BEREAVEMENT AND LOSS IN CHILDHOOD

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Cases:

- 16 yo male who suddenly lost his mom (accident while traveling)
  - Initial anger when told at school, throwing objects and yelling. Continued anger that this happened.
  - 6 months of refusal to talk about his mom or be in the room when she was being talked about
  - Continued to do well in school and acted as if nothing had changed
  - States that he feels like she hasn't died
  - Had a really tough time when he started college, ended up needing to take time off after the first trimester
- 13 yo male lost his older sister unexpectedly due to perioperative complication
  - Initial disbelief – denial lasted several months
  - Anger – what caused this?
  - Realization that death can happen to him
  - Guilt – all the times he was not the best brother
  - Continued to do well in school, however, began engaging in irresponsible/ delinquent activities

Why we chose this topic

- Personal experience
- Often overlooked
- More common that we think:
  - 5% of children will experience the death of a parent by age 15yrs
  - 40% of senior high school students have experienced a death of a friend or acquaintance their age

MY DAD DIED WHEN I WAS 7

by Logan

MY DAD DIED WHEN I WAS 7, AND I NEVER EVEN KNEW HIM. I NEVER EVEN KNEW HE WAS MY DAD UNTIL LAST YEAR, 2005.

ALL I know is that he was found with skin cancer and had a short amount of time till he was going to die. But he was a very big trouble maker. I think he gave me the courage to except that my dad died, and I think he knows now that I love him.

There are many different kinds of loss

- Who
  - Loss of a parent
  - Loss of a sibling
  - Loss of a friend
  - Loss of a grandparent or other relative
- How
  - Sickness (chronic or sudden)
  - Accident (sudden)
  - Trauma (witnessed or unwitnessed by child)
  - Suicide

Special issues with different losses

- Death of a sibling:
  - Has more losses than just the sibling
  - Parents the way he/she knew them, due to their grieving
  - May lose their own identity if they try to “replace” a deceased sibling
  - Survivor’s guilt
  - Parents can idealized deceased child and become frustrated with living child especially if he/she is acting out
- Parental loss :
  - profoundly affects a child’s development short and long term
  - Loss of their family structure as they knew it
  - Emotional availability of the living parent is very important
  - Children can idealize deceased parent and distort their image of the living one
  - Each family member had a unique relationship with the lost parent and therefore may each grief in a different way
- Pet loss
  - Is an opportunity to help children learn to deal with loss and strengthen coping skills

TABLE 1. Children's Understanding of Death at Different Ages

AGE GROUP	PERCEIVED UNDERSTANDING
Infants 0–2 years	• Have no cognitive understanding of death • Respond to changes in care-giving routines and parents' intense, negative emotions • Experience separation anxiety
Preschool-age 3–5 years	• Understand death as temporary and reversible • Are egocentric and may view death as punishment or wish fulfillment; may believe they caused illness or death • Believe that terminal illness is contagious—they or their parents may die too
Young school-age 6–10 years	• View death as permanent and real • Unable to comprehend own mortality
Preadolescence 11–13 years	• View death as real, final, and universal • Understand difference between living and nonliving, eg, living means breathing and that the heart is pumping • Are interested in biological aspects of illness and details of funeral
Adolescence 14–18 years	• Understand existential implications of death as they gain ability to think abstractly • May deny own mortality through risk-taking behavior

Figure 3. An 8-year-old girl ponders death. (Courtesy of www.childtrauma.org/images/Loss3.gif.)

"Normal" Bereavement

- Resembles an adjustment disorder
- "Normal" bereavement is the reaction to the loss of a loved one.
- Can lead to a *temporary* impairment in school and social functioning.
- May fulfill criteria for major depression, but bereavement is not considered a disorder unless these symptoms persist for **more than 2 months** and **cause significant impairment or dysfunction**.
- Uncomplicated bereavement gradually diminishes with time, and previous levels of functioning return.
- Most children will continue to "work through the sadness" by revisiting it months to years later.

- Family members grieve differently and at different rates
- Some do not accept the finality of the death until weeks or months after the event.
- Distinguishing normal grieving from pathologic grieving can be difficult.
- A particularly good rule of thumb is that grief that is resolving, no matter how slowly, probably is not pathologic.

Affective stages and Potential sxs

Age	Emotional/affective	Symptoms
< 3 yo	Feelings of loss	Sadness, poor feeding, sleep problems, developmental delay, regression
Preschool (3-6 yo)	Guilt, shame, fear of punishment b/c of my thoughts, of catching whatever caused the death, of other loved one dying	Enuresis, encopresis, sleep problems, nightmares, tantrums, hyperactivity, loss of behavioral control
School age (6-11 yo)	Anger, sadness, guilt, denial	Somatic complaints, resistance going to school, decr school performance, inattention, fighting, daydreaming, acting out
Adolescence (12+ yo)	Strong denial, anger, sadness, guilt, embarrassment, wanting to join loved one	Delinquency, drug and alcohol, somatic complaints, depression, suicidal ideation, sexual acting out, school failure

Book excerpt from Motherless Daughters by Hope Edelman

- “Lately I’ve had the almost uncontrollable urge to walk up to people I barely know and say, ‘My mother died when I was seventeen.’ Of course I don’t do it, but the impulse is there. I imagine saying this as if it could explain everything there is to know about me, because sometimes I think it does.”

