

Children's Grief: Mourning the Loss of Function and Normalcy After a Serious Medical Diagnosis or Acquired Disability

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“Students and Depression Triggers:
How Can School Personnel Help Kids &
Succeeding Academically
After a Stressor”

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An old issue

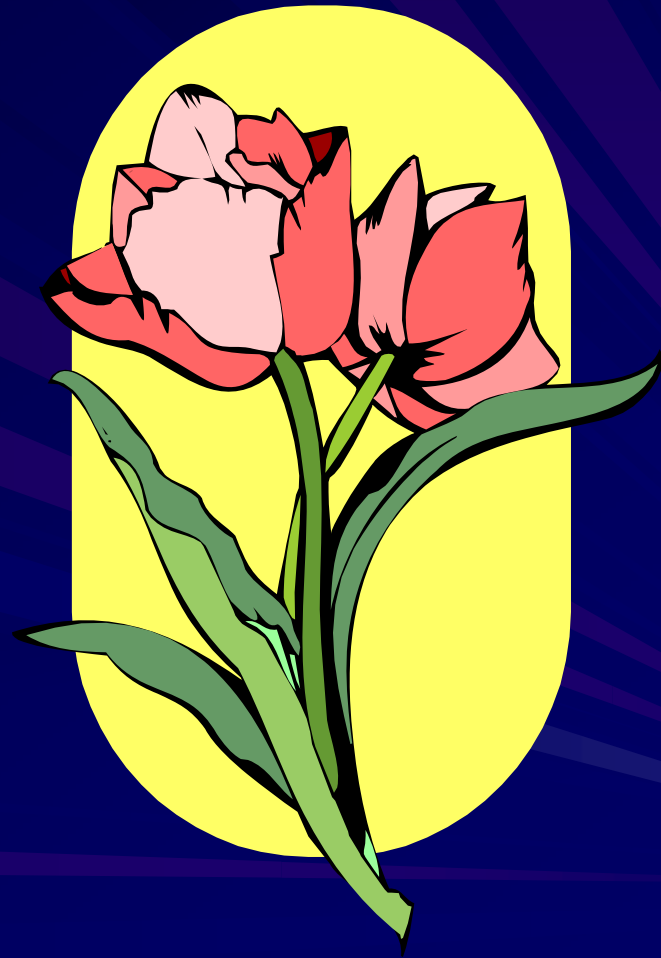
- ***Deformities and imperfections of our bodies, as lameness, crookedness, deafness, blindness, be they innate or accidental, torture many men; yet this may comfort them that those imperfections of the body do not a whit blemish the soul, or hinder the operations of it, but rather help and much increase it!***

Robert Burton, 1621

The Anatomy of Melancholy

Welcome to Holland!

- The journey changed... learning to read a new map and follow different directions... all on the spur of the moment and without forewarning.
- Often, various family members are traveling paths that may be parallel to one another, but very rich with differing experiences.



Topics du Jour....

- The Impact of Disability and the Grief of:
 - parents
 - siblings
 - others
 - the child (not last due to lesser importance)
 - The on-going impact of the child's disability
 - Theories of grief re: disability
- The Grieving Child and How Children Grieve
- Facilitating Healthy Coping and Change

Keles, H., Ekici, A., Ekici, M., Bulcun, E. & Altinkaya, V. (2007). Effect of chronic diseases and associated psychological distress on health-related quality of life. Intern Med J. 2007 Jan;37(1):6-11.

- Significant adverse effects of chronic diseases and psychological distress on HRQL in adults, the effect of psychological distress being the most important. Results suggest that in the management of comorbidities, the detection of the presence and severity of associated psychological distress and its treatment, besides the specific treatment of comorbidities, may provide dramatic improvement in HRQL of the patients.

Klassen, A.F., Miller, A., & Fine, S. (2004).

Health-related quality of life in children and adolescents who have a diagnosis of attention-deficit/hyperactivity disorder.

Pediatrics. Nov;114(5):e541-7.

- ADHD has a significant impact on multiple domains of HRQL in children and adolescents.
- Children with ADHD had more parent-reported problems in terms of emotional-behavioral role function, behavior, mental health, and self-esteem.
- Problems of children with ADHD had a significant impact on the parents' emotional health and parents' time to meet their own needs, and they interfered with family activities and family cohesion.
- The demonstration of a differential impact of ADHD on health and well-being in relation to symptom severity and comorbidity has important implications for policies around eligibility for special educational and other supportive services.
- Because the impact of ADHD is not uniform, decisions about needed supports should incorporate a broader range of relevant indicators of outcome, including HRQL.

Beattie, P.E. & Lewis-Jones, M.S. (2006). A comparative study of impairment of quality of life in children with skin disease and children with other chronic childhood diseases. *Br J Dermatol*. July; 155(1): 145-51.

