Broadening the Scope of Practice in Pediatric Oncology:

Considerations for Palliative and End-of Life Care Interventions

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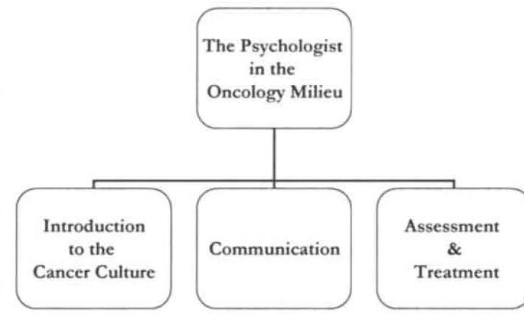
FPA 2008 CONVENTION

Objectives

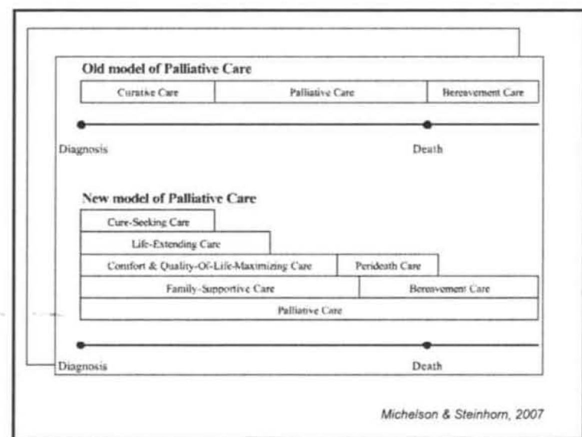
- To obtain *basic knowledge* in pediatric psycho-oncology, and in particular palliative and end-of-life care in an effort to broaden the scope of practice.
- To acquire specific *skills in communication, assessment, and evidence-based treatments* in pediatric psycho-oncology within a medical setting.
- To develop a solid framework which will enable participants to *provide quality care for children and their families* during a significant time in their lives.

OVERVIEW OF THE SCOPE OF THE SCOPE OF SERVICES IN PEDIATRIC PSYCHO-ONCOLOGY:



Definitions

Pediatric palliative care
vs curative care
vs end of life care

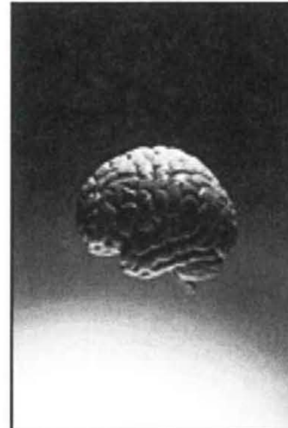


Michelson & Steinhorn, 2007

Epidemiology

- Less than 1 y/o
  - *Multiple factors*
- Ages 1-4 y/o
  - *Malignant neoplasms: # 3 (8%)*
- Ages 5-14
  - *Malignant neoplasms: # 2 (15.4%)*
- Ages 15-19
  - *Malignant neoplasms: # 4 (5.4%)*

Carter, Levetown, 2004



Risk Factors
tric Cancer

- Brain Tumor
- CNS disease
- Cranial irradiation (dose effect)
- Child's age (young children at greater risk)
- Time since end of treatment
- Intrathecal chemotherapy
  - systemic chemo to a lesser degree
- Frequent school absences

Neurocognitive Deficits & Risk Factors
Among Children Treated for ALL and Malignant Brain Tumors

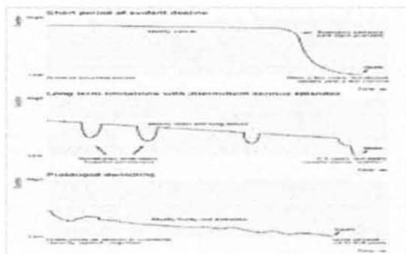
Butler, Mulhern, 2005

Neurocognitive Deficits: Working memory, processing speed Secondary Symptoms: Academic failure, vocational & social problems	Attention IQ loss
Risk Factors for Deficits: ALL (CRT, Intrathecal & IV MXT, Corticosteroids, Female) Brain Tumors (CRT, Tumor Invasion, Trauma sec. rxt, hydroceph, seizures) Female Gender	Young age at treatment Young age at treatment, sensory & motor impairments

