Palliative sedation: What is it & what is my role as a hospice social worker?

SWHPN General Assembly 2018
N. Rose Gaston, MSW, LGSW
Jill M. Randall, MSW, LICSW
“Beyond the lived experience of the patient, a decision to sedate influences the bereavement process and the legacy of the death as it is woven into the fabric of a family history.”

- Terry Altilio

Handbook of Palliative Care Social Work
Objectives

- Define palliative sedation (PS) and describe the accompanying ethical and psychosocial issues
- Describe the hospice social work role within the context of PS
- Name components specific to psychosocial assessment in PS
- Discuss experiences around the social work role and assessment with patients utilizing PS
What’s in a name?

Palliative sedation

- Continuous deep sedation
- Slow euthanasia
- Palliative sedation therapy
- Sedation at end of life
- Terminal sedation

Papavasiliou (2013)
Terminology and Definitions

- No term or definition has gained universal acceptance
- Terms may have different meanings but are often used as synonyms
- Lack of clarity:
  - reflects the complexity of the practice
  - leads to confusion in communication that may impact practice
  - is problematic for comparing and interpreting research studies
- Does the inconsistency in the terminology and definitions of PS reflect potential inconsistency and confusion in the practice of PS?

(Papavasiliou, 2013)
Palliative sedation is “the administration of nonopioid drugs to sedate a terminally ill patient to unconsciousness as an intervention of last resort to treat severe, refractory pain or other clinical symptoms that have not been relieved by aggressive, symptom-specific palliation,”

(National Ethics Committee Veteran Health Administration, 2006, p. 3)
Palliative Sedation is NOT:

- Euthanasia
  - When a doctor injects a patient with a lethal injection to end their life and relieve suffering and pain.
    - Voluntary: patients request
    - Nonvoluntary: patient does not possess the cognitive ability to make such decisions, therefore the decision is made by the doctor with or without the consent of family (Cohen et al., 2005)

- Physician aid in dying
  - “the process that allows terminally ill adults to request from their physician, receive from the pharmacist, and take a lethal dose of medication to end their life” (Death with Dignity, n.d.).

- Unintended and variable sedative side-effects of medications (VHA, 2006)
The Legal Side

- In 1997, the Supreme Court in *Washington v. Glucksberg* and *Vacco v. Quill* unanimously affirmed that “a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death” (*Vacco v. Quill*, S. Ct. 2293 U.S. 1997).

- While palliative sedation is not specifically referenced, this ruling gives strong support to aggressive symptom management, even to the point of rendering someone unconscious, at end of life.
Types of sedation

- Respite sedation: “transient use of sedation to relieve severe symptoms that are not necessarily refractory, to provide adequate relief before continuing with further trial of non-sedating palliative approaches” (Cherny, 2014)

- Intermittent sedation: a temporary sedation where the patient regains consciousness, a “time out” from symptoms, and gives the opportunity to assess if symptoms are permanently refractory (Royal Dutch Medical Association, 2009)
  
  - 30-67% of cases (Claessens et al., 2008)

- Continuous deep sedation: “continuous use of sedative medications to relieve intolerable and refractory distress by achieving almost of complete unconsciousness until death” (Morita, 2004)
  
  - 14-69% of cases (Claessens et al., 2008)
  
  - “Continuous deep sedation should only be considered if the patient is in the very terminal stages of their illness with an expected prognosis of hours or days at most” (Cherny & Radbruch, 2009, p. 584)

- Emergency sedation: “use of sedation to provide urgent relief of overwhelming symptoms in dying patients” (Cherny, 2014)
Prevalence

3.1-51%
- Systematic review of 33 research papers and one thesis
- Range of settings and countries
- (Claessens et al., 2008)

5-36%
- Systematic review of 6 research papers
- Homecare setting
- (Marcadante et al., 2011)

22%
- Inpatient hospice in Germany
- (Jaspers, et al., 2012)

Range reflects the incongruity of definition, setting, and practice
Intolerable Suffering

When a patient perceives suffering (physical, psychosocial, spiritual, temporal, and/or existential) as unbearable the medical team must assess the degree of suffering. If the patient is unable to speak, the medical team must collaborate with family or proxy to determine if patient would believe level of suffering is indeed intolerable. (Kirk & Mohan, 2010)

Refractory symptoms: “a symptom that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness.”

