

# A Case of Attempted Suicide in Huntington's Disease: Ethical and Moral Considerations

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## ABSTRACT

A 62-year-old female with Huntington's disease presented after a suicide attempt. Her advance directive stated that she did not want intubation or resuscitation, which her family acknowledged and supported. Despite these directives, she was resuscitated in the emergency department and continued to state that she would attempt suicide again. Her suicidality in the face of a chronic and advancing illness, and her prolonged consistency in her desire to take her own life, left careproviders wondering how to provide ethical, respectful care to this patient.

Tension between the ethical principles of autonomy and beneficence is central in this case. The patient's narrative demonstrated that her suicide was an autonomous decision, free from coercion or disordered thinking from mental illness. Beneficence then would seem to necessitate care aligned with the patient's desire to end her life, which created ethical uneasiness for her family and careproviders.

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The case highlights several end-of-life ethical considerations that have received much recent attention. With ongoing discussions about the legalization of aid in dying across the country, caregivers are challenged to understand what beneficence means in people with terminal illnesses who want a say in their death. This case also highlights the profound moral distress of families and careproviders that arises in such ethically challenging scenarios.

Mrs. J is a 62-year-old female with advanced Huntington's disease who was brought by ambulance after an apparent suicide attempt by overdose. Mrs. J's daughter and son-in-law called 911 when they found her approximately six hours after the overdose, still breathing. Upon arrival to the emergency department (ED), Mrs. J was noted to have decreased respirations and a Glasgow Coma Score of 6. Her daughter arrived shortly after and brought an advance directive (AD) dated five years earlier indicating that Mrs. J did not want intubation or resuscitation. Despite knowing about these directives and supporting them, her family called emergency medical services (EMS), in part because her son-in-law was in law enforcement and felt a duty to call 911.

Mrs. J was intubated, admitted to the intensive care unit, and then extubated after 24 hours of supportive care. Once extubated, psychiatry was consulted due to concern for her continued suicidality. She was placed on a mental health hold to allow

psychiatric assessment, given her high risk for self-harm. Psychiatry determined that she had decision-making capacity and she met criteria for major depression driven by both the biological and psychological impact of her Huntington's disease. Mrs. J declined antidepressant treatment and refused all psychiatric interventions including inpatient psychiatric hospitalization.

An ethics consult was requested based on the question: Should we commit this patient with persistent suicidal ideation against her will for inpatient psychiatric treatment, or do we need to honor her request for discharge despite ongoing suicidal intent?

Additional history, obtained by the primary care team and the ethics consultants, revealed that Mrs. J had been diagnosed with Huntington's disease seven years earlier and had tried various treatments, all of which she stopped due to side-effects. She had developed advanced chorea (involuntary movements) and was no longer able to eat without assistance, ambulate, or perform activities of daily living independently; she rarely left the house due to fear of falling. She had difficulty sleeping, restlessness, weight loss due to inability to swallow, low energy, poor concentration, and memory loss, all attributed to her Huntington's disease. Mrs. J had watched several family members including her father, two sisters, and several aunts suffer through the stages of Huntington's disease. She stated that she believed "it is time to exit stage left," while reporting tremendous grief because "I have lost who I once was and will never get it back." She had no history of previous suicide attempts or self-harm and asked careproviders for "compassion" by letting her leave the hospital to complete her suicide.

It was concluded that, given the chronicity of her suicidal ideation and the lack of any present or new active psychiatric conditions, an involuntary commitment for further evaluation was unlikely to change her thought process and would disrespect and disempower her further. Therefore, the 72-hour mental health hold was not renewed. She declined to remain for a palliative care consultation or to arrange for follow up with a primary physician or neurologist and left the hospital with her daughter.

Mrs. J's obituary was found in the newspaper several weeks later. The assumption that Mrs. J was ultimately successful in completing her suicide left all of the caregivers involved in the case wondering whether the care they had provided had been respectful and appropriate in this ethically challenging situation.

## IMPORTANCE

Several ethical considerations are highlighted in this case. Should this patient with suicidal ideation be considered autonomous? What would "beneficence" by healthcare providers look like in the face of this life limiting but not imminently terminal disease that would be expected to cause extreme suffering in subsequent years? How could the healthcare providers reconcile their professional duties with the patient's request for assistance in dying to alleviate suffering? And how should we address our moral distress as caregivers in an ethically ambiguous situation such as this?

## DISCUSSION

Prehospital personnel perform lifesaving interventions when summoned to the scene of a patient who is unstable or experiencing an altered mental state. Advance directive documents are advisory and may not be honored if they are unclear—EMS personnel will err on the side of life to resuscitate and stabilize a patient unless there is clear evidence that this is not wanted. Professional guidelines affirm the goal of preserving life, and legal caveats in several states (including Colorado, where this case played out) warn against abetting suicide or actively participating by honoring an advance directive in such an instance.<sup>1</sup> While many states have adopted prehospital do-not-resuscitate (DNR) policies or directives regarding cardiopulmonary resuscitation (CPR) that permit paramedics to withhold unwanted resuscitative measures in cardiac or respiratory arrest, these documents must be signed by a physician and are only indicated for seriously ill or terminal patients. Approximately 33 states also have legislated a physician orders for life-sustaining treatment (POLST-paradigm) order set, which is enacted in the face of a terminal illness expected to cause death within six months. EMS and other careproviders are required to honor state-specific POLST-paradigm orders, which often require that CPR not be initiated.<sup>2</sup>

In the face of a need for emergent action and a lack of knowledge of the details of the medical situation for Mrs. J, however, EMS and ED careproviders would not be expected to honor the wishes expressed in her AD. This is particularly true in the face of a suicide attempt, since the presumption is that suicide attempts are part of a mental illness that itself is potentially treatable.<sup>3</sup> Completed suicide is not that common after an attempt, with one study

indicating a 10 percent suicide completion rate in women following an attempt, in 37 years of follow up.<sup>4</sup> When it is unclear if a patient's decision is truly an autonomous decision, as in a suicide attempt, physicians reasonably argue that the patient's best interest is to restore the patient to a level of functioning in which it is possible to assess autonomy.<sup>5</sup> Mrs. J's scenario was particularly challenging and forced her careproviders to consider how to best care for a patient who "rationally" wished to hasten death, as opposed to a transient, mental illness-based suicidal ideation.