Psychopharmacology in Pediatric Oncology

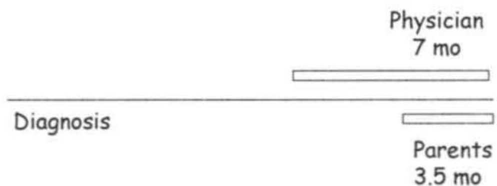
- Methylphenidate for ADHD
  Mulhurn, et al. 2004, Kazak, 2005
- Midazolam for procedural anxiety, discomfort, pain
  Ljunman et al. 2000
- Midazolam & psychological interventions for procedural distress
  Kazak, et al. 1998
- Typical anti-psychotics for steroid-induced psychosis
  Ingram & Hageman, 2003
- Typical anti-depressant for mood symptoms secondary to corticosteroids
  Drigen, Spirito & Gelber, 1992

Illness Trajectory and Palliative Care



adapted from Lunney, Lynn, and Hogan 2002

Timing of understanding that there is no realistic chance for cure



Wolf, et al, 2000

Other Important Elements in Pediatric Palliative and End-of Life Care

- Developmental considerations
- Experience with cancer
- Experience with death
- Style of child's information gathering and questions about the disease
- Style of parent's response

Cancer Kids 101

Adapting to the cancer culture:

On being a temporary guest in an existing situation

- The pre-established
  - organizational climate
  - medical turfs and hierarchies
  - notion of social services, psychologists
  - prior experiences: the history with you

Working in pediatric palliative care:

Time out strategies for yourself

- Compassion fatigue
  Rourke, 2007, Baranowski, 2006
- It is the defense against the loss that hurts, not the loss
  - Giving yourself the freedom to experience the full range of emotions
  - Need to articulate in talking & listening
  Cassell, 2006

DAVID ARISTOTLE HAUGHTON*
Vancouver, British Columbia

Kindertotentanz: Chemotherapy I

Ten years ago, I trained as a pediatrician on the cancer ward of a children's hospital. I witnessed children in pain and children dying. The anger and helplessness I felt compelled me to begin the Kindertotentanz: a series of etchings, watercolors, and oils that expressed my ambivalence about modern medicine. In this ongoing series of works, I have an outlet; they drain my rage. They shout what I cannot say aloud.

Stress in Pediatric Palliative Care:

Personal Characteristics

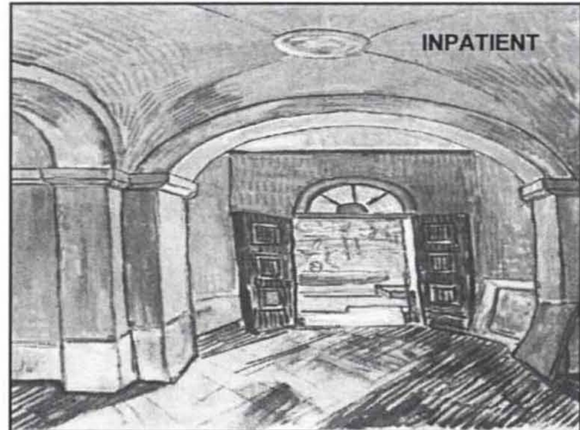
- perfectionism
- over involvement with patients
- identification with patients
- self-esteem
- sense of mastery
- purpose in life
- unrealistic expectations

Baranowski, 2006

Stress in Pediatric Palliative Care:
Personal Characteristics

- feelings of inadequacy
- history of psychiatric illness
- emotional demands
- increased awareness of own losses, vulnerabilities, and fear of own death
- cumulative losses

