Psychological Assessment of Children

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Overview

1. Brief overview of two cases we will be discussing at the end of the presentation
2. Role of psychologist and approach to assessment
3. Basics of child and adolescent psychological assessment: Methods and domains
4. Special considerations and domains for palliative care assessment
5. Psychiatric symptoms and psychosocial adjustment
6. Development of concept of death
7. Communication of important themes at end-of-life
8. Case discussion
Case synopses

Jeremy

- 6-year-old boy with a history of high risk medulloblastoma, tumor resection and radiation with recurrence 7 months following diagnosis. Now presenting with frequent seizures, nausea and vomiting and balance problems. Recently transitioned to comfort care only.

Cristina

- 14-year-old girl Latina female with a history of CF, hospitalized with pneumonia that resulted in intubation. Recently extubated and transferred out of ICU. Experiencing severe de-conditioning and is working with PT. Presents as irritable, anxious, has fear of eating/swallowing following extubation, and is oppositional regarding medical procedures.
Introduction to Psychological Assessment in Pediatric Palliative Care

• **Benefits of psychology involvement**
  – Expertise in psychiatric assessment, family systems, coping, and evidence-based behavioral health interventions
  – Different content and quality of interaction when focus is specific to support for psychosocial adjustment
  – Dedicated provider to fulfill key functions:
    – Assess emotional and cognitive status
    – Assist team in addressing underlying psychological issues
    – Provide recommendations for managing behavioral crises
    – Recommend psychiatric referral, as indicated

(Freyer, Kuperberg, Sterken, Pastyrnak, Hudson, & Richards, 2006)
Introduction to Psychological Assessment in Pediatric Palliative Care

• **Goals of psychological assessment**
  – Inform and provide direction for treatment
  – Provide information regarding psychosocial variables that could impact palliative care intervention
  – Identify patients’ and families’ strengths
  – Add depth of understanding about patient and family as a whole, including who they are outside of the hospital

• **Approach**
  – “…readily available without being intrusive.”
  – Flexible, accommodate patient and family needs by gathering most pertinent information as medical status of patient allows

(Kasl-Godley, King & Quill, 2014; Freyer, Kuperberg, Sterken, Pastyrnak, Hudson, & Richards, 2006)
Psychological Assessment in Pediatric Palliative Care

• Psychological assessment methods
  – Ideally multi-informant and mixed methods (e.g., self-report, parent-report, observation, chart review)

  • Psychiatric symptom inventories
    – e.g., Beck Depression Inventory-Youth, SCARED, Child Stress Disorders Checklist

  • Coping measures
    – e.g., Adolescent Coping Orientation for Problem Experiences, Pain Coping Questionnaire

  • Psychosocial risk and intervention needs
    – e.g., Psychosocial Assessment Tool

  • Observational measures
    – e.g., Child Adult Medical Procedure Interaction Scale
Psychological Assessment in Pediatric Palliative Care

• **Typical psych assessment domains:**
  - HPI
  - Psych history
  - Family history
  - Developmental history
    • Cognitive development, executive functioning, problem-solving
    • Regression in functioning/abilities?
  - Academic history
    • Setting, LD’s, Accommodations (IEP, 504, homebound)
  - Social-emotional history
    • Interpersonal relationships, hobbies, activities, emotion regulation
  - Other assessment considerations
    • Culture, language, SES
  - Mental Status
  - Behavioral Observations
Special considerations for palliative care assessment

*With emphasis on child’s developmental level, assess…*

- **Understanding of the disease**
  - Name, other terms
  - Treatments, interventions and why being done
  - General course, time line for treatments

- **Child/adolescent involvement in care and decision-making**
  - Appropriate and manageable degree of knowledge and shared decision-making? Flooded with information and burdened by decisions? Under-involved and completely removed from decision-making?
  - How prefer information to be delivered?
  - How do they like decisions about treatment to be made?
Special considerations for palliative care assessment

• **Pain**
  – Pain beliefs: Child and family beliefs about what contributes to pain, personal and cultural beliefs about how to “manage” pain
  – Anticipatory distress for pain
  – Parent-child interactions around pain

• **Quality of Life**
  – Child and family priorities for daily functioning
  – What represents good quality of life for this child and family?
  – What disrupts quality of life?
  – Do symptoms such as incontinence, diarrhea and dyspnea impact sense of identity?
Special considerations for palliative care assessment

• **Stress & Coping**
  
  – **Stressors**
    • Encompass objective (life events) and subjective (perceived threat)
    • Direct questioning and indirect references to changes in life
  