- Chronic disease can have physical and psychological effects which affect social functioning. These effects can be better understood from the perspective of parent and child by the use of health-related quality of life (HRQL) measures.
- Using the Children's Life Quality Index (CLQI) it was shown that HRQL impairment in children with chronic skin disease is at least equal to that experienced by children with many other chronic diseases of childhood, with atopic dermatitis (AD) and psoriasis having the greatest impact on HRQL among chronic skin disorders and only cerebral palsy scoring higher than AD.

Nisevic, S. (2006). The importance of social support to chronically ill adolescents.
Med Pregl. Jul-Aug;59,7-8:331-4.

- The results of this study showed that chronically ill adolescents are more depressed than their healthy peers.
- This group of adolescents also perceives that they have less social support from their families than their healthy peers.

Immelt, S., (2006). Psychological adjustment in young children with chronic medical conditions.
J Pediatr Nurs. Oct;21(5):362-77.

- Children with chronic medical conditions are at higher risk for behavioral and emotional problems compared to physically healthy children.
- This study used a conceptual model to examine factors associated with psychological adjustment in children aged 7-11 years old with any of four chronic illnesses.
- The variables most closely associated with child adjustment included the following: mothers' evaluation of the impact of the child's illness on the family; child's perceptions of parental acceptance; and child's self-perceptions of physical appearance, social acceptance, and athletic competence.
- These findings confirm the importance of maternal and child perceptions in understanding the psychological adjustment of children with chronic conditions.

Breitmayer, B.J., Gallo, A.M., Knafl, K.A. & Zoeller, L.H. (1992).
Social competence of school-aged children with chronic
illnesses. *Pediatr Nurs.* Jun;7(3):181-8.

- This study examines social competence among 67 chronically ill children, aged 7 to 14 years, whose families participated in a grounded theory study of how families define and manage a child's chronic illness.
- Child Behavior Check List ratings (Achenbach & Edelbrock, 1983) by both fathers and mothers indicated a significantly greater risk for social competence difficulties among the chronically ill children as compared with the normative sample.

Perrin, J.M. & MacLean, W.E. Jr. (1988). Children with chronic illness. The prevention of dysfunction. *Pediatr Clin North Am.* Dec;35(6):1325-37.

- Children with long-term illnesses are at risk of developing problems in psychological adjustment and in functioning in activities of daily life. Their families face increased risks of marital and economic dysfunction, and siblings face special tasks living with a chronically ill child.
- A variety of interventions can help children and families to cope effectively with the tasks of chronic illness.
- Children respond to family stress in very predictable ways. Inasmuch as the stress of chronic illness may affect the marital relationship, there is a likelihood of concurrent behavioral and school problems.

Experiencing Loss



- Top 10 list
- Loss experienced differently by various individuals
- Grief expressed in a unique fashion
- What may seem to be a minor loss to one may be significant to another

Chronic Illness in Childhood

- Results in grief due to the experienced losses
 - Normalcy
 - Childhood
 - Parental goals
 - Child's/adolescent's goals
 - Significant events

Loss of one's hopes and dreams



“Rob the average man of his life illusion, and you rob him of his happiness at the same stroke...”

Herik Ibsen

It's a family affair



- cannot discuss child's grief without first understanding parents' grief, sorrow
 - parents' grieving style and intensity will determine child's
- siblings' grief
- peers' grief
- grandparents', aunts' and uncles', cousins' and so forth

Grief is not a finite experience

- Grieving is a *process* and should not be perceived as bad or unusual.
- It is something that happens, and needs to be dealt with over the course of time.
- Best to move through one's grief, rather than around it



Which of our students may be at risk of depression?

- birth anomalies (Down syndrome, cerebral palsy, spina bifida, etc.)
- later onset disabilities (autism, learning disabilities, etc.)
- injury (TBI, spinal cord injury, burns)
- disease (cancer, cystic fibrosis, diabetes, epilepsy, brain tumor, etc.)
- learning challenges



Child/Parent Connection

- **Injury/serious illness of child impacts entire family** (Shudy, M., deAlmeida, M.L., Ly, S., Landon, C., Groft, S., Jenkins, T.L. & Nicholson, C.E (2006). Impact of pediatric critical illness and injury on families: a systematic literature review. Dec;118 Suppl 3:S203-18)
- **Coping strategies of moms/kids interrelated**
(Kaminsky, L., Robertson, M. & Dewey, D. (2006). Psychological correlates of depression in children with recurrent abdominal pain. J Pediatr Psychol. Oct;31(9):956-66).

Parent/Child Relationship



- Bruce et al (1991) found no significant differences in reports of happiness in parenting between the disabled and non-disabled group
- intense level of attachment of many parents
- attachment and grieving or depression can exist in concert

Parents' grief... impacted by many factors



- onset/progression of disability
- type of disability
- feelings of responsibility
- attitudes of other family members, health care providers, etc.

Shared issues....

