OVERCOMING BARRIERS TO UTILIZATION

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Introduction

- Primary goal of care for dying patients is the palliation of distressing symptoms
- Efforts to relieve uncontrolled suffering are sometimes unsuccessful
- When all routine palliative care practices fail to provide symptom control, palliative sedation may be the only viable means to prevent suffering

What is Palliative Sedation?

- Palliative Sedation
  - The controlled use of medication to cause decreased consciousness at the end-of-life for the purpose of relieving the suffering that is caused by intractable and intolerable symptoms
Causes of End-of-Life Suffering

- Physical Symptoms
  - Pain
  - Dyspnea
  - Nausea & Vomiting
  - Anxiety

- Psychological, Spiritual, & Existential Symptoms
  - Spiritual Distress
  - Social Isolation
  - Death Anxiety
  - Meaninglessness

Justification for Palliative Sedation

THE DECISION TO INITIATE PALLIATIVE SEDATION MAY ONLY BE JUSTIFIED FOLLOWING THE CONSIDERATION OF SPECIFIC ETHICAL PRINCIPLES AS WELL AS OTHER COMPLEX CLINICAL ISSUES

Barrier to Utilization of Palliative Sedation

- Lack of evidence based, standardized guidelines
Development of Guidelines

- Literature Review
- Review of ethical, end-of-life decision-making

Pain & Suffering Are Not Equivalent

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<tr>
<th>Pain</th>
<th>Suffering</th>
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<td>“an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 2010)</td>
<td>“a state of severe distress associated with events that threaten the intactness of the person as a complex physical, psychosocial, and spiritual being” (According to Cassell as cited in Herbert et al., 2007)</td>
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Sources of End-of-Life Suffering

- First step is understanding the source of distress
- Five major categories of factors (Chochinov et al., 2008)
  - Symptom Distress
  - Existential Distress
  - Dependency
  - Peace of Mind
  - Social Support
Symptom Distress

- Physically distressing symptoms
- Feelings of being depressed, anxious, and/or uncertain
- Worry about the future
- Not being able to think clearly

Existential Distress

- How their looks have changed
- No longer being who they once were
- Not being worthy or valued
- Not being able to carry out important roles
- Life no longer having meaning or purpose
- Being a burden to others

Dependency

- No longer being able to perform the tasks of daily living
- Not being able to attend to bodily functions
- Reduced privacy
### Peace of Mind

- Angst over one’s spiritual life
  - Not having made a meaningful contribution and of unfinished business
  - Concerns about spiritual life

### Social Support

- Not being supported by friends or family
- Not being supported by healthcare providers
- Perceptions about not being treated with respect

### Psycho-existential Suffering

- There is greater acceptance for the initiation of palliative sedation to control physical symptoms as opposed to psychological, spiritual, and existential symptoms
**Definitions**

- “The experience of agony and distress arising from an unbearable state of existence” which is “typically understood as a psychological or spiritual condition that robs individuals of their capacity to find solace or peace in their present state of being” (Williams, 2004)

**Definitions**

- “Psychological distress not accompanied by physical symptoms, such as a feeling of meaninglessness/worthlessness, burden on others/dependency/inability to take care of oneself, death anxiety/fear/panic, wish to control the time of death by oneself, isolation/lack of social support, and economic burden” (Morita, 2004)

**Palliative Sedation & End-of-Life Decision-Making**

- Certain crucial questions must be answered before palliative sedation can be suggested as a therapeutic treatment
### Crucial Questions

- Is the patient’s suffering severe, intolerable, and refractory?
- Is the foundation for the use of sedation based on the principles of double effect, proportionality, and autonomy?
- Is informed consent received from the patient and/or proxy decision-maker(s)?

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### Crucial Questions

- If deemed necessary, are consultations made by experts and/or specialists to assess for clinical depression and to affirm the patient’s competency and ability to make informed choices about his or her care?
- Is the terminality of the patient’s condition (a prognosis of days to weeks) confirmed by one or more health practitioners who are knowledgeable regarding the patient’s underlying disease?

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### Crucial Questions

- Is a Do Not Resuscitate (“DNR”) order in place?
- Are concerns regarding the nutrition and hydration of the patient addressed?
- Is there participation in the decision-making process by an interdisciplinary team of professionals who are immediately involved in the care of the patient?
Refractoriness of Suffering

- Refractory symptoms are symptoms that are not effectively controlled
  - Routine treatments
  - Tolerable treatments
  - Without decreased consciousness

Differentiating Difficult from Refractory Symptoms

- Difficult Symptoms
  - Symptoms that can be relieved, within an acceptable period of time, through the use of noninvasive and/or invasive interventions and that do not result in diminished consciousness or undesirable effects

Refractory vs. Difficult Symptoms

- Recurrent assessment
- Objective and subjective criteria
- Specialty consultations
- Collaborative, multidisciplinary approach
Algorithm for Identifying Refractory Symptoms

Ethical Principles

- Double Effect
- Proportionality
- Autonomy

Double Effect

- Central to the intent of treatment

“A harmful effect of treatment, even resulting in death, is permissible if it is not intended and occurs as a side effect of the beneficial action” (According to Arntzen as cited in Sykes & Thorns, 2003)

- Distinction between ability to predict and intent
- Also applies to decreased consciousness
Double Effect & Palliative Sedation

- Potential to hasten death
- Not the primary goal

Proportionality

- Proportional reasons for initiation of treatment
- Balance between the harmful and beneficial effects of a treatment

Proportionality & Palliative Sedation

- Implies that the intolerability and refractoriness of suffering at the end-of-life substantially outweigh the risks of potentially harmful outcomes of hastened death and decreased consciousness
Autonomy

- Denotes respect for patients’ and/or families’ wishes

Autonomy & Palliative Sedation

- Sufficient information for informed consent
- Should involve the patient’s wishes
- Understand the patient’s goals for care
  - Three categories of goals: “(a) prolonging survival, (b) optimizing comfort, and (c) optimizing function” with recognition that the second goal of comfort is the primary goal for care (Cherny & Portenoy, 1994)

Informed Consent & Palliative Sedation

- Repeated discussions
  - Clarification of goals and options
- Involvement of interdisciplinary representatives
  - Explore end-of-life issues and concerns
  - Ensure questions are answered
Recommendations

PALLIATIVE SEDATION IS A TENABLE OPTION FOR PROVIDING RELIEF OF SEVERE AND INTRACTABLE SUFFERING AT THE END-OF-LIFE

THE DISMISSAL OF PALLIATIVE SEDATION AS A POSSIBLE MEANS FOR ACHIEVING PALLIATION OF SYMPTOMS AT THE END-OF-LIFE IS UNJUSTIFIED

Critical Pathway

Requirements

- Suffering
- Ethical Principles
- Informed Consent
- Consultations
- Confirm Prognosis
- "DNR" Order
- Nutrition & Hydration Concerns

Questions?

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