The clinician must believe that further treatments are:

- Unable to provide adequate relief
- “Associated with excessive and intolerable acute of chronic morbidity”
- Unlikely to provide adequate relief within an acceptable amount of time

Prevalence of refractory symptoms necessitating sedation ranges 10-50% (Cherny, 2014)
Physical Suffering

Most common symptoms during the last four days of life

- Delirium and agitation 13.8-68%
- Dyspnea 10-50%
- Pain 2.5-25%
- Others listed: fatigue, agitation, physical restlessness, insomnia, and nausea/vomiting

Medications used

- Most common drug used: Midazolam
- Alternatives: levomepromazine, chlorpromazine, phenobarbital, and propofol
- Others used alone or in combination: haloperidol, phenobarbital, and opioid

(Claessens, et al., 2008; Engstrom, et al., 2007)

(Cherny, 2014; Claessens, et al., 2008)
Existential Suffering

“suffering that arises from a loss or interruption of meaning, purpose, or hope in life... often used to connote suffering that is not physical in etiology... suffering arising from a sense of meaninglessness, hopelessness, fear, and regret in patients who knowingly approach the end of life.”

(Kirk & Mohan, 2010)

- 27% of studies reviewed mentioned psychoexistential suffering besides physical as the reason for sedation, but only true for a small amount of patients
  - Most frequently mentioned: anxiety, mental anguish, and psychoexistential suffering with no elaboration (Claessens et al., 2008)

- In Japan, patients received PS for feeling meaningless (61%), being a burden on others/dependency (48%), death anxiety (33%), wishing to control death (24%), isolation (22%), and economic burden (8.7%) (Morita, 2004)

- In Belgium and London, studies suggest that PS is being used more often to treat psychoexistential suffering than physical. (Claessens et al., 2008)
PS & existential suffering in the USA

“As with any other type of suffering, NHPCO believes that hospice and palliative care professionals have an ethical obligation to respond to existential suffering using the knowledge, tools, and expertise of the interdisciplinary team. Whether palliative sedation should be a part of that response is an important, growing, and unresolved question. Having carefully reviewed the data and arguments for and against using palliative sedation for existential suffering, the Ethics Committee is unable to reach agreement on a recommendation regarding this practice.”

National Hospice and Palliative Care Organization Position Statement, 2010

- “NASW does not take a position concerning the morality of end-of-life decisions, but affirms the right of the individual to determine the level of his or her care.” (NASW, 2004, p. 16).
- Hospice & Palliative Care Federation of Massachusetts has guidelines while not formally endorsing
- Veteran Health Administration and the American Medical Association do not support
Using PS to treat existential suffering: The debate

Distinguish from psychological distress

- No agreed upon definition of existential suffering
- Difficult to distinguish if distress is a normal reaction to impending death and ambiguous losses
- Difficult to determine refractoriness

Principle of proportionality

- Is the goal of relieving severe, refractory existential suffering sufficiently grace or “proportionate” to justify sedating the patient into unconsciousness for their remaining time?

The goals of medicine

- Is a pharmacological intervention appropriate for non-medical suffering?
- Is it within the scope of a medical provider?