Baranowski, 2006



Overcoming medical data fears in an intense work schedule

- When in Rome…
  - Learn the language
- Preparedness
- Practice

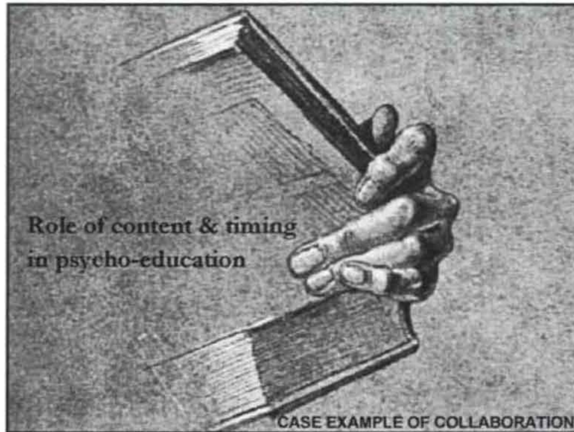
Strengthening communication & liaison work

- JCAHO Standards Regarding Collaboration
  - Standard PC.5.5 "Care and services are provided in an interdisciplinary, collaborative manner."
    - Rationale for PC.5.5 *"A collaborative, interdisciplinary approach to meeting the patient's needs & goals helps to coordinate care, treatment, services & achieve optimal outcomes. The mix of disciplines & intensity of collaboration will vary as appropriate to each patient and the scope of services provided by the hospital… "*

JCAHO, 2005

Strengthening communication & liaison work

- Communicating impression, assessment results and treatment
  - CASE EXAMPLE OF COLLABORATION



Strengthening communication & liaison work

- Self-Identification
- Reason for referral
- Pt Identification
- ETA

Strengthening communication & liaison work

- Sample items of handout for referring physicians:
  - high emotional distress
  - complaints out of proportion to physical pathology
  - repeatedly raised issues already addressed
  - resistance to wean of some meds

Belar & Deardorff, 1999

Strengthening communication & liaison work

- Other examples of potential referrals
  - agitation
  - tearfulness
  - behavioral issues during intervention

Strengthening communication & liaison work:

The SBAR Technique *(of communicating with the health care team)*

1. Situation
2. Background
3. Assessment
4. Recommendation

Leonard, Graham & Bonacum, 2005

Strengthening communication & liaison work: *presentation based on the C/L model*

- HPI: History of Present Illness
- PMH: Past Medical History
- FMH: Family Medical History
- PPH: Past Psychiatric History
- FPH: Family Psychiatric History
- PSH: Patient's Social History
- MSE: Mental Status Exam

Strengthening communication & liaison work: *presentation based on the C/L model*

- Dx/Impresion
- Recommendations

Communicating effectively with accurate information without overwhelming the child and family to the point of breaking

" You had me at ...

'unfortunately, the treatment results were not as good as we had hoped' "

Common Communication Barriers

- Closed Qs
- Leading Qs
- Talking about neutral issues (physical sx)
- Giving only selected attention to cues
- Premature or inappropriate advise

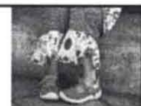
Giansiracusa, 2006

Other Common Communication Barriers

- Ignoring cues
- False reassurance
- Topic switch
- Passing the buck
- Premature problem-solving
- Avoiding the patient

