

Palliative Sedation for Intractable Existential Distress...

What's All The Fuss?

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By any other name

- Terminal sedation
- CUS (continuous sedation to the point of unconsciousness)
- PPS (proportionate palliative sedation)
- PUS (palliative sedation to the point of unconsciousness)
- RS (respite sedation)

Working definition

- “The use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness”

Morita, et al

What are Refractory Symptoms?

- Aggressive palliative treatments have failed or caused intolerable side effects
- Additional treatments are unlikely to bring relief and/or
- The patient is likely to die before a treatment could work
- Pain, dyspnea, delirium, N&V, agitation, seizure, nonphysical symptoms

Nonphysical symptoms

- A survey of palliative care experts reported in 1998 that 34% of their patients received palliative sedation before their death yet less than 1/3 of all hospices in the US consider existential distress to ever qualify as “refractory” or intolerable
- Therein lies the “rub”

What is Existential Distress?

- Distress caused by a completely unacceptable way that one finds themselves in the world
- It is discovered in a patient by much the same way pain is....by dialogue, by description, by what relieves it, by what makes it worse. And most importantly by the patient's expressed experience of it
- Like pain, there is no blood test to attest to its existence

Who Experiences Existential Distress?

- Many terminally ill patients at some point in their illness
- Patients with body image distortions (H&N cancer, loss of body parts)
- Patients with poor support systems
- Baby-boomers?

Palliative Sedation

- Estimates range from 5-52% of patients have intractable symptoms
- 15-30% of all receive palliative sedation
- It has been estimated that the majority of patients with refractory existential distress do not receive adequate sedation at the end of life.

WHY?

- The ethical principles of autonomy, beneficence, nonmaleficence, and justice are not applied because of
 - Psychiatric concerns
 - Religious tenets
 - Social constructs
 - Fear of family retribution (litigation)

Obligation to Relieve

- No obligation to kill
- Each case should be “airtight” with respect to critical issues
 - The distress is indeed refractory (all methods to address it are attempted & documented)
 - Primary intent is to relieve distress
 - The patient & family agree and understand the protocols to be used
 - Separate plan for nutrition & hydration is made
 - Discuss option for respite sedation?

Time to Ponder.....

- Ought we not stand by our patients right up until the end?
- How can we be there for patients with intractable existential suffering when it may be “way into” our personal comfort zone to sedate them?
- Shouldn't we, when asked by patients with intractable existential distress, become our most ultimate compassionate selves?