

## CLINICAL VIGNETTE

---

# An Unforeseen, Prolonged End of Life

---

Shannon Bell, DO and Shelley J. Choi, MD

### *Case Description*

A 67-year-old female with progressive multiple sclerosis (MS) presented with altered level of consciousness and increased stiffness in her extremities. Her MS was complicated by right hemiparesis, neurogenic bladder with recurrent urinary tract infections, seizure disorder, dysphagia with gastrostomy-jejunostomy (GJ) tube and tracheostomy. She was found to have acute hypoxic respiratory failure and septic shock due to a presumed aspiration event from her GJ tube being clogged. Due to her progressively worsening hypoxic respiratory failure and tracheostomy cuff leak, she underwent intubation with endotracheal tube placement and she was admitted to the Intensive Care Unit for further management.

Prior to this admission, the patient had two additional hospitalizations due to sepsis within the past six months. According to the patient's husband, although she was bedbound and dependent on others for most of her activities of daily living, she was verbal and able to meaningfully interact with her family. She was able to breathe spontaneously via her tracheostomy which had been placed for pulmonary clearance.

The Palliative Care team was consulted to assist in clarifying the patient's goals of care and to provide caregiver support. Overall, the patient's husband demonstrated good prognostic awareness and was mindful of the patient's values and goals in the setting of living with a chronic medical illness. Given the patient's recurrent hospitalizations and overall poor prognosis without the potential for meaningful recovery, the patient's husband believed that the patient would consider her current quality of life to be unacceptable. The decision was made to transition to comfort-focused end-of-life care and the patient underwent palliative extubation. All artificial life-prolonging measures such as artificial nutrition and supplemental hydration were discontinued.

Due to the severity of her respiratory failure with ventilator dependence and reduced level of consciousness, a prognosis of hours to short days was communicated to the patient's family. As time progressed, however, the patient's respiratory status and vital signs stabilized and it became clear that her end of life would be more prolonged than anticipated.

The patient spent another month on comfort care before her death in the hospital. During this dying phase, she received comprehensive end-of-life symptom management. The Palliative Care interdisciplinary team closely followed to provide

ongoing emotional support for the husband who was caring for the patient at the bedside daily. Witnessing each step of the patient's dying process, the husband shared how this unexpected, prolonged course caused anxiety, exhaustion, and complicated grief while allowing him the gift of time with the patient. The Palliative Care team engaged in several discussions with the patient's husband during the month the patient was on comfort care. The topics addressed included the uncertainty of the dying process and timeline, the decisions leading up to the transition to comfort care, and any potential suffering the patient may have endured during her prolonged end of life.

### *Discussion*

As physicians, we use a patient's diagnosis, clinical course, medical data, physical examination, and symptom assessment to make the best predication of a patient's prognosis. Despite our best efforts, however, at times we either over- or underestimate prognosis. Studies show that doctors, on average, overestimate survival time by a factor of 5.3 and additional studies demonstrated that the longer the relationship between a physician and patient, the worse the accuracy in prognosticating.<sup>1</sup> But what happens when we underestimate survival time, especially in a patient who is at the end of life? What happens when our expectation of a swift passing is inaccurate and we are left to support a patient, family, and medical providers during a prolonged dying process?

There are few targeted studies with limited data addressing this topic. As palliative care physicians, we frequently encounter complex end-of-life situations where an unexpectedly prolonged dying process leads to profound anticipatory grief based on loss of control, fear, anxiety about the unknown nature of death, and guilt surrounding the decision to transition to comfort care among patients, families, and medical providers.

The following are considerations that guide our end-of-life care in patients with unforeseen prolonged dying processes:

1. Reframing the expectations of family members related to the dying process and normalizing the stress originating from the unknown nature of death.<sup>2</sup>
2. Managing a family's complex anticipatory grief as they reflect on their decision to make the transition in patient's goals of care and treatment focus.<sup>3,4</sup>

