



Relieving suffering

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There is a kind of void that fills my soul whenever I think about the concept of continuous palliative sedation. That void is not the result of a lack of technical or theoretical knowledge, or the feeling of facing new situations, which medical students must grow accustomed to daily over the course of their educational journey. Neither is this void a sense of unease brought on by being confronted with death in general or patients at the end of life. Instead, it arises out of a profound sense of the unknown, an existential darkness that manifests upon encountering a concept so counter-intuitive to the human mind.

I found myself grappling with the idea of what palliative sedation means for human beings, to the point of not being able to sleep the following night. I tried to understand why such an impenetrable fog kept enshrouding this idea, why such an incomprehensible noise seemed to emanate from this concept.

I imagined myself in the patient's place. I imagined myself holding the orange form in my trembling hands and reading the heading, "Continuous Palliative Sedation Consent Form." I imagined myself in their shoes, asking myself "What did I do to deserve this?" and "How is it possible to have so easily taken life for granted?" I imagined myself watching the melancholy narrative of an incurable disease unraveling so quickly before my eyes without even having the time to fully process the reality of it. I saw my life in fast forward, confronted with the sheer magnitude of the disease and the feelings of helplessness it could incite within a person. This disease that will only continue to take hold faster and faster. I thought about how time would stand still the moment I realized they were offering this morbid form to me. The world would stand still.

Questions without answers

How are human beings supposed to react when faced with the imminent loss of their own existence? How are they supposed to react when faced with an urgent decision that goes against their very nature, weighing unimaginable suffering against the immeasurable strength of a survival instinct responsible for sustaining nearly 8 billion human lives on this planet?

None of these questions have answers. And there is no "one size fits all" response. This unease perhaps comes from my own propensity to want to understand everything, research everything, control everything. Extremely useful qualities in a physician treating curable diseases, but

totally ineffectual when faced with the imminent death of a patient at the end of life. This unease perhaps also comes from the desire to rationalize and intellectualize concepts that cannot be made to make sense through numbers and scientific facts.

Helplessness

Helplessness is the feeling that has dominated or, rather, haunted my thoughts during the final days of caring for patients at the end of life. First, the helplessness felt when faced with their suffering. The physical pain, but even more so the psychological pain experienced by the patients in my care is unimaginable. Something profound is awakened within each of us when faced with such suffering in fellow human beings. Something intolerable emanates from the cries of pain, wheezing, and eyes full of despair. The helplessness felt when faced with a living being who is experiencing so much pain that the idea of a deep sleep seems like a slightly more acceptable way to live than being aware of one's own existence.

Gratitude

The gratitude that, in the most difficult moments of their remaining existence, these patients have allowed me—a young, awkward trainee—to help them and share their final yet exceedingly precious moments. Gratitude for their openness and the ease with which they express their feelings of joy and distress to me, but especially the invaluable learning and wisdom they impart to me through their lived experiences. The gratitude of knowing that somewhere within our health care system are measures for easing suffering, such as a deep sleep that allows us to better tolerate the arduous of disease until we are overcome.

Anger

There is something that incites anger in me when it comes to the concept of continuous palliative sedation. Maybe that anger is a defense mechanism against its irreversible nature. Despite that it does not cause death—a concept that I can instantly rationalize—death still has something in common with the invitingly deep sleep of palliative sedation. This fog. This existential fog. Is the desire for death not reserved for those with major depression standing before the mesmerizing abyss of suicide? Do patients with other diseases have the right to want to end their suffering?

Patients under palliative sedation are comfortable; we are told that they do not feel pain. But do they dream? Do they hear the voices of their loved ones telling them that they love them? Are they still with us? Or are they among the dead? Will they be aware of their own death when the time comes?

What about their families, their friends? How do they accept the loss of their loved ones before death actually comes? How are they supposed to accept that the already too-short time they have left to look back on the love and memories shared has been shortened further still? How do we accept our role in assisting a process that is in direct opposition to the very essence of life and human nature, and for which we could never prepare?

Many more questions

I feel helpless and angry, but above all I feel eternally grateful for and sometimes even uncomfortable with the important role these patients have allowed me to play in their lives. I am grateful for the immense life experience and knowledge I will have gained from my short time in a palliative care home, but I must admit that I will be leaving with many more questions than I arrived with. 

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Competing interests

None declared

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