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Mini-Review

When No One Knows the Patient: A Reflection on Guardianship and End-of-Life Care

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Watching medicine prolong suffering in patients who no longer have a voice is one of the most difficult experiences in healthcare. I found myself confronting this reality while caring for a 99-year-old woman with functional quadriplegia and dementia who had been admitted with sepsis, electrolyte abnormalities, severe malnutrition, and worsening functional decline.

According to the nursing facility, she had stopped swallowing nearly a week prior to admission. Despite repeated swallow evaluations, she continued to demonstrate minimal oral intake and remained dependent on continuous parenteral nutrition. As her condition stabilized medically, discussions shifted toward possible percutaneous endoscopic gastrostomy (PEG) tube placement: a decision carrying significant ethical implications in a patient of her age and condition. For days, I repeatedly attempted to contact her court-appointed legal guardian to discuss goals of care and code status. Each attempt ended in frustration and delay. During our most recent conversation, he briefly stated that all current measures should continue and that her full code status could not be changed without court authorization, a process that could take weeks. I remember leaving that conversation feeling helpless. Each day I entered her room, I found myself wondering what her life had once been like and whether the care we were providing reflected anything she would have wanted for herself. She never spoke, but her eyes tracked every movement in the room. There was a profound emptiness in those encounters, a feeling that medicine was continuing to act upon her body while no one truly understood the person she had once been.

Situations like this are not uncommon. Approximately 1.5 million adults in the United States live under guardianship arrangements, and a significant proportion are represented by professional guardians who had no prior relationship with them before their appointment [1]. In healthcare settings, particularly among elderly patients with prolonged incapacity and no available healthcare proxy or family decision maker, professional guardians are often tasked with making complex medical decisions despite having little knowledge of the patient's personal values, beliefs, or wishes. Existing literature suggests that professional guardianship can unintentionally contribute to prolonged aggressive care near the end of life. Studies describe that professional guardians may lean toward maximal treatment because it appears legally safer, or they may defer difficult end-of-life decisions to the courts even when judicial involvement is not clearly required [2]. In both situations, critically ill patients often continue receiving high-intensity interventions while healthcare teams await legal clarification or court approval. These delays are not rare. Research examining end-of-life care under guardianship found that nearly half of patients experienced delays in medical decision-making, while approximately one-third of professional guardians sought judicial review before authorizing limitations in care or changes in code status [2,3]. In acute hospital settings, particularly ICU, these delays may expose profoundly frail patients to invasive interventions that provide little meaningful benefit while substantially worsening quality of life.

Furthermore, one of the greatest ethical difficulties in professional guardianship is the inability to apply substituted judgment. Unlike family members or loved ones who may understand a patient's long-standing values and preferences, professional guardians frequently make decisions without any personal understanding of the individual they represent [1]. As a result, decision-making often shifts toward a generalized "best interests" standard rather than one rooted in the patient's own wishes. This becomes especially problematic near the end of life, where perspectives on resuscitation, artificial nutrition, and life-prolonging treatment vary greatly between individuals.

In my patient's case, the ethical conflict became increasingly apparent. At 99 years old, she had already survived sepsis and profound functional decline. Yet if she were to deteriorate suddenly, the medical team would still be obligated to pursue full resuscitative measures because her code status could not be changed without prolonged legal processes. The possibility of chest compressions, intubation, mechanical ventilation, and ICU-level interventions in a patient with advanced dementia and functional quadriplegia raised difficult questions about whether we were preserving life or merely prolonging suffering. The current dilemma surrounding PEG tube placement further highlights this tension. Ethical principles in medicine emphasize that invasive procedures should only be pursued when the expected benefits meaningfully outweigh the burdens and risks to the patient. However, evidence regarding PEG placement in advanced dementia suggests that feeding tubes often do not improve survival, functional recovery, or quality of life and may instead contribute additional complications and discomfort [4]. Having thoughtful palliative discussions regarding these interventions becomes significantly more difficult when decision-making authority is constrained by delayed court processes and the absence of someone who truly knows the patient. Overall, court-appointed guardianship serves an important legal role in protecting vulnerable individuals who cannot advocate for themselves. However, when guardians lack emotional connection, understanding of a patient's prior values, or timely authority to adjust goals of care, the system can unintentionally default profoundly frail patients into burdensome and potentially non-beneficial interventions. Cases like this force healthcare providers to confront an uncomfortable question: when a patient can no longer speak for themselves, who is truly protecting their dignity?.

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