PALLIATIVE CARE CASE OF THE MONTH

"Voluntary Stopping of Eating and Drinking"
by
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Case: PF was a 70-year-old woman with metastatic melanoma with abdominal carcinomatosis. She was followed closely by the palliative care outpatient and inpatient teams. In conversation with the outpatient palliative care team, she shared an understanding that her cancer was progressing and that while she was hopeful to enroll in a clinical trial, if there were no further treatment options for her cancer, she planned to move to Hawaii and complete the process for physician aid in dying. She hoped to maintain as much functional and cognitive independence as possible and avoid experiencing life while being dependent on others. She shared this plan with her oncology team and asked them to apprise her when there were not any further treatment options available so she could change course. As her cancer progressed, she developed a small bowel obstruction and was hospitalized. During that admission, she acknowledged both that she was not a candidate for clinical trial and that she was too weak to fly to Hawaii for physician aid in dying. Given she was adamant in not prolonging the dying process, she shared that she intended to voluntarily stop eating and drinking.

Background: As awareness of and access to medical aid in dying (MAID) grows in American culture, an increasing number of patients contemplate this option. For clinicians who practice in a state in which MAID in not legal and care for patients who are unable to either functionally or financially travel to a different state, it is imperative to understand the legal, ethical and practical implications of alternative options. While both palliative sedation and voluntary stopping of eating and drinking (VSED) are alternatives to MAID, this case focuses on VSED.

Voluntary Stopping of Eating and Drinking (VSED)
Definition: VSED is an action initiated by a patient with decision-making capacity to hasten death in the setting terminal illness. A patient may choose this option to avoid physical symptoms refractory to optimal palliative interventions or a prolonged dying process.

Ethics: While some view VSED as suicide, others view it as a choice to forgo life-sustaining therapy (1). VSED assessments should include thorough evaluation and management of physical symptoms, mood and coping as well as spiritual well-being. Appropriate referrals and interventions should occur prior to pursuing VSED. Of note, the ethical considerations involved in VSED increase as a patient's prognosis lengthens. Additionally, there are informed consent considerations that are specific to VSED. Along with being able to share an understanding of the diagnosis and prognosis without VSED and to show consistency over time in choosing to pursue VSED, patients should be able to describe the potential physical challenges associated with VSED including thirst/dry mouth and an understanding of the social and emotional challenges of VSED for themselves and their surrogates.

Logistics: Clinicians should discuss with patients and their surrogates where VSED will occur and who will provide caregiving for the patient in this period. It is important to confirm that staff at the decided location are willing to support a patient who intends to pursue VSED. Guidelines have been developed to support nursing facility staff in caring for such patients (2). It can be helpful to plan with the patient and caregivers, what to do in the event that the patient becomes delirious (loses decision making capacity) and requests food/nutrition. The care location should be stocked with required supplies including mist humidifier, mouth lubricant, eye drops, small spray bottle, and mouth swabs (3).

Symptom management: Common symptoms experienced with VSED include dry mouth, constipation, hunger, medication side effects, muscle soreness, fatigue/weakness, and confusion/agitation. To manage dry mouth, humidified air, meticulous mouth care with brushing teeth/gums/tongue, and topical treatment with moistened sponges or artificial saliva are helpful. Small amounts of water from sips or ice chips can prolong the dying process and should be avoided in patients committed to VSED. Anticipatory guidance that the sensation of hunger usually fades after the first few days and providing distractions from usual mealtime routines can be helpful in managing hunger (3).

Back to the case: Given that PF's wishes had been consistent over time and she did not have untreated physical or mood symptoms, arrangements were made to support VSED at an inpatient hospice unit. PF's surrogate decision maker supported her wishes and remained committed to the plan as PF became delirious in the hospital. While it is unclear if PF's choice of VSED impacted her prognosis given her underlying metastatic malignancy and bowel obstruction, the patient and her surrogate voiced appreciation to have this control at the end of her life. She was transferred to the inpatient hospice unit and died several days later.

Personal details in the case published have been altered to protect patient privacy.
For palliative care consultations please contact the Supportive and Palliative Care *programs at PUH/MUH, 412-647-7243, pager # 8511, Shadyside, 412-647-7243, pager # 8513, Perioperative/ Trauma Pain, 412-647-7243, pager # 7246, UPCI Cancer Pain Service, pager 412-644-1724, Magee Women's Hospital, pager 412-647-7243 pager # 8510, VA Palliative Care Program, 412-688-6178, pager # 296. Hillman Outpatient: 412-692-4724. For ethics consultations at UPMC Presbyterian-Montefiore and Children's pager 412-456-1518*
With comments about "Case of the Month" call Dr. Robert Arnold at (412) 692-4834.

References:

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