- Loss of 'anticipated child'
- Grief over developmental milestones, major life events
- Lack of predictability in life, loss of freedom
- Guilt
- Fear
- Uncertainty
- Loss of identity ("Jimmy's mom")



Issues specific to each population

- Birth anomalies, congenital diagnoses and disability apparent at birth
 - may have some warning, or not
 - in which case, may be precipitated by choice to carry baby to full-term, possible guilt
 - may be significant, or not
 - may have predictable course, or not
 - guilt may exist if it is a genetic condition
 - concerns intensify with subsequent pregnancies

Issues specific to each population

- Disabilities that appear with development (autism, muscular dystrophy, learning disabilities)
 - loss becomes apparent gradually, complicates process
 - level of disability greatly unknown - must unfold
 - ‘shifting gears’ - much like acute onset disease
 - guilt of parents

Issues specific to each population

■ Injury

- possibility of preventing the accident
- guilt if parent feels remiss in preventing
- guilt: “maybe he would have been better off if he had not survived”
- resentment - if another party is considered responsible or, perhaps, toward child
- hope for “cure” (i.e. stem cell research/spinal cord injuries)
- helped by stability of disability, usually

Issues specific to each population

■ Diseases

- guilt - family predisposition
- didn't get the child to the doctor in time
- fear for other children in family
- unknown course
- frequent decisions re: treatment options
- unpredictability re: family events, planning
- often, instability of disease process and physical status

The process

- On-going
- Varies in intensity
- Shock
- Guilt
- Mourning
- Confusion
- Lack of closure
- Acceptance harder to achieve
- Acceptance becomes the process
- Compromising
- Coping

Finding the “new normal”

- May be a different road than previously traveled, and the course must be redefined.



Common Occasions of Stress/Grief

- diagnosis or acquisition of disability
- discovery of additional problems
- pre-school or school
- puberty, adolescence
- when child becomes aware of her disability
- school leaving age
- birthdays, Mother's Day, Father's Day, Christmas
- when siblings marry, have more responsibility
- permanent care application
- aging/death of parent

Parents' Grief



- “The child’s parents have not accepted their son/daughter’s disability”.
- What does that mean?
- Should parents perceive their child from point of view of the professional helper, and not ‘their’ child?

Parent/Spouse Relationship



- potential for some difficulties
- increased demands on both parents
- parents may grow together on the journey
- marital discord and divorce more prevalent

Parent/Sibling Relationships

- parents often challenged in every dimension
- at the hospital/attending to needs of child with disability
- working, spouse, house
- sibling video - to come



The Grief of Siblings



- many losses
 - ‘normal’ sibling
 - family normalcy
 - parent attention
 - family events
 - sometimes, equal status
 - peer acceptance (real or perceived)
 - predictability of future
 - concern over caring for sibling

Changing roles & expectations of siblings

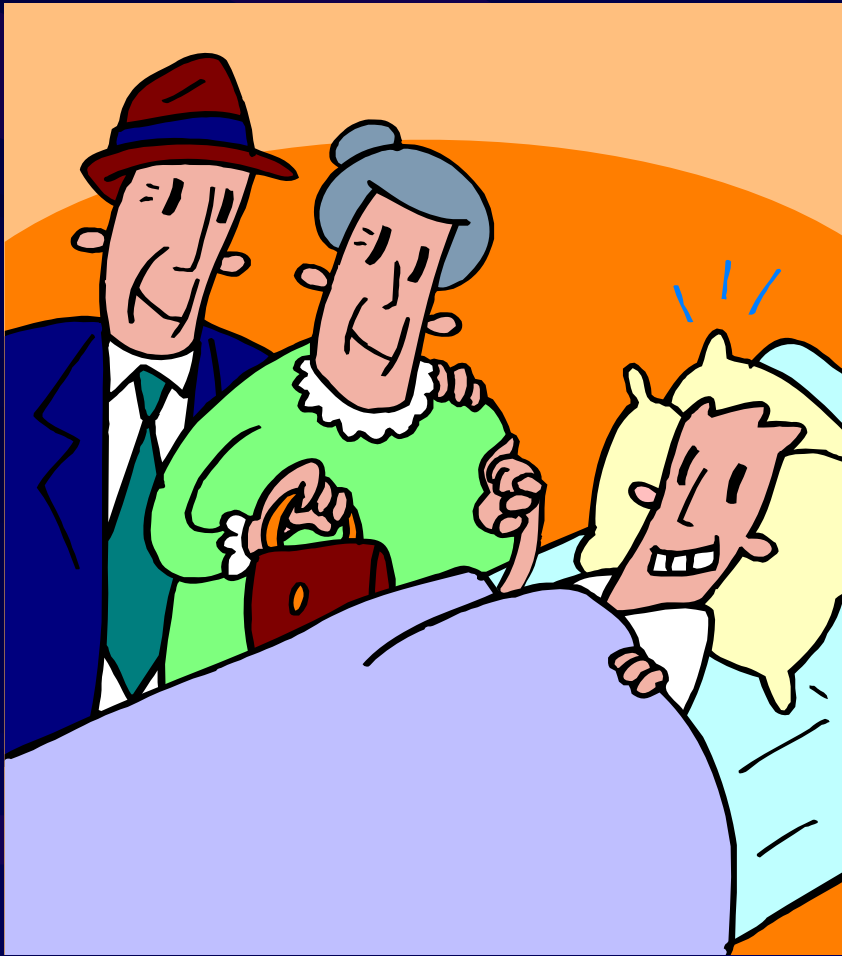
- Increased responsibility at home
- change in level of emotional support
- often, few steady advocates
- magical thinking
- emotions (fear, guilt, anger, jealousy, confusion, sadness, relief that it is her)
- school issues

