Newborns to Adolescents:
*A family centered approach to
addressing the changing
psychosocial needs of children
with life-threatening diseases*



Understanding Children and Death

Depends on the child's:

- Developmental level
- Concept of death
- Life experiences
- Personality



Theories of Childhood Death

➤ Nagy (1948)

- 3 developmental stages
 - Stage 1: Death is not final (<5yo)
 - Stage 2: Death is final but avoidable and **not** inevitable (5-9yo)
 - Stage 3: Death is final and inevitable (>12y)

➤ Speece and Brent (1984)

- 4 concepts
 - Irreversibility, Finality, Universality, Causality

Child's perception of death

American Academy of Pediatrics , Pediatrician and Childhood Bereavement ; PEDIATRICS , volume 105 , number 2 , February 2000

- 0-2 years -death perceived as separation and abandonment; no cognitive understanding of death
- 2-6 years -death is reversible/temporary, may be seen as a punishment; Magical thinking that wishes can come true
- 6-11 years –gradual understanding of irreversibility and finality. Specific death of self difficult to understand
- >11 years – death is irreversible, universal, inevitable All people and self must die ,although latter is far off Abstract and philosophical reasoning

Child's concept of death – ways to illicit conversation

- **Bluebond – Langner** “seriously ill children become aware of their mortality even in the event of deception”
The Private Worlds of Dying Children, 1978
 - Q & A: Listen for unasked questions
 - Avoid confusing euphemisms
 - Use nonverbal expressions – art, play & storytelling
 - Allow children to see your sadness
 - Teach parents to overcome reflex to shield their child from “*bad things*”

Any Data?

“Talking about death with children who have severe malignant disease”

- Survey of parents whose children died of cancer between 1992-1997
- 449 of 561 eligible parents responded
- 147 of 429 reported speaking to their child about death
- None regretted having the conversation
- 69 (27%) of 258 parents who did not talk with their child about death regretted not having done so
- Parents who sensed that their child was aware of his/her imminent death were more likely to regret not having talked about it (47% vs. 13%)

*Kreicbergs U et al.
NEJM, 2004*

What the literature says

- No prospective studies looking at effects of conversation and communication on patient, siblings, parents
- Some retrospective surveys indicating that parents value clear communication about what to expect at the end of life (*Troug et al, 2006, Mack et al, 2005*)
- Small case series indicating that siblings of children who die of cancer lack support and may benefit from more direct communication with the medical team (*Nolbris M J 2005; Finke LM 1992; Wilkins KL 2005*)

One study of Parents' priorities and recommendations

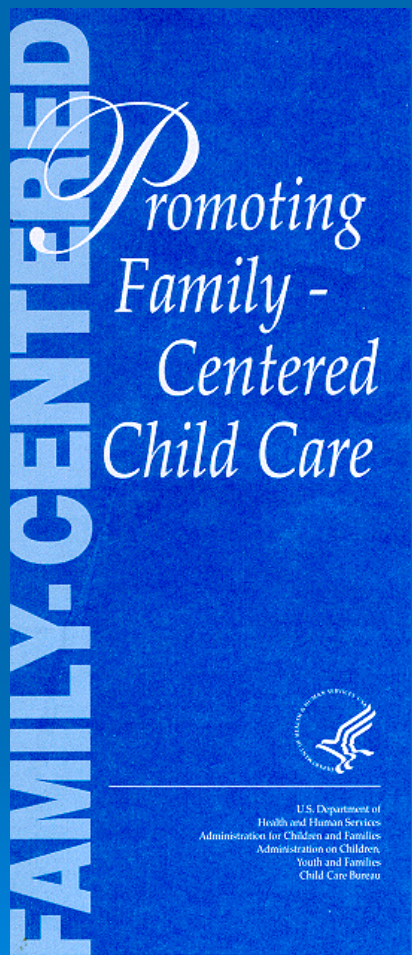
- 56 parents of children who died in pediatric intensive care units in 3 Boston hospitals
- Parents identified 6 priorities for pediatric end of life care
 - Honest and complete information
 - Ready access to staff
 - Communication and care coordination
 - Emotional expression and support by staff
 - **Preservation of the integrity of the parent child relationship**
 - Faith

Meyer EC, Ritholtz MD, Burns JP, Troug RD;
Pediatrics March 2006

What defines a Family Centered Approach to Care?