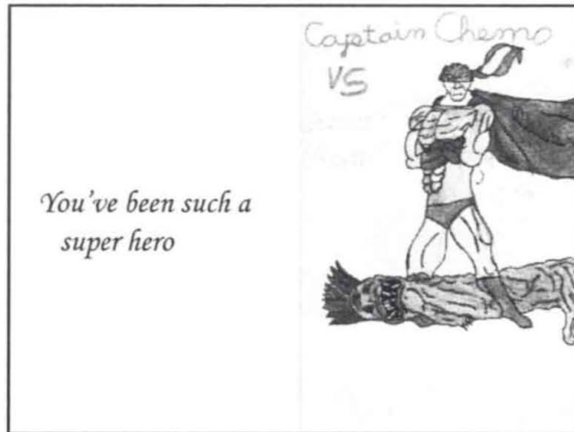
Giansiracusa, 2006

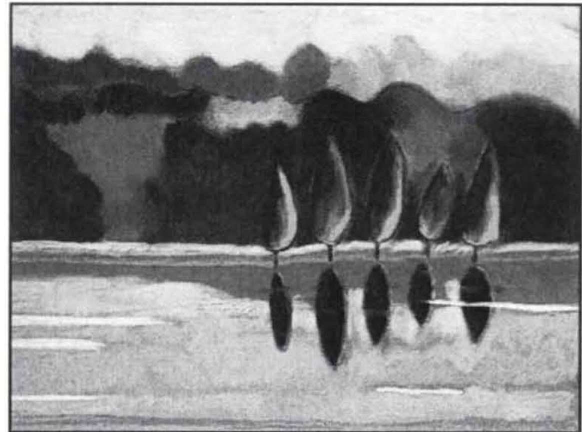
Communicating empathy & trust to children



in my shoes...

- scoot down to eye level
- sit down
- respond to feelings
- honesty
- reliability
- updated accurate information (with parental consent)





Consultation in Pediatric Psycho-Oncology: Establishing a therapeutic relationship with parents

- The consult as an intervention
  - Referral
  - Etiology
  - Differential Diagnosis

Common Pain Assessment Issues

- role of parents in pain assessment
- pain from different etiologies with similar clinical indicators

Common Pain Assessment Issues

- Adolescents with chronic/recurrent pain resulting from a long-term life-threatening condition:
  - assessing physiological/cognitive/emotional components of a patient's pain perception
  - adequate pain history

Common Pain Assessment Issues

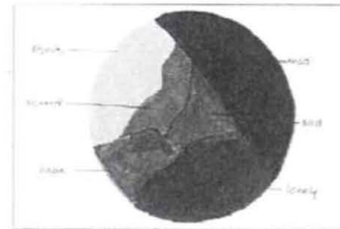
- children unable to report their pain verbally
- observing behavioral and physiological indicators, even in children who have the capacity for verbal communication.

Common Pain Assessment Scale

- *Children who are too young to express pain may demonstrate it by behavior changes*
  - <u>Psychomotor atonia</u>: child adopts a posture that minimizes pain, or over time appears to become resigned to it

Hain, 2004

Sample of assessment option:



Taken from Sourkes, 1995

Sample of assessment option:

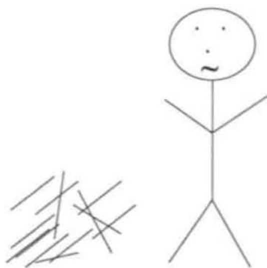
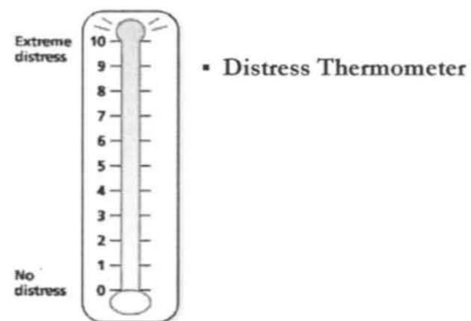


Figure: "Losing my hair"
Adapted from Sourkes, 1995

Sample of assessment option:



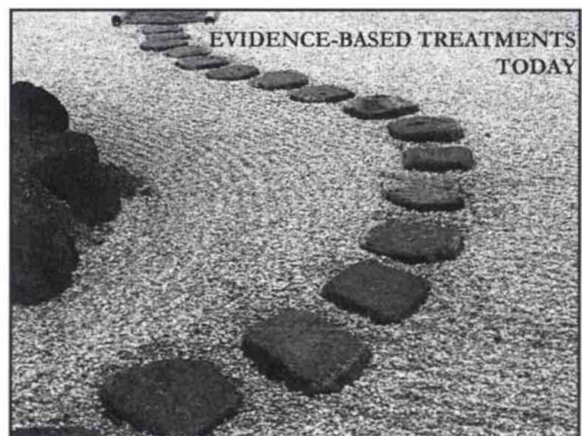
- Distress Thermometer

Assessment:

Selected medical problems/complications that can present with psycho/neurological symptoms

- Brain neoplasms
- Hypo/hyperthyroidism
- Hypercalcemia
- AIDS
- Hepatic encephalopathy
- Vitamin deficiencies
- Post-op delirium
- Opiods
- Several chemo agents
- Injuries/trauma

Kaplan and Sadock's Synopsis of Psychiatry: Behavioral Sciences/Clinical Psychiatry, 2007

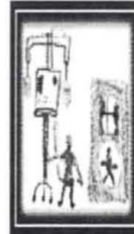


Historical
Evidence-Based Treatments
Selected Well Established Treatments
(Chambless Criteria)

- Interventions for procedure-related pain
  - Breathing exercises + other distraction & relaxation
  - Filmed modeling
  - Reinforcement/incentive
  - Behavioral rehearsal
  - Coaching by psychologist, parent and/or other medical staff

Powers, 1999

Historical
Evidence-Based Treatments
Possibly Efficacious



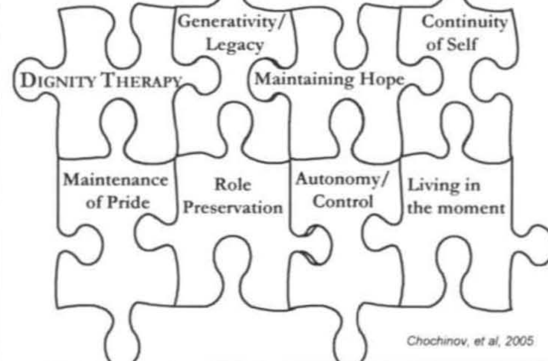
- Behavioral Interventions
  - Relax & distraction for decreasing chemo side effects, anticipatory n/v

Powers, 1999

Historical
Evidence-Based Treatments
Promising

- Behavioral Interventions
  - Video games for decreasing chemo side effects, anticipatory n/v

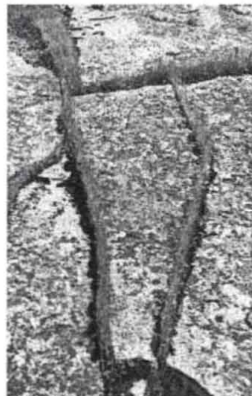
McQuaid & Nassau, 1999



Chochinov, et al, 2005

"...the little grasses crack through stone, and they are green with life"

Silvia Plath



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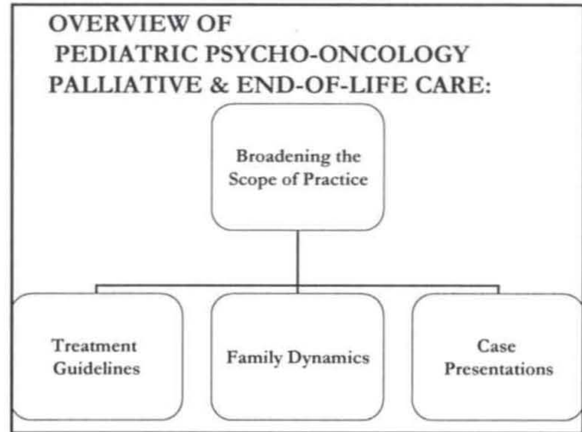


AMERICAN PSYCHOLOGICAL ASSOCIATION

Report of the Children and Adolescents Task Force of the Ad Hoc Committee on End of Life Issues