Identify sibling's advocate



- during times of crisis, stress, change... who will advocate for and take primary responsibility for caring for the siblings?
- should be a consistent person, when possible
- minimal disruption in routine, rituals

Extended family and friends



- Personal issues, concerns and needs
- may color the experience of child, parents, siblings - positively or negatively
- good intentions, not always good outcomes
- identifying roles
- identifying ways to help

Family choices

- Families should be supported in developing effective communication, allowing parents of child with disability to make decisions independently without fear of hurting others' feelings



Community response

- May ease family's burden
- May intensify family's burden
- For some family's, disability/disease may offer a degree of secondary gain
- May enable family to interact and partner with others in the community in a common bond
- Sensitivity to family needs and wishes

Kids' grief over a disability

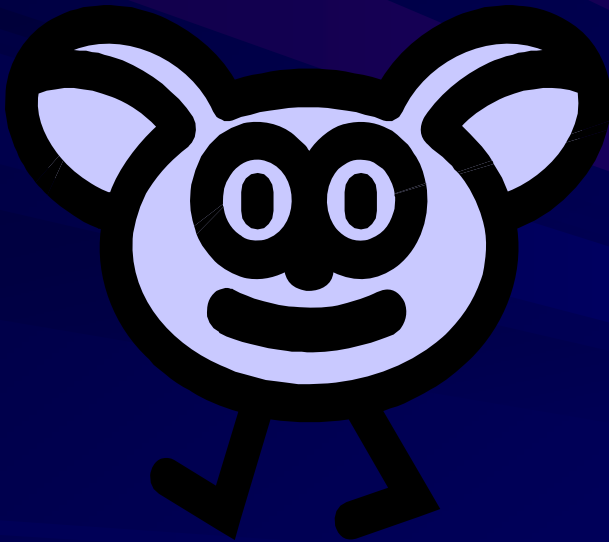
- Developmental issues
- Degree of disability
- Stability of the child's health status
- Peer relationships
- Family support
- Level of independence

Grieving children



- Kids do not grieve like adults
- Can be grieving one minute; playing next
- Laughter, tears – closely related
- Grieving does not = depression

Active listening



- To determine where the kid is
 - Developmentally
 - Prior experience with loss
 - Understanding of disability/disease/etc.
 - What he/she perceives the loss to be
 - Where he/she is getting support

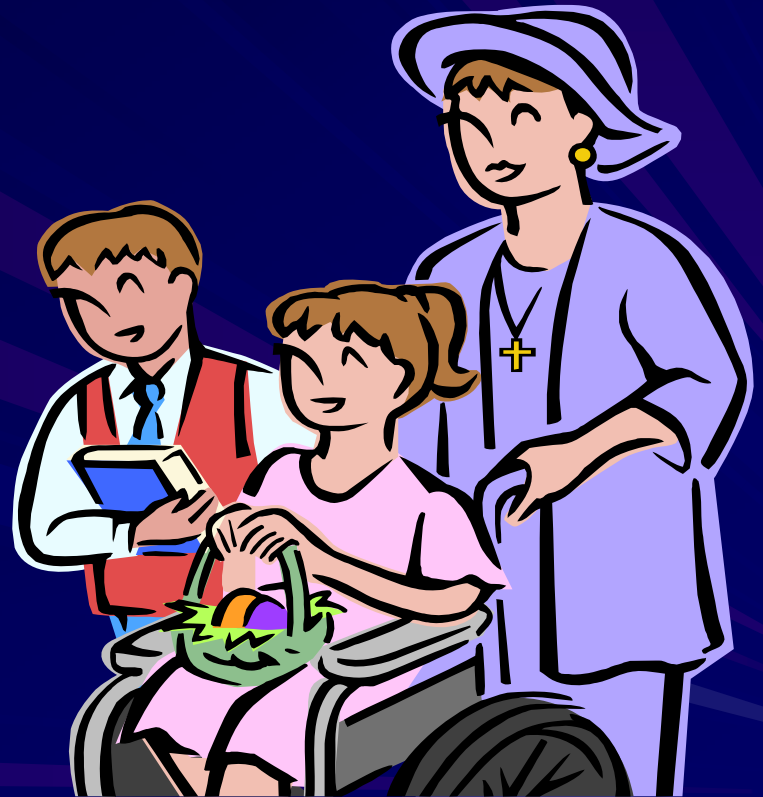
Kids' grief



- Is often disenfranchised grief... not taken seriously... thought that they don't understand or will 'learn to live with it'
- Lack of recognition (by others) of the child's losses over time