- Acknowledges the role of the family in the child's care
- Encourages collaboration between patient, family and health care team
- Honors patient and family strengths, cultures, traditions and expertise
- Supports and facilitates choice for child and family about approaches to care and support

Family Centered Care



- Can improve patient and family outcomes
- Increase patient and family satisfaction
- Increase professional satisfaction
- Decrease health care costs
- Is proactive not reactive
- Encourages a healthy environment

Incorporating family centered care

- How can this model of care be incorporated into the psychosocial care of children with life limiting diseases and their families?
 - Open effective communication
 - Addressing issues specific to child and parent
 - Specifically addressing sibling needs
 - Utilizing multidisciplinary team structure to individualize care plan

Communication

- Maintaining hope is essential
- Ability to reframe hope essential



HOPEs

Lack of
pain

Quality
time with
family

Comfort

HOPE

Peaceful Death



When talking to children about death:

- Be mindful of their developmental level
- Choose medium most easily used by the child including
 - non-verbal communication
 - symbolic language
 - art
- Lack or misinformation may lead to anxiety and/or fear

Communication

- Inherent desire to protect may result in constricted communication
- Children often know intuitively
 - Encourage parents to prepare child and sibs
- Maintain trust through honest communication



Communication to elicit spiritual & cultural context

- How do you understand your child's illness?
- What is the meaning of pain and/or suffering for your family?
- What is your child's understanding of his/her illness?
- What have you told your other children about the illness?

Child Issues

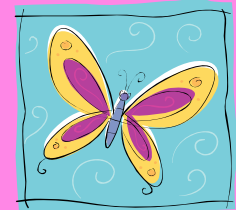
- Information
 - Parent's desire to protect may deny facing reality and meaning making
- Social isolation from siblings & peers
- Feelings of loneliness and anxiety
- Grieve loss of normal life and experiences
- Facing pain, physical & emotional symptoms

Child Issues

- ❖ Facing mortality,
- ❖ Legacy building,
- ❖ Complications of adolescents & young adults

Tayli's List

Tayli doesn't want to be on a ventilator.
Tayli doesn't want head gear (no halo)
Tayli wants an ambulance to the hospital and home (with sirens on!)
Tayli doesn't want a walker
Tayli doesn't want to worry
Tayli wants food
Tayli doesn't want to be afraid
Tayli doesn't want to be in pain



Tayli wants visitors on request by name only.
Tayli wants oxygen and an oxygen monitor
Tayli wants speech therapy when needed and when not needed

Tayli wants lots & lots of cuddle time with Mom
Tayli wants to walk (by Christmas) independently

Tayli wants pink everything
Tayli wants a cure - even an experimental treatment.
Tayli doesn't want the doctors to start her heart again if it stops.
Tayli wants to believe in God.

Tayli wants all conversations in front of her.
Tayli never wants to be lied to.
Tayli wants Mom to keep reminding her about her list and her goals and victories.

Range of Common Grief Manifestations in Children and Adolescents

AAP February 2000

Normal or Variant Behavior	Potential Symptoms of Complicated Grief
Shock or numbness	Long-term denial and avoidance of feelings
Crying	Repeated crying spells
Sadness	Disabling depression and suicidal ideation
Anger	Persistent anger
Feeling guilty	Believing guilty
Transient unhappiness	Persistent unhappiness
Keeping concerns inside	Social withdrawal
Increased clinging	Separation anxiety
Disobedience	Oppositional or conduct disorder
Lack of interest in school	Decline in school performance
Transient sleep disturbance	Persistent sleep problems
Physical complaints	Physical symptoms of deceased
Decreased appetite	Eating disorder
Temporary regression	Disabling or persistent regression
Believing deceased is still alive	Persistent belief that deceased is still alive
Adolescent relating better to friend than to family	Promiscuity or delinquent behavior
Behavior lasts days to weeks	Behavior lasts weeks to months