✓Practice
✓Research
✓Training
✓Policy

APA Task Force, 2005

IOM

Highlights

IOM, 2008

SIOP Working Committee on Psychosocial Issues in Pediatric Oncology

- Highlights 2 time periods:
  - curative to palliative & palliative to death
- Key issues:
  - *"duration and quality of remaining life*
  - *rights of the child to careful, compassionate management"*

Masera, Spinetta, Jancovic, et al, 1999

SIOP Working Committee on Psychosocial Issues in Pediatric Oncology

- The personal philosophical and cultural values of the family and the hospital health care team members all influence what happens

Masera, Spinetta, Jancovic, et al, 1999

Overview of death and dying in children

- ✓ *Why is caring for children and their families difficult?*
- ✓ *What makes caring for children meaningful?*
- *How competent are oncologists in terms of end-of life care with children?*
- *What are the barriers to optimal care?*

Wolf, et al, 2005

Important Elements in Pediatric Palliative and End-of Life Care

- Developmental considerations
- Experience with cancer
- Experience with death
- Style of child's information gathering and questions about the disease
- Style of parent's response

Developmental considerations:

Understanding of Death: School age child (6-9 years):

- irreversibility of death
- focus on the physical/bio aspects of death
- alternately confront and deny their grief
- may not question or discuss death and appear to be unaffected
- may encounter strong feelings of loss, yet it is difficult for them to express these emotions

Developmental Considerations:

...on decision making

- **There is evidence that children are capable of decision making about their own palliative care**

McConnell, Frager, Levetown, 2004

Developmental Considerations:

...on decision making

- An 8 y/o boy with neuroblastoma Dx at 2.5 y/o told his mother that he was too tired to fight anymore.

"It'll be O.K., Mom. If I have to continue hurting, I would rather go to heaven".

Developmental Considerations:

...on decision making

- A 17 y/o emancipated minor with sarcoma Dx 6 months prior with a young baby was offered the option of radiation therapy for tumor shrinkage/pain control. She said:

"I'm scared because I don't want to disappoint my dad. He wants me to have radiation, but it hurts if they even move me to have the radiation. My mom tells me to do whatever I feel is best for me. I know I'm not going to make it, but it's important to my dad that I continue to fight."

Child's Experience with Cancer:
Comparison in terms of exposure

- 8 y/o w/ NB dealing w/ it since age 2 ½
- Long-term exposure to cancer and death

- 17 y/o w/ aggressive sarcoma Dx about 3-4 mo ago, requiring labor induction to commence Tx
- Shorter-term exposure to cancer and death

Child's Experience with Cancer

- generally accelerates the development of a child's maturity *but* the reverse may be true for some children, particularly those whose illness impacts cognition.

Decision Making in Pediatric Palliative Care, 2005

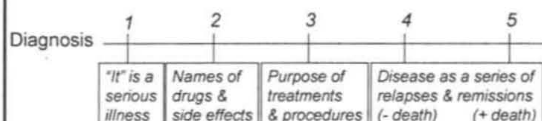
Child's Experience with Cancer

- Other manifestations:
  - regression to previous developmental stage
  - irritability

Child's Information Gathering Style

- Direct:
  - *"What is death?"*
  - *"You can talk here. I have the heart of an adult and can understand"*
- Indirect:
  - *"I've had as many relapses as he has"*
  - *"They've moved her to a room by herself, so she must be dying"*

Child's Experience with Cancer:
Facets of awareness of prognosis as a socialization process



Bluebond-Langner, 1978

Parental Response Styles:
Parental decision to talk about dying with their child

- Q: Did parents talk to their children about their imminent death?
- Q: Did they have regrets about it?
- Results:
  - Majority did not talk to their child
  - No parent who did, had regrets
  - 1/3 who did not talk to their child, regretted it

Kreicbergs, et al, NEJM, 2004

Parental Response Styles:

Parental decision to talk about dying with their child

8 y/o Child:

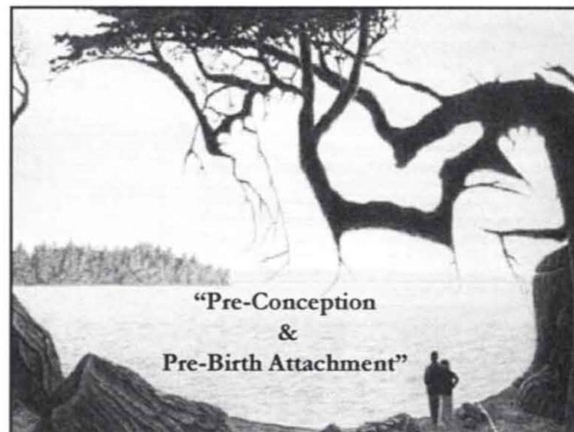
"What is death?"

Mother:

"Death is when your heart stops and the person's breath stops. But, my love, I won't call it death. I will say that you are just resting because you are in so much pain".

Selected Contributions of Family Dynamics on EOL Issues

- ✓ Decision making
- ✓ Parental "care tenor"
- Early attachment
- Family life cycle

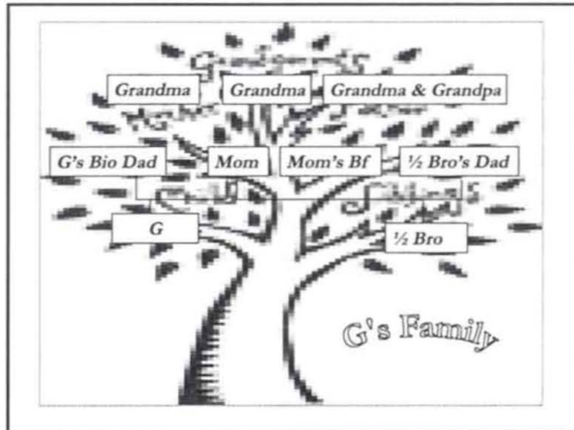


CASE PRESENTATION:

- 8 year old male with metastatic NB
- Dx 6 yrs prior
- s/p chemo, RT, surgery, BMT
- Ref for agitation towards mother
  - MSE: *psychomotor agitation, mood: "angry", affect: labile, thought processes evasive, pressured speech, hi vol, poor attention/conc, poor memory*
  - Expression of anger: *"I want to kill her"*
- PΨH: ADHD; FΨH: +

Family & Social Risk Factors

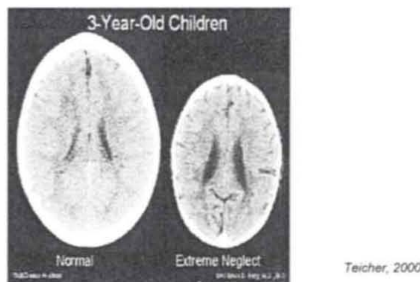
- ✓ Low income
- Overcrowding
- ✓ Maternal depression
- ✓ Paternal antisocial behavior
- ✓ Parental conflict
- Removal of child from home
- ✓ Peers, neighborhoods, & societal influences
- ✓ Reciprocal socialization between parenting & child behavior
- ✓ Conflict & inconsistent discipline



Risk Factors for Attachment Problems

- ✓abuse (physical, emotional)
- ✓maternal ambivalence toward pregnancy
- ✓sudden separation from primary caretaker (i.e.., illness or death of mother or sudden illness or hospitalization of child)
- ✓frequent moves and or placements, more…

The Effects of Abuse & Neglect on the Developing Brain during Children's First Few Years



Teicher, 2000

Differences Between G & J

- G
  - In-house behavioral plan
  - Dyadic intervention
  - Mom: *"Who will I fight with?" – "What if I cry?"*
- J
  - Exploration of potential adaptation of innovative intervention (Dignity Therapy) to pediatric cancer
  - Mom: followed his lead; read together from their books