- “I realize that I’d turned the simple act of leaving a job into a full-blown annihilation scene, but it didn’t seem all that far-fetched to me. Early loss has a way of turning the phrase “worst-case scenario” into an apocalyptic nightmare.”

Grief Manifestations -

TABLE 2. Range of Common Grief Manifestations in Children and Adolescents

Normal or Variant Behavior	Sign of Problem or Disorder*
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
Being good or bad	Being much too good or bad
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

* Should prompt investigation by pediatrician; mental health referral is probable

CONFUSION

By Shelby Caitlin, Age 12
Oklahoma

CONFUSION
What do you do when the one you loved isn't there anymore?
Who do you turn to?
Where do you go?
CONFUSION
What do you do when you still have fellings for the one who isn't there?
The one you usually run to isn't there, who do you run to?
Who's shoulder do you cry on?
CONFUSION
He's gone, you're too afrad to turn to him.
You're confused. It seems like you're in a neverending hole.
You're trapped. No where to go. Nobody to help you.
CONFUSION

http://kidsaid.com/stories/confusion.html

TABLE 1. DSM IV Criteria for Major Depressive Episode

Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either depressed mood or loss of interest or pleasure.

- Depressed mood or irritable mood
- Diminished interest or pleasure in activities
- Weight change or appetite disturbance
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Feelings of worthlessness or guilt
- Disturbed concentration or indecisiveness
- Recurrent thoughts of death, suicidal ideation, or suicide attempt

Adapted from DSM IV, Diagnostic and Statistical Manual of Mental Disorders, ed. 4.

What can be done to help: for parents

- Don’t avoid the topic.
  - Acknowledge the child’s loss and grief.
  - Tell them it is okay to ask questions.
  - Encourage them to share their feelings.
  - Listen carefully
- Books are available to help facilitate discussion
- Non-verbal activities allow expressions of grief
  - Listen to music, draw pictures, write
- Holidays and anniversaries are difficult. Seek ways to acknowledge the deceased.

What can be done to help: for medical providers

- Competence requires not only a willingness to explore these issues with families but also a reflection of one's own thoughts and feelings about death.
- Understand the importance of being present, not feeling like you need to know the right thing to say
- Scheduling an appointment with the family about 1 month after the death provides an opportunity to address coping concern
- Reaching out to the family by writing a card
- Optional – attending the funeral
- Direct them to available resources
- Refer when appropriate (discussed earlier)

Office visit brief intervention

The usual question is, “Am I doing all right?” or “Is my son/daughter doing all right?” What the individual really is asking is, “I feel like I’m going crazy missing X. I hear her voice or see her in crowds. I wish she were here to help me with all the things I need to do. I miss her so much. Will it ever get better?” Suggesting that the family, or just the father alone if he wishes, return in 2 weeks gives the family additional time to adjust, shows that the pediatrician is not abandoning them, and acknowledges that what they have been through is a major loss to which the clinician will pay attention and give time and thought. It is likely that having shared their situation with the pediatrician and received some information about what to expect over time will result in some grief resolution, even from this brief intervention. Providing the names of some local support groups to contact if they wish is reasonable even at the first visit.

TABLE. Questions Surrounding Death and Grieving

Coping With the Illness

- Should children stay at home or go to another household?
- Should a parent stop working?
- Should schools be notified when a student has a very sick family member?

Visiting

- Should children visit when the dying person is disfigured or on life support?
- How do you answer the question, "Is mommy going to die?"
- How do you know when it is *that question* that is motivating exclusion of a child?

Mourning and Grieving

- Should a 13-year-old attend the funeral? A 7-year-old? A 3-year-old?
- What should be done about the dead person's belongings? Pictures?
- Why is Debbie never home?
- What is Mark gaining by acting out?
- Is Heather depressed? Is she suicidal?

Managing Grief

- What is your advice to the surviving parent?
- When do you want him or her to contact you again?
- When would you make a referral to a bereavement specialist?