Disablism

- Reflects the dominant cultural images of people with disabilities
- Influence process of forming one's identity
- Difficult task of challenging the personal, cultural and structural discrimination
- May be internalized



Disablism results in

- Social death (Glaser and Strauss, 1965)
- Withdrawal of involvement in relationships with others and life
- Cessation of the individual as an active agent in others' lives
- Leads to loss of 'citizenship' (Clark and Seymour, 1999)



Pity and help

- Chronic illness and disability often viewed as less fortunate, in need of pity and help
- External and internal pressures can undermine sense of being a valued citizen with rights to self-determination
- Fosters a sense of helplessness and hopelessness

Preschoolers



- Bedwetting
- Thumb sucking
- Clinging to caregivers
- Excessive crying
- Excessive fears
- Temper tantrums
- Stubbornness
- Fear of separation
- Regression

Helping preschoolers through grief

- Give child open, honest, simple answers
- Provide simple routines and rituals
- Provide ample opportunities for expression of grief through play, art, music
- Help child recognize full range of his emotions and learn to name feelings
- Be patient. Expect and accept regressive behaviors.



School-Aged Children



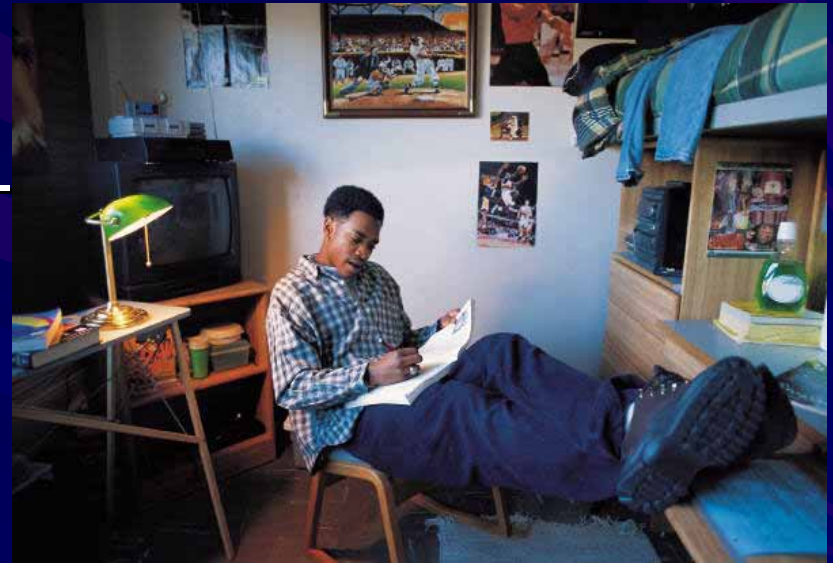
- Academic problems
- Behavior problems
- Daydreaming
- Preoccupation with disability and related losses
- Eating (over or under)
- Sleeping/nightmares
- Regression
- Fighting, anger

Helping the school-aged child

- Explain experiences in advance (i.e. doctor visits, procedures and provide anticipatory guidance
- With child/parent consent, educate others
- Provide structured, consistent environment with (limited) choices
- Encourage expression of grief through words, art, music, play
- Use natural consequences for inappropriate behaviors. Keep expectations as normal as possible.
- Be available.

Grieving Adolescents

- Physical symptoms
- Mood swings
- Feelings of helplessness and hopelessness
- Increased risk-taking and self-destructive behaviors
- Anger, aggression, fighting oppositional
- Withdrawal from adults
- Depression, sadness
- Lack of concentration, attention
- Declining grades
- Testing the limits
- Identity confusion



Supporting adolescents

- Accept the mood swings & physical symptoms
- Encourage honest recognition of painful feelings
- Encourage them to find outlets – physical, creative
- Listen for the feelings behind the words
- Be empathetic
- Be truthful
- Help them develop/maintain sense of identity
- Allow teens to make choices that are not harmful.
- Encourage independence

When grief is not
simple...depression may result



Disability and Depression

- Depression becomes the frequent response to the multiple losses of disability. Physically disabled patients were found to demonstrate two times the prevalence of major depression as the norm, with no relationship between depression and severity of disability.
(Langer 1995)

Factors for consideration re: depression

- Future course of condition
- Amount of time since onset
- Pain/discomfort
- Social resources
- Impact on functioning
- Meaning to others in society
- Personal ability to sustain hope
- “Domino effects” of disability
- Prior experience with disability
- Stigma of disability cause
- Anticipatory grieving

Trauma



- Early intervention
- Ensure as much protection as possible from further harm
- Protect from onlookers and media
- Kind, but firm, direction
- Watch for panic/intense grief and get help
- Offer frequent reassurance
- Resume normalcy as soon as possible



Trauma

- Sleep with light/person
- Reassure that it was not their fault (if true)
- Do not criticize regressive behavior or shame child
- Allow child to cry or be sad. Do not expect braveness.
- Encourage child to feel in control (decisions about meals, what to wear, etc.)

Trauma brings with it...