Siblings' Needs and Issues When a Brother or Sister Dies of Cancer

Nobris et al. Journal of Oncology Nursing 2005; 22, 227

- Questionnaire/ interviews
- Sibling age ranged 10-30 years
- 6 common themes emerged
 - Dissatisfaction with information and support
 - Loneliness
 - Expressions of anxiety>anger>jealousy
 - Need to find place of refuge
 - Mourning not continuous. Needed “time out” periods from grief
 - Positive memories of dead sibling
 - Bond between siblings remained
 - Needed other places than grave to remember sibling

Sibling care

- Encourage siblings to ask questions
- Provide age appropriate honest information
- Create safe place to talk about feelings and worries
- Share your own feelings and worries
- Involve siblings in decision making whenever possible
- Let siblings help out
- Encourage normal activity
- Keep things consistent

Issues for Parents

- Intense & complex emotions-
 - pre-morbid mental health issues relevant
- Anticipatory grief
- Need to provide emotional support and information
 - for siblings, grandparents, cousins
 - Community, school, church, groups
- Intense & complex decision-making needs complicated by
 - Relationship of parents/guardians
 - Deciding for child
- Increased demand to negotiate
 - With medical system
 - Social service system
- Uncertain path of life-limiting illness-often chronic
- Death = ultimate failure of parent

Maintaining parental roles

- Helping parent remain present
 - Providing emotional care in face of physical care giving needs
 - Focus on whole child, not just illness
- Maintain family integrity
 - Nurture the playfulness/joy of child
 - Encourage “routines” i.e. Wednesday night dinners, school, church
 - Maintain family celebrations, rituals
 - Encourage sibling involvement

Memory Making

➤ Infant

- Encourage normal parent roles –bathing, holding, feeding
- Consider creative memory making – trips to garden/museum
- Tangible memories – hair/hand-foot prints/
- Encourage photos/videos/creating a scrap book
- Involve siblings

Memory Making - School aged children

- Finding ways to continue the “work” of school – adapt as needed
- Keeping social networks active
- Provide honest/developmentally appropriate information to create opportunity
- Normalize routines/celebrate holidays/create special events
- Use multiple media to help children acknowledge who they are and how they want to be remembered
- “I don’t want to be forgotten”
- Involve siblings

Adolescents

- Find ways to maintain relationships/peer importance
- Keep connections with school
- Find ways to support independence in context of increasing dependence
- Encourage writing/journaling – create lists of “what I want” or “How I want to be remembered”
- Maintaining physical appearance and normal teenage activities (make-up, trip to the mall, trip to school, sporting events)

Examples of child specific therapies

- Play therapy can be a useful tool in assisting children and adolescents in expressing their feelings associated with hospitalization, illness, death
- Child life specialists develop a therapeutic relationship where patients feel safe expressing their fears

- Even very young children can express their feelings through art
- A 4 year old with refractory leukemia painted the picture on the left on a day he was feeling particularly badly. After he was finished he told the therapist he wanted a picture of something that looked better than he felt and had her draw a picture of his house. He told her what to draw and what colors to use



- School aged children can express their negative feelings about their illness in appropriate ways.
- This was done by a child with cancer who drew a picture of planes bombing the hospital. The child in the middle was done so people knew he only wanted the building destroyed and that all the children were safe.



- Play and Art can be used as tools to help siblings connect and communicate.
- These were done by sisters the older of which had refractory AML. She was 9 and her sister was 5. They were separated during a long hospitalization and these were done on a day they could spend together
- The child with cancer soon after drew a picture for her school of a girl going to heaven in a hot air balloon.



Examples of child specific therapies - Music

- Considered an important part of a child life program
- Some nonrandomized studies indicate benefit to child's comfort during hospitalization for pediatric cancer (*Barrera, 2002*)

Summary

- Using a family centered approach is essential in caring for children with life limiting illnesses
- It's important to consider a child's developmental level in communicating with children and families about illness and death
- Parents need guidance in maintaining their parental roles
- Specific tasks can be used to help families and children communicate

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