3. Supporting families in their desire to be present at the bedside throughout their loved one's end of life, but also recommending the importance of self-care to minimize caregiver burn out.
4. Managing various complex symptoms as the patient progresses through the dying process.
5. Exploring and discussing matters related to lack of nutrition and concerns related to potential suffering from starvation at the end of life.
6. Minimizing artificial fluid intake via intravenous route to prevent fluid overload leading to painful symptoms and to avoid potential artificial prolongation of life.
7. Responding professionally and empathetically to the patient or family's request to hasten the dying process.<sup>5,6</sup>
8. Re-evaluating a patient's prognosis regularly and clearly communicating new prognostic information to the family.
9. Identifying the family's communication preference given anticipated emotional distress related to the process.
10. Developing routine and standardized patient care to minimize family or friend distress related to lack of control or the unknown.<sup>7</sup> Standardization might include familiar RN staffing, set times for rounding on the patient and for when we call the family, routine basic care and medication administration, and daily detailed updates for loved ones.
11. Communicating a consistent and unified plan-of-care to all care team members and to the family.

Further consideration is also needed in supporting the medical providers and staff who are providing ongoing care for both the patient and family. Palliative Care's interdisciplinary team support for anticipatory grief and emotional and spiritual wellness is an important key in high quality end of life care.<sup>8,9</sup>

### Conclusion

There is substantial need for additional research on this topic, which could allow medical providers to properly prepare patients and their families for this experience as well as reflect on their own communication and management strategies to best optimize patient and family support. There is potential for pre-bereavement support that would include targeted materials and management for distress related to this unique experience. As further investigation and research is done on prolonged end of life, we may be able to better standardize our approach to prognosticating as well as our accuracy. Ultimately, being able to prepare for a prognosis that includes active management of a patient at end of life, for potentially several weeks, will improve our care for our dying patients and for those families that we hold space for as they face the loss of a loved one.

### REFERENCES

1. **Christakis NA, Lamont EB.** Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ.* 2000 Feb 19;320(7233):469-72. doi: 10.1136/bmj.320.7233.469. PMID: 10678857; PMCID: PMC27288.

2. **Mélin M, Amieva H, Frasca M, Ouvrard C, Berger V, Hoarau H, Roumiguère C, Paternostre B, Stadelmaier N, Raoux N, Bergua V, Burucoa B.** Support practices by an interdisciplinary team in a palliative-care unit for relatives of patients in agonal phase. *BMC Palliat Care.* 2020 Nov 19;19(1):173. doi: 10.1186/s12904-020-00680-4. PMID: 33213448; PMCID: PMC7678093.
3. **Moon PJ.** Anticipatory Grief: A Mere Concept? *Am J Hosp Palliat Care.* 2016 Jun;33(5):417-20. doi: 10.1177/1049909115574262. Epub 2015 Feb 23. PMID: 25712106.
4. **Tan-Ho G, Choo PY, Patinadan PV, Low CX, Ho AHY.** Blessings or burdens: an Interpretative Phenomenological Analysis (IPA) study on the motivations and their impact on end-of-life caregiving among Asian family caregivers. *BMC Palliat Care.* 2020 Aug 20;19(1):132. doi: 10.1186/s12904-020-00638-6. PMID: 32819339; PMCID: PMC7441659.
5. **Muskin PR.** The request to die: role for a psychodynamic perspective on physician-assisted suicide. *JAMA.* 1998 Jan 28;279(4):323-8. doi: 10.1001/jama.279.4.323. PMID: 9450720.
6. **Block SD, Billings JA.** Patient requests to hasten death. Evaluation and management in terminal care. *Arch Intern Med.* 1994 Sep 26;154(18):2039-47. PMID: 7522432.
7. **Hansen MIT, Haugen DF, Sigurdardottir KR, Kvikstad A, Mayland CR, Schaufel MA; ERANet-LAC CODE project group.** Factors affecting quality of end-of-life hospital care - a qualitative analysis of free text comments from the i-CODE survey in Norway. *BMC Palliat Care.* 2020 Jul 7;19(1):98. doi: 10.1186/s12904-020-00609-x. PMID: 32635903; PMCID: PMC7341649.
8. **Harrop E, Morgan F, Byrne A, Nelson A.** "It still haunts me whether we did the right thing": a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. *BMC Palliat Care.* 2016 Nov 8;15(1):92. doi: 10.1186/s12904-016-0165-9. PMID: 27825330; PMCID: PMC5101847.
9. **Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, Hall C, Trauer T, Bolleter A, Clarke DM, Bauld C.** Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med.* 2012 Jun;15(6):696-702. doi: 10.1089/jpm.2011.0466. Epub 2012 Mar 2. PMID: 22385026; PMCID: PMC3362953.