The **psychological** emergency, that accompanies the physiological emergency of sudden onset injury or illness



Post Traumatic Stress Disorder (PTSD)

- **What is post-traumatic stress disorder?**
Post-traumatic stress disorder (PTSD) is a debilitating condition that often follows a terrifying physical or emotional event - causing the person who survived the event to have persistent, frightening thoughts and memories, or flashbacks, of the ordeal. Persons with PTSD often feel chronically, emotionally numb. PTSD in children and adolescents can become a chronic disorder

Symptoms of PTSD

- sleep disturbances
- depression
- feeling jittery or "on guard"
- being easily startled
- loss of interest in things they used to enjoy; detachment; general lack of responsiveness; feeling numb
- trouble feeling affectionate
- irritability, more aggressive than before, or even violent
- avoiding certain places or situations that bring back memories
- physical symptoms (i.e., headaches, stomach aches)
- flashbacks or intrusive images (images, sounds, smells, or feelings; a person usually believes that the traumatic event is happening all over again)
- losing touch with reality
- reenactment of an event for a period of seconds or hours or, very rarely, days
- problems in school; difficulty concentrating
- worry about dying at an early age
- regressive behaviors; acting younger than their age (i.e., thumb sucking, bedwetting)

PTSD and chronic illness or disability

- Many of the events that cause physical disability are sudden and unexpected, such as accidents.
- Post-traumatic stress can accompany a person's reaction to their injury and onset, especially when they were conscious and remember how it happened and what it felt like.
- Chronic illness with more gradual onset can also involve traumatic events during the course of the illness, such as a sudden decline, loss of a life activity such as work, or an event related to the illness that causes fear or a loss of hope.



PTSD and rehabilitation

- symptoms can interfere with participation in therapies and the rehabilitation process.
- nightmares and poor sleep can limit energy for therapies.
- withdrawal and a tendency to isolate can interfere with therapy relationships or even cause avoidance of the therapy
- anxiety can interfere with concentration and understanding new and important information
- hospitals are often very busy, stimulating places and can cause a person with post traumatic stress to easily feel overwhelmed
- important to help a person with post traumatic stress have as much predictability and control over their surroundings as possible.

Facilitating coping and supporting families....

- understand recurring grief (sudden image of 'normal' child years later)
- gender and cultural differences
- even 'normal' grief is painful (avoid telling parents that their grief is normal - dismissive)
- self-help groups
- trusting, stable relationship that offers choices in support and understanding about change and loss reactions

Facilitating coping and supporting families.... (cont.)

- Recognize signs of complicated grief or PTSD, and refer for assistance
- Help others understand that children's grief may look very different from the grief of an adult
- Be there!



Staff Grieve, too.



- high volume of multiple and chronic loss situations
- helpless/overwhelmed vs. well-defended/callous
- debriefing
- professional supervision
- communication skills training

Not always an easy road to travel

- We must broaden our knowledge base and awareness of disability to include the emotional experience, even when this confronts us with their own fragility and vulnerability.



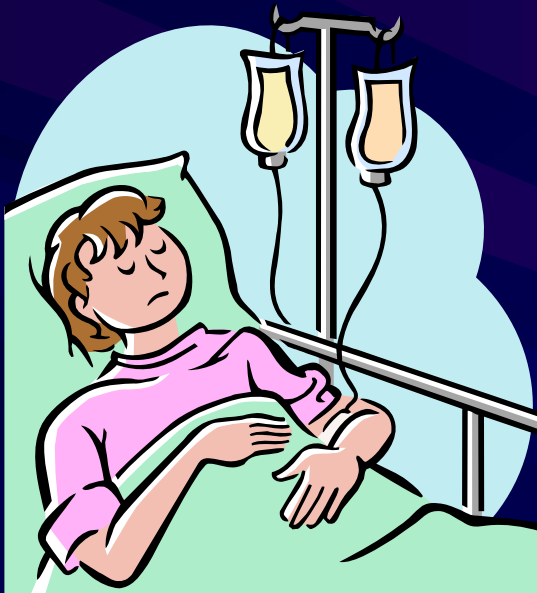
Impact of disability/depression on learning

- Depression may affect
 - Concentration
 - Attention
 - Focus
 - Motivation
 - Social relationships
 - Attendance
 - Much more

Definition of 'other health impaired'

- "...having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and sickle cell anemia;
- **and adversely affects a child's educational performance."**

Other Health Impaired



- Does not only mean cognitive effect on educational performance

What's the problem?

- Determining which children need education support/interventions
- 504 Plans vs. IEPs
- Determining eligibility for students who are 'other health impaired' (OHI)
- Getting the information from medicine and health care to education (and vice versa)
- Closing the "Med-Ed" gap

The impact of chronic illness on learning

- 31% of children have at least one chronic health condition (Bureau of Maternal and Child Health)
- 12.8% have chronic health conditions that result in a functional disability (Bureau of Maternal and Child Health)
- Students considered 'other health impaired' considered low-incidence condition
- Result: academic, social, emotional, psychological challenges and problems that are not addressed
- Health care needs addressed; educational needs often are not recognized

Eliminating “Sickual Discrimination”

- Students with chronic illness – the last population of learners to remain underserved or unserved at school
- Not a matter of malintent by school districts
 - Legal requirements
 - Lack of information
 - Attitudes regarding illness

What's happening in
special education?

