Broadening the Scope of Practice in Pediatric Oncology:

Considerations for Palliative and End-of Life Care Interventions

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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.

Definitions

Pediatric palliative care vs curative care vs end of life care

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

The Psychologist in the Oncology Milieu

Introduction to the Cancer Culture

Communication

Assessment & Treatment

Old model of Palliative Care

New model of Palliative Care
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%)

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

<table>
<thead>
<tr>
<th>Neurocognitive Deficits:</th>
<th>Risk Factors for Deficits:</th>
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<tbody>
<tr>
<td>Working memory, processing speed</td>
<td>ALL (CRT, Intrathecal &amp; IV MXT, Corticosteroids, Female)</td>
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<tr>
<td>Academic failure, vocational &amp; social problems</td>
<td>Brain Tumors (CRT, Tumor Invasion, Trauma inc: hot, hydrocephalus, seizures)</td>
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<tr>
<td>Female Gender</td>
<td>Young age at treatment, sensory &amp; motor impairments</td>
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Attention
IQ loss
Young age at treatment

Psychopharmacology in Pediatric Oncology

- Methylphenidate for ADHD
  Mulhem, et al. 2004 Kazak, 2005
- Midazolam for procedural anxiety, discomfort, pain
  Lerman 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
  Digen, Sprafs & Geber, 1992

Illness Trajectory and Palliative Care

Timing of understanding that there is no realistic chance for cure

- Physician 7 mo
- Diagnosis Parents 3.5 mo

adapted from Lunney, Lynn, and Hogan 2002

Risk Factors for 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
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

Adapting to the cancer culture:
*On being a temporary guest in an existing situation*

- The pre-established
  - organizational climate
  - medical turf 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
  - 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
  - Cassel, 2006

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, 2005
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

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...”

Strengthening communication & liaison work

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

  Bailer & 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

- Dx/Impression
- 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

Other Common Communication Barriers

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

Communicating empathy & trust to children

- 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
  - Psychomotor atonia: child adopts a posture that minimizes pain, or over time appears to become resigned to it

Sample of assessment option:

* Distress Thermometer

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

- Brain neoplasms
- Hypo/hyperthyroidism
- Hypercalcemia
- AIDS
- Hepatic encephalopathy
- Vitamin deficiencies
- Post-op delirium
- Opioids
- Several chemo agents
- Injuries/trauma
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 & Nesse, 1999

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

Sylvia Plath

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OVERVIEW OF PEDIATRIC PSYCHO-ONCOLOGY PALLIATIVE & END-OF-LIFE CARE:

- Broadening the Scope of Practice
- Treatment Guidelines
- Family Dynamics
- Case Presentations

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

- Practice
- Research
- Training
- Policy

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 carefree, compassionate management"

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

Mansari, 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?

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

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."

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

- 8 y/o w/ NB dealing w/ it since age 2 1/2
- 17 y/o w/ aggressive sarcoma Dx about 3-4 mo ago, requiring labor induction to commence Tx
- Long-term exposure to cancer and death
- 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.

Child’s Information Gathering Style

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

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

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

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...

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 Steedland & Wiers, 1995
- No reliable estimates of the incidence of delirium in children Schievel & Leenders, 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

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

- 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?

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?

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