Services available

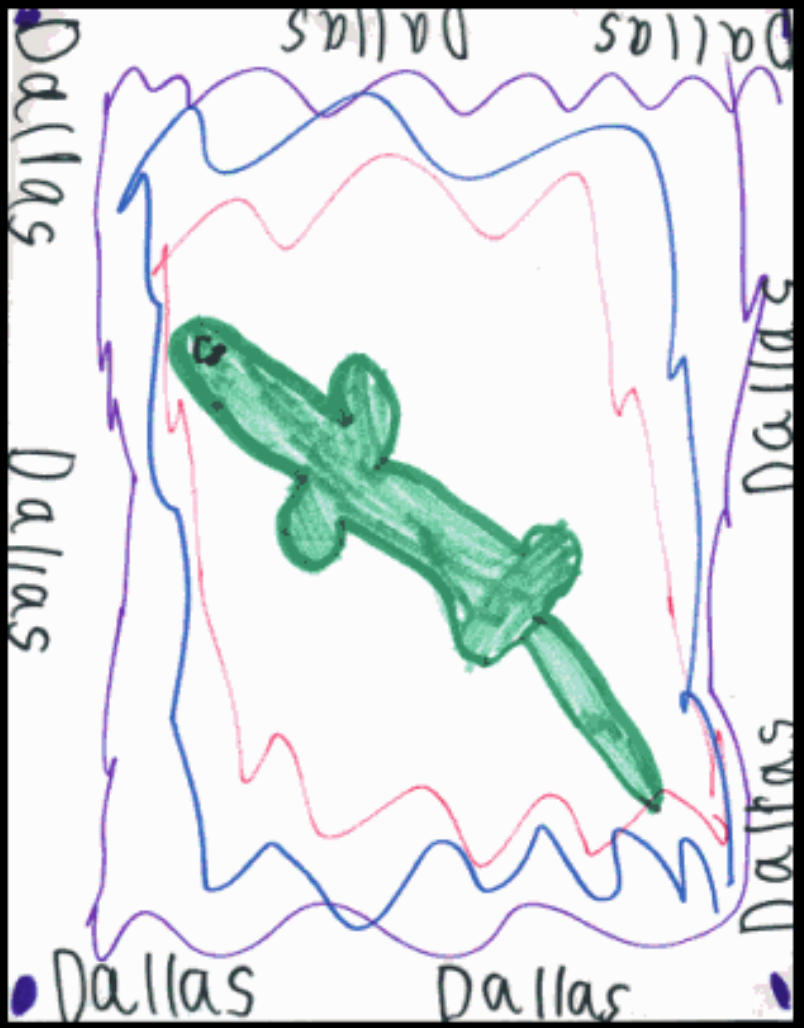
- Providing support to siblings of hospitalized children
  - Study in Journal of Pediatrics and Child Health
  - Data on sibling support services collected via a web-based survey from administrative and clinical practice leads in identified Child Life Departments
  - 34-item survey targeted three domains: Facility Demography, Sibling Support Resources, and Capacity Building and Funding.

Table 2 Sibling support resources and characteristics ($n = 109$)

	n (%)
Provision of sibling support	
Yes	52 (48)
No	56 (51)
Don't know	1 (1)
Sibling support providers	
Child Life Specialist	103 (94)
Social Worker	76 (70)
Pastoral Care	67 (61)
Mental health provider (psychiatrist, psychologist)	68 (62)
Recreation Therapist	8 (7)
Unanswered	5 (4)
Therapeutic services	
Grief therapy/palliative care support	98 (90)
Therapeutic play	81 (74)
Family-based programmes	26 (24)
Unanswered	8 (7)
Resources	
Basic entertainment (e.g. books, toys, movies)	91 (83)
Special events/tickets to events	75 (69)
Educational resources	21 (19)
Unanswered	6 (5)
Evaluation of services	
Yes, regularly	9 (8)
Yes, irregularly	14 (13)
No current procedure	72 (66)
Unanswered	14 (13)
Venues	
Play room	82 (75)
Teen room	54 (49)
Family room	57 (52)
Outdoor space	46 (42)
Spiritual/religious space	48 (44)
Child minding	13 (12)
None	1 (1)
Unanswered	6 (5)

Table 5. **Guidelines for Assistance to Siblings of Children Who Have Cancer (18)**

- Siblings should be included in discussions of care from the time of diagnosis, through death of the child, and beyond.
- "Protecting" siblings by excluding them may cause long-term harm.
- Siblings should be included in discussions about end-of-life care.
- Siblings should be included in funeral planning.
- Certain resources should be made available to support siblings through their grief and bereavement.



In Memory of Dallas Giles 05/05/89 — 02/21/05

by His Sisters Haley & Laney

http://kidsaid.com/stories/

Common pitfalls

- Avoidance
- Not recognizing development delay, somatic symptoms or other maybe be a manifestation of bereavement
- Trying to “protect” children and not include them in aspects of loved ones death or not being honest with them
- Saying “I know exactly what you are going through.”
- Saying “it will be okay.”
- Not acknowledging that children re-experience at different development stages.
- Not referring in appropriate cases.

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Whispers

by angel

http://kidsaid.com/stories/

Discussion points

- What are your experiences as a medical professional with bereavement and loss in childhood?
  - What has been successful?
  - What has not worked?
- Have you seen symptoms of bereavement in children present in unusual ways?
- Suggestions on how to prepare medical professionals to address issues related to children's bereavement.