First, what's not happening...



The Law



Results in....

Schools are not looking for additional students to classify as students in need of special education.

OHI

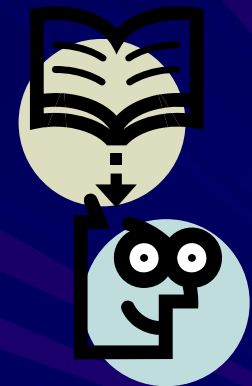
- 59% of students identified as OHI have ADD/ADHD
- *Health* needs typically addressed by schools; challenges in addressing *educational* needs
- Plenty of research – in all the wrong places for educators:
 - *Blood,*
 - *Pediatrics,*
 - *JAMA, etc.*

Our natural tendencies



Universal Challenges for Students with Health Conditions

- Absences
- Fatigue
- Medication side effects
- Diminished expectations
- Psychological implications
- Social concerns
- Depression/anxiety



The Research Tells Us

- Lower graduation rate among students with chronic illnesses
- Less college prep courses taken by kids with chronic health conditions
- Number one issue listed as problematic (adult survivors of childhood cancer) = issues related to school
- Employability problems and decreased wages for adults who had/have chronic illnesses of childhood

Leukemia

- Fatigue, PTSD, psychosocial concerns
- CRT - drops of 10 – 15 points in IQ
- Intrathecal chemotherapy and no CRT
 - no significant deficits in global and verbal areas of functioning,
 - significantly lower performance - nonverbal performance, perceptual organizational skills, and freedom from distractibility/attention measures.
 - performance on nonverbal measures significantly lower than performance on verbal measures
 - visual-motor integration showed mild impairments
 - Thirty-seven percent of the students received at least part-time special education services
 - 7% were in full-time special education classes.

(Brown, Madan-Swain, Walco, Cherrick, Ievers, Conte, Vega, Bell & Lauer, 1998).

Leukemia, cont.

- Methotrexate – systemic and intrathecal
 - associated with increased risk of calcification and other white matter changes in the brains of children with leukemia (Margolin et al, 1997)
- Corticosteroids
 - Mood changes, lethargy, depression, euphoria, physical side effects (Mitchell, Richards, Kinsey, Lilleyman, Vora & Eden, 2005)

Asthma/Allergies

- Leading cause of school absences (Lemanek, 1990)
- Leading cause of limited participation (Taggart & Fulwood, 1993)
- Memory of past attacks – trigger fear, anxiety, difficulty concentrating (Kendall, Chansky, Kane, Kim, Kortlander, Ronan, Sessa & Siqueland, 1992)
- 2X as likely to evidence behavior problems (internalizing and externalizing) (Furrow, Hambley & Brazil, 1989)
- 1988 U.S. Nat. Health Survey - moderate risk of academic problems (Fowler, Davenport & Garg, 1992)

Asthma/Allergies

- Sleep – or lack thereof
- Restrictions in activities
- Steroids – subtle effects on memory and mood (Bender, 1995, Celano & Geller, 1993)
- behavior problems with the use of aerosolized steroids for asthma treatment (Connet & Lenney, 1991; Lewis & Cochran, 1983).

Diabetes Mellitus

- Early diabetologists believed that children with juvenile diabetes mellitus were of average, if not above average intelligence (Grishaw, West & Smith, 1939)
- and that they performed adequately in school (Weil & Ack, 1964)
- more neuropsychological impairments such as difficulty with verbal skills, visuospatial abilities, attention, memory and learning, psychomotor efficiency and executive functioning (Rovet & Fernandes, 1999; Hannonen et al, 2003).
- regions of the brain targeted the most by diabetes are those that underlie the specific skills which are necessary in the management of diabetes (Rover, 1998)

Research suggests....

- the most impacting effects of diabetes on a child's brain are severe episodes of hypoglycemia (Eeg-Olofsson & Petersen, 1966; Goldstein, England, Hess, Rawlings & Walker, 1981)
- and frequent episodes of less severe hypoglycemia (Golden, Ingersoll, Brack, Russell, Wright & Huberty, 1989)
- diagnosis at a young age, metabolic condition at diagnosis and long-term metabolic control, as opposed to experienced hypoglycemic attacks, as risk factors for intellectual development. (Schoenle et al 2001)

Diabetes

- **generally poorer academic performance** (Fowler, Johnson & Atkinson, 1985; Sansbury, Brown & Meacham, 1997; McCarthy et al, 2003)
- **lags in specific subject areas such as reading or spelling** (Ryan, Longstreet & Morrow, 1985)
- **Difficulty with arithmetic** (Northam, 1996)
- **greater need for special education services**
(Rovet, Ehrlich & Hopee, 1988)
- **underachievement does not always become evident soon after diagnosis but, rather, may take a number of years to manifest itself** (Rovet, Ehrlich, Czuchta & Akler, 1993)