  – **Coping**
    • Dimensional perspective
      – Approach coping/preventive strategies more adaptive than avoidant/reactive
    • Assess:
      – Do the child and family initiate conversations about emotional distress, address fears?
      – Is the child prepared for procedures and tests with rationale for test and provided sensory information and demonstration?
Special considerations for palliative care assessment

• **Common psychiatric symptoms and psychosocial adjustment difficulties over course of disease and treatment**
  – **Anxiety** *(ask about worries or fears, intensity and frequency)*
  – **Irritability** *(ask about “crankiness”, easily annoyed by others)*
  – **Sadness, depressive mood** *(has pt been down or not willing to engage in activities he/she used to find fun/enjoyable?)*
  – **Inattention and hyperactivity** *(has pt been fidgety, restless, or has he/she had difficulty focusing and paying attention?)*
  – **Traumatic stress** *(recurrent thoughts of scary/traumatic events, avoidance of situations/people that are associated with stressful event?)*
  – **Psychosocial regression** *(is pt more “clingy”, does pt seem “younger” in terms of interests and behaviors?)*

• **Competency-based approach**
  – Psychosocial distress common and waxes and wanes, with typically trajectory of lessening over time as major events pass

(Kazak & Noll, 2015)
Special considerations for palliative care assessment

<table>
<thead>
<tr>
<th>Psych Symptom</th>
<th>Assessment Questions</th>
<th>Possible Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>Fears, worries, avoidance behaviors?</td>
<td>Gradual exposures to fear producing situation; do not reinforce reassurance seeking; worry time; relaxation skills</td>
</tr>
<tr>
<td>Irritability</td>
<td>Crankiness, emotional lability?</td>
<td>Provide outlet for emotional expression; relaxation skills; acknowledge</td>
</tr>
<tr>
<td>Sad/Depressed Mood</td>
<td>Has patient been down or not willing to engage in activities he/she used to find fun/enjoyable?</td>
<td>Behavioral activation- plan pleasant activities into pt's day; cognitive acceptance-based skills</td>
</tr>
<tr>
<td>Inattention and Hyperactivity</td>
<td>Has patient been fidgety, restless, or has he/she had difficulty focusing and paying attention?</td>
<td>Behavior charts, rewards, lists, stimulant medication</td>
</tr>
<tr>
<td>Traumatic Stress</td>
<td>Recurrent thoughts of scary/traumatic events, avoidance of situations/people that are associated with stressful event?</td>
<td>Relaxation skills; create narrative of pt's traumatic stressor and provide opportunity to share narrative</td>
</tr>
<tr>
<td>Psychosocial Regression</td>
<td>Appropriate social/interpersonal/interactions</td>
<td>Behavior charts, communication skills training, parent-management training</td>
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Special Considerations in End-of-Life Assessment

- **Infancy and toddlerhood, 0 – 2 years** - no concept of death
  - Needs: comfort, proximity to family and familiar people, surround by transitional objects, maintain consistency schedule and routines

- **Preschool, >2 – 6 years** - death perceived as sleep
  - Needs: concepts re-explained, affection and reassurance that they are loved and will not be abandoned

- **Early childhood, 5 – 9 years** - understand universality of death
  - Needs: clear language and avoidance of euphemisms, explanation with pictures and examples

- **School age, 9 – 12 years** - understand universality and irreversibility of death
  - Needs: clear and explicit language, explanation with pictures and examples, help to preserve body image/physical appearance, reassurance that they will not suffer

- **Adolescence, 12+ years** - mature, complete understanding of core concepts of death, including abstract/spiritual concepts
  - Needs: clear and explicit language, acceptance, respect, autonomy and maintaining identity, processing their life journey and having control over their legacy
Special Considerations in End-of-Life Assessment

- Do parents and family, providers and staff convey important messages to child/adolescent in a developmentally appropriate way?

  - You will not be alone at death or after death.
  - You have done all you could do with your life.
  - Death will not hurt
  - Parents and important others will always remember you and the happy times
  - You can say good-bye to friends and family if you want
  - We don’t understand why children die and we cry because we know that we’ll miss them
  - It’s okay to cry, feel sad, angry or have any other mix of feelings. It’s okay to talk about it or to not talk about it.
Case Examples - *Jeremy*

- **Reason for palliative care consultation:** goals of care discussions, symptom management and emotional support

- **HPI:** 6-year-old boy with a history of high risk medulloblastoma, tumor resection and radiation with recurrence 7 months following diagnosis. Now presenting with frequent seizures, nausea and vomiting and balance problems. Recently transitioned to comfort care only.