(Cherny, 2014; Veterans Health Association, 2006)
Ethical Principles

- **Beneficence** - promote well-being
- **Nonmaleficence** - do no harm
- **Autonomy** - the right to self-determination (culturally bound)
- **Informed Consent** - the patient has the right to full information of the risks, benefits, and potential consequences of accepting or declining PS
- **Double Effect** - considers the distinction between an intended, direct effect and an unintended, foreseen, but indirect effect
- **Proportionality** - Does the expected benefit of the intervention outweigh the risks?
Ethical Considerations

- “Loss of social selfhood” (Park & Ford, 2005) due to palliative sedation is fundamentally different than the loss due to natural disease progression.

- PS entails physical, psychosocial, spiritual, and moral considerations. The decision making process and administration of PS must therefore involve all disciplines on the hospice team.

- Offer to sedate must not reflect the inadequate training of the team. Each team member needs to be skilled in this area and recognize their own emotions and how they may be clouding clinical judgement (Altilio, 2011)

- When is a symptom truly refractory?
Ethical Considerations, continued

- Can PS be provided to patients who lack decision-making capacity?
  - Due to the seriousness of the intervention, some argue that patients must be able to consent
  - But limiting it to those with decision-making capacity excludes patients who are otherwise appropriate
  - Surrogates make other treatment decisions and PS should not be viewed differently than those

- Does PS hasten death?
  - No evidence that it does
  - Mean survival after the onset of PS ranged from 1-6 days and there was no difference in survival time between sedated and non-sedated patients (Claessens et al., 2008)
  - Even when morphine was medication utilized (Daly et al., 1996)
## Perception of PS

- 67% of families were satisfied with the treatment and 90% agreed that PS was the best option.
- Families believed that PS was dignified and that there was meaning to be found in the process.

## Distress

- 25% experienced high levels of emotional distress determined by high levels of persistent distress in patients after PS, insufficient information, fear of shortening the patient’s life, staff lacking compassion, and lack of discussion with patients.
- 30% perceived the decision making process as a burden.

## Needs

- To be certain there was no other treatment option.
- Education on the aim for PS, what to expect, and symptom management.
- Time to say goodbye to the patient before sedation.
- To feel that sedation patients get same dignified care as nonsedated.
- Ongoing emotional support from IDT.

(Chiu et al., 2001; Morita et al., 2004; Morita et al., 2004; van Dooren et al., 2009)
Role of a Hospice Social Worker

“Social workers are essential participants as we assess; listen for exhaustion in our patients, families, and colleagues; explore the meaning for the decisions for patients and families; and monitor the outcome, not only for the death experience itself but for the future integration of that experience in the legacy of the family, the team, and the professionals who participate”

(Altilio, 2011, p. 668)
Self Evaluation

- Be aware of our own beliefs, values, and feelings towards PS (NASW, 2004)
- It takes more than knowledge and skills to become a competent social worker; one must also have keen self-awareness and continually assess how their own values and attitudes impact their practice (Gwyther et al, 2005).
Patient & support system prior to sedation

- Goals of care conversations & the decision making process
  - Health care directive
    - Those who do not have DNR order are not appropriate for PS (Veterans Health Administration, 2006)
    - Artificial hydration and nutrition
  - Understand the values, beliefs and goals of patient and support system while also taking into consideration cultural influences
  - Provide separate spaces for patient and their support system to ask questions and express concerns
  - Encourage support system to express thoughts and feelings and ask questions while observing and responding to verbal and nonverbal communication
  - Encourage loved ones to be with patient, facilitate legacy building before patient becomes unconscious, and give an opportunity to say goodbye
  - Reminded and reassured that all other means were tried or considered ineffective and that sedation will not shorten their life
  - Keep support system informed of what to expect

(Altilio, 2011; Cherny, 2014; Higgins & Altilio, 2007)
Patient & support system during sedation

The social worker “was the clinical responsible to reach out to each family member to listen carefully and respond to any thoughts or worries that the intent of sedation was to shorten patients life and to reinforce the medical, ethical, and spiritual parameters that guided each of these decisions... minimize any feelings of abandonment... listen and responded to the complex feelings that often accompany end-of-life decisions such as regret, anger, guilt, or relief.” (Altilio, 2011, p. 667).