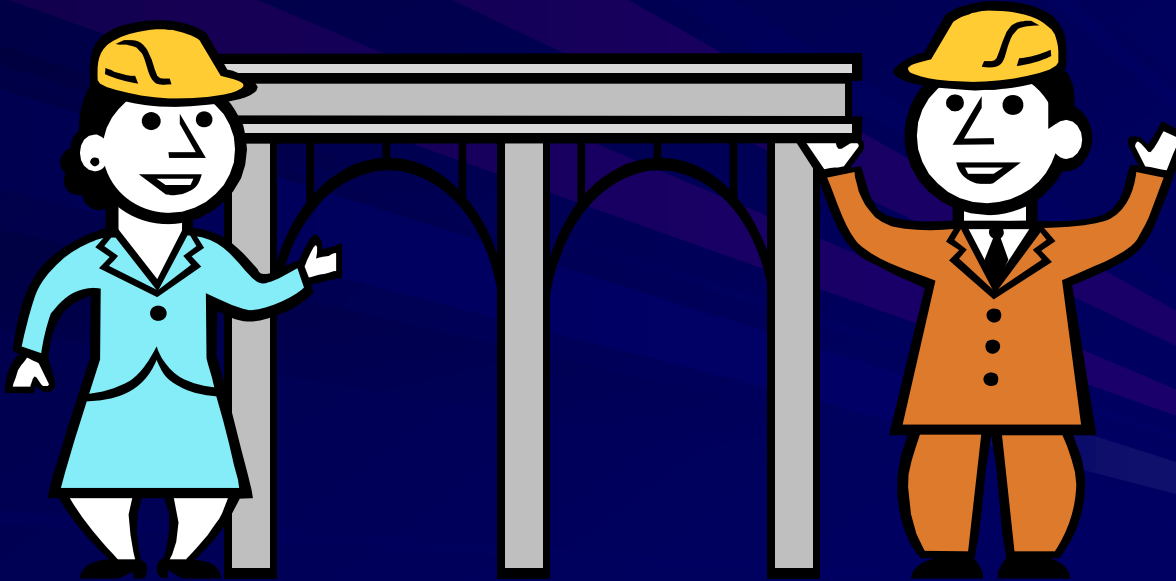
Sickle Cell Disease

- few studies exist that examine the cognitive functioning of children with sickle cell disease (Frank, Allison & Cant, 1999)
- compared children with SCD who had experienced a CVA to children with SCD who had not had a stroke - patients from both groups exhibited impairments in intellectual functioning, language functions and social and personal adjustment (Hariman, Griffith, Hurtig & Keehn 1991)
- “silent strokes” in 11 -20% of children with SCD (Craft, Schatz, Glauser, Lee & DeBaun, 1993)

Sickle Cell

- learning problems and areas of diminished function in this population of students and risk of neuropsychological impairment appears to become more significant with age (Armstrong, Thompson, Wang, Zimmerman, Pegelow, Miller, Moser, Bello, Hurtig & Vass, 1996).
- children with SCD who had experienced clinically apparent CVAs were likely to evidence pervasive impairments, including decrements in general intellectual functioning, academic achievement, memory, language and verbal ability, visual-motor and visual-spatial processing and processing of prosodic information. (Kral, Brown & Hynd 2001)
- children with SCD who had silent strokes had more subtle neurocognitive deficits in the areas of attention, concentration, executive function, and visual-motor speed and coordination. (Kral, Brown & Hynd 2001)

Bridging the Med-Ed Gap



Grief may impact various stakeholders



Issues and Concerns of Students with Chronic Health Conditions

- Feeling of disconnect from school
- Fear of returning to school
- Fear of teasing and rejection by peers
- Changes in perception of self, abilities
- School avoidance
- School phobia
- Parental concerns
- Educators' concerns



Issues and Concerns of Parents

- Will my child be harmed (physically) at school?
- Will her feelings be hurt?
- Will this put my child under too much pressure?
- Shouldn't I be with my child, at all times, caring for her?
- Can I trust that the school will do a good job caring for my child?



Issues and Concerns of Siblings



- Fear
- Guilt
- Loneliness
- Sadness
- Abandonment
- Jealousy
- Anger
- Confusion

Issues and Concerns of Peers



- Will I catch it?
- How do I support my friend?
- What do I say?
- Should I invite him?
- Will others think differently of me if I hang out with him? If I don't?
- Out of sight; out of mind

Issues and Concerns of Educators

- How can I keep her caught up?
- Paperwork!
- Is it fair to the other students?
- Is it contagious?
- What about confidentiality?
- How do we provide related services (OT, PT, speech, etc.)?
- What if she gets sick at school?
- What if she dies at school?



Issues and Concerns of the School Nurse



- Availability/shared schools
- Getting information about disease, treatment
- Educating staff
- Confidentiality
- Encouraging follow through by staff
- Communication: parents, health care providers, administration, etc.

It takes a village....



Questions.....