- **Psych hx:** behaviorally and emotionally well-adjusted; no concerns for psychiatric disorder

- **Family hx:** Mother is single parent with no contact with biological father, 4-year-old sister

- **Developmental hx:** All early motor, language, social and emotional milestones within normal limits

- **Academic hx:** Achieving academic skills on pace at time of diagnosis. No hx of LDs. Attendance had been good. Now 1st grader at neighborhood public school, combination of homebound and hospital-based school services
Case Examples - **Jeremy**

- **Social-emotional hx:** Strong attachment to mother and a female adult neighbor, interpersonally shy and slow to warm, well-liked by peers, enjoys playing and watching sports, extended time to calm when upset

- **Cultural considerations:** Lives in rural community, Caucasian, monolingual English, very limited financial resources

- **Mental status & Behavioral Observations:** Extended periods of awake states with full orientation. During those times, socially interactive with mother and familiar staff members. Seizures several times per day, lasting 10-15 minutes.

- **Understanding of disease:** Family avoids using the word “cancer” & instead describes Jeremy as “sick”; very limited understanding of reasons for medications, treatments, procedures and surgeries; not aware that disease is progressing and no longer receiving curative treatments

- **Child involvement in care:** Minimal, mother is sole decision-maker & Jeremy receives little information about care plan
Case Examples - Jeremy

- **Pain:** Headache source is “my sickness”, takes all medications for pain and discomfort without difficulty or resistance, pain best managed by rest and medication, mother provides physical affection and reassurance when Jeremy has discomfort.

- **Coping:** Family models avoidant coping, uses distraction as only coping skill and encourages Jeremy to “be tough”, does not discuss his or adults’ emotional reactions.

- **Quality of life:** Jeremy and his mother comment that Jeremy has been “miserable” since symptom burden has increased and mother made statement about “not seeing the light of her little boy any longer”. Good quality of life means laughing and playing, being alert and engaged with family members, which has been rare for Jeremy over the past several weeks.
Case Examples - *Cristina*

- **Reason for palliative care consultation:** symptom management and emotional support

- **HPI:** 14-year-old girl Latina female with a history CF, hospitalized with pneumonia that resulted in intubation. Recently extubated and transferred out of ICU. Experiencing severe de-conditioning and is working with PT. Presents as irritable, anxious, has fear of eating/swallowing following extubation, and is oppositional regarding medical procedures

- **Psych hx:** Pre-existing anxiety (“was always a worrier”), but never formally diagnosed or treated for anxiety disorder

- **Family hx:** Lives with mother, father, and 3 older siblings

- **Developmental hx:** All early motor, language, social and emotional milestones within normal limits

- **Academic hx:** 9th grader in CPS with history of academic difficulties due to frequent school absences, receives IEP services on the basis of her medical condition and specific services for reading and math
Case Examples - **Cristina**

- **Social-emotional hx:** Strong attachment to family members and a large extended family network (e.g., cousins), but has few friends.
- **Cultural considerations:** Mexican-American and Catholic family. Parents immigrated to U.S. and speak Spanish primarily. Cristina is bilingual in English and Spanish. Family lives in southwest side of Chicago and has limited financial resources.
- **Mental status & Behavioral Observations:** Irritable mood most of the day, often refuses routine medical procedures and does not put forth much effort during PT, is easily startled, and often becomes tearful.
- **Understanding of disease:** Parents and older siblings have appropriate understanding of CF and its course, but Cristina has limited understanding- parents wish to “protect” her from knowledge about her illness.
- **Child involvement in care:** Historically has had minimal involvement in care, but is starting to ask medical team more questions about the course of her illness and her treatment.
Case Examples - **Cristina**

- **Pain:** Moderate chest pain and throat pain. Has severe pain swallowing/eating and avoids meals (says “I’m not hungry”).
- **Coping:** Family models faith-based coping, but Cristina primarily engages in avoidant coping.
- **Quality of life:** Parents acknowledge that Cristina has had a difficult time during her hospitalization, but minimize her current emotional and behavioral difficulties. Cristina reports that this is “the worst I have ever felt” and says she does not know if she will ever get “back to normal.”
For discussion...

- What are the challenges with performing a psychological assessment for this patient and family?
- In which of assessment domains is this family struggling? In which are they most adaptive?
- How do we distinguish a typical/expected adjustment response from psychopathology for this patient?
- What are the developmental considerations we need to keep in mind while assessing psychiatric symptoms for this patient?
- How do we distinguish physical symptoms/side effects related to the disease and its treatment from symptoms of depression/anxiety?
- How and to what extent is the family affecting the patient’s coping and emotional distress? Either by exacerbating or facilitating coping to ameliorate distress
- What are the child’s and family’s strengths?
- What interventions are recommended?
References