- Keep support system updated on patients well being
- Give advice on ways loved ones can help or be with patient (talking, touching, and providing cares)
- Adjusting aspects of patient environment (bed, lighting, music, smells, etc)
- Hold a vigil

(Altilio, 2011; Cherny, 2014; Higgins & Altilio, 2007)
Patient’s support system after death

- PS influences bereavement process and legacy of death
  - Was everything done that could have been?
  - Do they feel robbed of quality time with patient?
- Family should be given an opportunity to meet with members of the care team to give them an opportunity to express grief and any concerns
- Provide bereavement support

(Altilio, 2011; Cherny, 2014; Higgins & Altilio, 2007)
Supporting Staff

- All staff need to understand the rationale for PS and patient’s goals of care (before, during, and after) (Cherny, 2014)

- Working with interdisciplinary team reduces emotional burden for medical providers (Hospice & Palliative Nurses Association, 2016)
  - 24% of medical providers (MD, nurses, and nursing assistants) experienced moral or psychological stress when using PS (Serresse et al., 2015)

- Debriefing - process professional and emotional issues related to this decision
  - What is a good death? When is a particular mode of treatment still beneficial and how long should it be continued? What can be done to alleviate the suffering of the patient and his family? What are the patient’s remaining wishes and options regarding any unfinished business in his life and how can the patient and his family take leave of each other? What sources of inspiration are available in this respect? What norms and values are driving the patient, his family and us as professionals? How can we explicitly and implicitly recognize the patient as a unique individual, so that he and his family will feel safe and supported? (Royal Dutch Medical Association, 2009)
Within our Agencies

Policies

• All hospice and palliative care organizations need clear policies and guidelines on the use of PS
• IDT involvement
• Advocating for social work involvement - HPNA (while encouraging consultation with IDT and other end of life professionals) states that the required professionals are MD, bedside RN, advanced practice RN, and pharmacist

Education

• Education on PS should be mandatory for any provider who cares for the terminally ill
• Symptom assessment and management, review evidence-based protocols for inducing sedation, and discuss the ethical considerations of the process and the procedure
• Family centered care
• Differences between palliative sedation, physician-assisted death, and euthanasia

(Awadi & Maryam, 2016; Kirk & Mohan, 2010)
“While acknowledging that specific best practices have not been rigorously developed, procedural guidelines at the institutional level are necessary for clinicians to have a framework for decision making and implementation. This promotes and protects the interests of patients, their families, and the health-care providers administering care. Sound procedural guidelines such as checklist can reduce the risk of adverse outcomes in medicine.” (Cherny, 2014, iii50)
Checklist for Hospice Social Workers when a patient is sedated at the end of life

▶ Can the patient make the informed decision choosing PS? What does their health care directive say?
▶ Is family involved in decision making process? Have discussions been held with patient and family separately to ensure all questions and concerns are addressed?
▶ What are the patient’s and families’ beliefs and values about consciousness? What are their spiritual, cultural, and philosophical influences?
▶ What are family/friends concerns? Burdens? Expressed emotions? Grief experience?
  ▶ How will sedation impact the family's process as they integrate the patient's death?
  ▶ Will they feel robbed of precious time or at peace that the patient's comfort was assured at end of life?
▶ How will the IDT collaborate to avoid duplication and confusion for the patient, staff, and family?
  ▶ Which clinicians should lead discussions with patients and families to ensure they receive the best information and do not feel abandoned?
▶ What care can family provide and where do they need help?
▶ Has patient’s support system had a chance to say goodbye?

(Altilio, 2011; Cherny, 2014; Higgins & Altilio, 2007; Royal Dutch Medical Association, 2009)
Thank you!

Contact information
N. Rose Gaston
Rosie_016@hotmail.com

Jill M. Randall
Jill.Randall@louisville.edu
References


References, continued


References, continued


References, continued