Similarities Between G & J
EOL Issues in Pediatric Oncology

- Nausea
- Pain
- ✓ Delirium
- Constipation
- ✓ Dyspnea

Psychological Symptoms of Impending Death: Delirium

- Adult Delirium in Ca Pts APA, 2000; Breitbart, 2005
- Considerable variation: Adult vs. Childhood Delirium Stoddard & Wilens, 1995
- No reliable estimates of the incidence of delirium in children Schieveld & Leentjens, 2005

Psychological Symptoms of Impending Death: Delirium in Children

- Symptoms:
  - Psychomotor retardation / agitation
  - Anxiety
  - Difficulty getting the child's attention
  - Regression with loss of previously acquired skills
    - Dyspraxia, Dysphasia

Turkel & Tavare, 2003

Psychological Symptoms of Impending Death: Delirium in Children

- Assessment / Etiology / Differential Dx
  - Observed behavior & caretaker info
  - Infections, medications (most freq etiology)
  - Medication w/d; multiple contributing factors

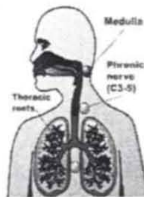
Stoddard & Wilens, 1995

- Trzepacz Delirium Rating Scale:
  - Useful in evaluating delirium in children

Turkel & Trzepacz, 2003

Psychological Symptoms of Impending Death: Pediatric Dyspnea

- Role of psycho-education
- The limits of psycho-education as a psychologist



Psychological Symptoms of Impending Death: Pediatric Dyspnea
Assessment

- Clarify the symptoms
  - *What is the child saying is happening?*
  - *What do the parents say is happening?*
  - *Check child's behavior*
  - *Is there an underlying fear?*

Psychological Symptoms of Impending Death: Pediatric Dyspnea
Assessment

- Is there a functional impairment?
  - OTHER QUESTIONS TO CONSIDER:
    - *Is the child able to perform her usual activities? Are some/most activities stopped? When did the change occur? What are the child's 'usual' activities: normal activities for the age group; short walks outside on level ground only; indoors only; still able to climb stairs; only level walking and essential ADLs; sitting or lying only?*

Pediatric Dyspnea:
Assessment

- Must frequently reassess b/c if it is a delirium, it will have a fluctuating course

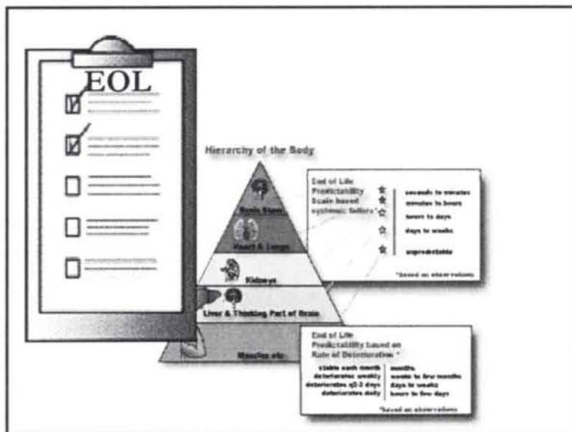
Psychological Symptoms of Impending Death: Pediatric Dyspnea

Etiology & Differential Diagnosis

- Anxiety may be:
  - a cause of dyspnea or a result

Difficult EOL Conversations

- Questions from parents:
  - *"What should I tell my child?"*
  - *"How long"*
- Questions from the child/adolescent:
  - *"Am I going to die?"*
- Other potential scenarios



Other Family Dynamics & EOL Issues

- The family's reaction:
  - *"No one cares about my child (us) anymore."*
  - *"No one tries to understand what is happening to my child (us)."*

Transitioning from Palliative Care to End Stages

- Planning "last supper"
- Making multiple recordings, drawings, advise giving
- Giving away his possessions

J's Time Capsule

"The important thing is the heart, not the outside, not if you're fat or dark. There are no ugly people. People should value themselves"

J