Palliative Sedation in Pediatrics

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Disclosure

• I have no relevant financial disclosures.
Objectives

Upon completion of this activity, participants will be able to:

• Discuss the justification and ethical concerns about using palliative sedation for children.
• Identify strategies for resolving these cases that can guide policy development.
1. Children die.
2. We undertreat their symptoms when dying because #1.
Suffering in Pediatrics

Medication exposure at end of life in children

n=34,456
End of life care in pediatrics

• Most children die in the hospital
• Most involve withdrawal of life sustaining treatments
• Evolving practice to give medications for pain and suffering as standard approach
Palliative Sedation

• Neonatal:

6 week old baby girl on ventilator with airway anomaly.
Palliative Sedation

• Child:
10 year old with osteosarcoma for the past 7 years, now widely metastatic.
Fig. 2. Algorithm for initiation of palliative sedation. ANH, artificial nutrition and hydration; DNAR/POLST, do not attempt resuscitation/physician orders for life-sustaining treatment.
Family distress

• High level of distress and trauma in family watching child suffering

Parents

Kahana et al. (2006), Landolt et al (2003), Fein et al. (2002)
Family Palliative Sedation survey

• Burdened by decision for sedation
• Wanted more information prior to starting sedation
• Overall positive experience
• Improved symptom control
• Hastening death worries
Provider unease/distress

• No agreement on definition
• Not many institutions have guidelines
• Worry about euthanasia
• “Doing no harm”

Table 4. Availability and Use of Palliative Sedation Procedural Guidelines.

<table>
<thead>
<tr>
<th>Does your institution have procedural guidelines in place for implementing palliative sedation? (N = 679)</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>130</td>
<td>19.1</td>
</tr>
<tr>
<td>No</td>
<td>321</td>
<td>47.3</td>
</tr>
<tr>
<td>I don’t know</td>
<td>228</td>
<td>33.6</td>
</tr>
<tr>
<td>(Skipped)</td>
<td>(152)</td>
<td>(18.3)</td>
</tr>
</tbody>
</table>

(If Yes to the above) How frequently do you, yourself, follow the procedural guidelines? (N = 129)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>1</td>
</tr>
<tr>
<td>Rarely</td>
<td>4</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12</td>
</tr>
<tr>
<td>Often</td>
<td>57</td>
</tr>
<tr>
<td>All of the time</td>
<td>55</td>
</tr>
<tr>
<td>(Not asked)</td>
<td>(549)</td>
</tr>
<tr>
<td>(Skipped)</td>
<td>(153)</td>
</tr>
</tbody>
</table>
Conscientious Objection

• Refusal to participate in care that violates deeply held beliefs
  • Abortions, Contraception

• At UK employees can petition to not participate in care that violates their cultural, ethical or religious beliefs

• Within reason, accommodations can be made on a case by case basis

• Cannot be cover for discrimination
AMA Opinions

• AMA insists that “physicians’ ethical responsibility [is] to place patients’ welfare above the physician’s own self-interest” (Opinion 1.1.1)

• AMA permits physicians to refuse to treat patients who are seeking care that is “incompatible with the physician’s deeply held personal, religious, or moral beliefs” (Opinion 1.1.2[a])

• should not “unduly burden” patients, does not apply in emergencies or to patients’ end-of-life decisions
Physicians, Not Conscripts — Conscientious Objection in Health Care
Ronit Y. Stahl, Ph.D., and Ezekiel J. Emanuel, M.D., Ph.D.
NEJM 2017

• “To invoke conscientious objection is to reject the fundamental obligation of health care”

• “The health care professional who wants to prioritize personal values over professional duties must choose a less personally fraught occupation”

• “Laws may allow it….but professional medical associations should insist that doing so is unethical”
Rebuttal

• “Medical profession used to view eugenics as acceptable and homosexuality as a disease”
• “Voices of conscientious objectors eventually influenced the field”