The tension between the ethical principles of beneficence and autonomy is central in this case of a patient whose suicide attempt could be considered and reasonable, given her situation. While beneficence would seem to justify resuscitation in the most common situation of depression and disordered thinking due to mental illness, the most beneficent approach to Mrs. J is more ambiguous, once her narrative is better understood.<sup>6</sup> Mrs. J was able to demonstrate the lack of coercion, lack of mental illness, and the reasoning that underlay her attempt—all aspects that compelled her careproviders to believe that she could express her autonomous values and wishes. For her medical careproviders, it was uncertain whether resuscitating her was beneficent or respectful for a woman who appeared to have documented as much as possible through her note and her AD that she wanted to control her death before she could no longer do so.

The ethical ambiguities and challenges in this case caused significant moral distress for Mrs. J's caregivers. (Ulrich, Hamric, and Grady define "moral distress" as "the inability of a moral agent to act according to his or her core values and perceived obligations due to internal and external constraints."<sup>7</sup>) This case caused moral distress for all involved. The medical careproviders understood that among the primary goals of medicine is relief of suffering and provision of comfort, and they found Mrs. J's narrative compelling. She faced several years of the progressive disability that she had seen in family members, without medical interventions that could alter its course. While it is dangerous for careproviders to judge the quality of life of a patient and to determine what is in her best interest, Mrs. J herself was the one who deemed her situation and her quality of life as unbearable. If she was autonomous and her decision making was not distorted by mental illness, she had the right to refuse unwanted medical interventions. Although this was not possible to determine emergently, agreeing to honor her wish to be discharged felt like abandonment. Mrs. J re-

mained suicidal at discharge and would not accept a referral for primary care, neurology, or palliative care to manage her disease progression and accompany her on her disease course. For the hospital careproviders, this meant that they had not relieved, but rather had exacerbated and prolonged her suffering.

The moral distress also involved the patient and her family. For the patient, failing to control the end of her life as she desired was frustrating, and she expressed this through her anger at waking up in the hospital and her anxiety to leave the moment her 72-hour mental health hold was over. She had not taken enough medication to kill herself, since she was found six hours after her overdose still breathing and responsive to resuscitative measures. This overdose had been the culmination of years of planning, and Mrs. J feared that she was running out of time to physically accomplish her death on her own terms, given the progression of her disease. The family too, upon finding her following her overdose, was left with the difficult decision to call 911 despite knowing her wishes. We can only imagine how this "failed" suicide attempt felt for her daughter, who had participated in fulfilling her mother's "bucket list," and lived with her mother, watching her progressive disability, and knowing how she was suffering.

For the ethics consultants, getting to "doing right" for Mrs. J presented an unresolvable dilemma. To allow Mrs. J to leave when the clock said her mental health hold was over, without the ability to find her a careprovider, garner a support structure for her, or to support her family in their moral distress felt incomplete and inadequate. Balanced against the patient's autonomous and steadfast belief that the future was unacceptable was the inability of the healthcare team to change her future. Beneficence seemed to require some kind of longitudinal professional expertise, multidisciplinary support, and sharing of this painful end-of-life journey. Mrs. J would not accept this, leaving the moral distress of an incomplete resolution to the ethical dilemma.

## CONCLUSIONS

Mrs. J deserved and needed a healthcare provider who would travel the road of Huntington's disease with her. She had no previous relationship with such a careprovider. During the several ED visits to stitch up lacerations from falls in the prior two to three years, the ED might have questioned how she was doing with her Huntington's disease and

tried to link her with a continuing care physician. Early palliative care involvement might have been able to support her through this difficult life trajectory and provide spiritual and psychosocial support, as well as symptom control. Physician assistance in dying is not legal in Colorado, but Mrs. J would have been a persuasive person to plead for that right, even though her life expectancy was still measured in years; had she been a resident of Oregon, she would not have qualified as having a “terminal disease” for purposes of their legislation.

In describing the goals of clinical medicine, Matlock and Mandrola recently described the role of careproviders as follows: “The essence of being a caring clinician is working with patients to help them achieve the life they want to lead. That’s it. We are consultants in the service of people. We are the experts in medical science, and patients are the experts in what is important to them.”<sup>8</sup> For some physicians, this role would extend to facilitating the kind of death that a patient like Mrs. J would want. We have compiled a list of lessons learned from this case, as table 1.

**TABLE 1.** Lessons learned

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- Recognize that moral distress can occur in ethically challenging situations
  - Acknowledge the moral distress and get support for families, staff, and caregivers
  - Seek the patient’s narrative within the disease
  - Work with the patient and family to discern what beneficence looks like in their situation
  - Explore resources to support the patient and family that are aligned with their goals
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#### MASKING OF THE CASE

Details of this case were masked to protect the identity of the patient and family.

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#### NOTES

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