

The Right to Decide: Navigating Autonomy and Cultural Insensitivity in Critical Care (A short commentary)

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This commentary article highlights an ethical dilemma in critical care in which patient autonomy was disregarded in favor of family decision-making. It examines the impact of cultural insensitivity on end-of-life care, emphasizes the importance of respecting patients' choices, and advocates for advance directives and supportive policy frameworks to promote equitable, patient-centred care. The paper concludes that advocating for patient autonomy within culturally sensitive care requires balancing ethical obligations with compassion, fostering shared decision-making, and establishing institutional frameworks that safeguard patients' voices throughout the care process.

Key Words: Patient Autonomy, End-of-Life Care, Decision-Making, Cultural Insensitivity, Critical Care

INTRODUCTION

The ethical principle of autonomy grants patients the right to be informed and involved in decisions about their healthcare, particularly in critical and end-of-life care scenarios.¹ However, in culturally complex societies such as Pakistan, patient autonomy is often surpassed by familial dominance and cultural norms that prioritize surrogate decision-making.² This commentary explores a real-life clinical scenario in which a fully conscious, sedated patient faced the possibility of life support withdrawal without being consulted about his own care preferences. Despite the patient's capacity to make informed decisions, cultural expectations and the family's role in healthcare choices became the driving force in determining his treatment trajectory. Through this case, we critically examine the ethical implications of cultural blindness, question the legitimacy of surrogate dominance in such decisions, and argue for greater emphasis on individual autonomy, guided by core bioethical principles and legal frameworks. The article positions nurses and other healthcare professionals as advocates for patient rights and calls for a shift toward ethically sound, culturally sensitive practices that respect the patient's voice.

Clinical Scenarios

A 60-year-old patient was admitted to the ICU following pulmonary resection surgery and required full inotropic and mechanical ventilatory support due to postoperative complications. Repeated attempts to

wean him from the ventilator were unsuccessful. Although the patient remained sedated while receiving ventilatory support, he achieved a Glasgow Coma Scale (GCS) score of 15/15 whenever sedation was temporarily withheld. However, formal decisional capacity beyond the GCS assessment was not evaluated, and potential confounding factors such as delirium, hypoxia, or sedation-related cognitive impairment were not rigorously excluded. The patient had no documented or previously expressed wishes regarding end-of-life care. After counseling the family about his guarded prognosis, the multidisciplinary team initiated exploratory, rather than imminent, discussions regarding the possible withdrawal of life-sustaining treatment. As nurses involved in his care, we questioned whether it would be ethically appropriate to awaken the patient, formally assess his decisional capacity, and involve him in discussions regarding the continuation or possible withdrawal of life support. Another case from Pakistan also highlighted how family decision-making can override patient autonomy, as a 19-year-old girl with metastatic ovarian cancer wished to remain full code, but her family chose do-not-resuscitate (DNR) status without her involvement.³

Ethical Analysis

Disclosure of a patient's clinical condition and respect for patient autonomy are fundamental ethical obligations in healthcare.¹ In this case, although the patient regained full consciousness with a Glasgow Coma Scale (GCS) score of 15/15 during sedation

breaks, his preferences regarding continuation or withdrawal of life-sustaining treatment were not explored, and his decision-making capacity was not formally reassessed. Instead, the multidisciplinary team accepted the family's decision as final, raising ethical concerns about excluding a potentially competent patient from decisions directly affecting his care and survival. Previous research also suggests that more than half of intensivists and ICU nurses report prioritizing family members' requests when patient preferences are unclear or not explicitly documented.⁴

While relational autonomy recognizes the importance of family involvement in healthcare decision-making, particularly in collectivist cultures, family preferences may sometimes override the patient's own values and wishes. Family involvement in healthcare decision-making for competent patients varies across societies; however, most legal and ethical frameworks affirm that competent patients should be supported in making their own treatment decisions, even when these differ from the views of family members or healthcare professionals.⁵ Ethical practice requires balancing cultural sensitivity with respect for individual autonomy. Therefore, when a patient demonstrates potential decision-making capacity, healthcare professionals have an ethical responsibility to assess that capacity in relation to treatment goals and end-of-life decisions, rather than relying solely on surrogate or family-based decision-making.

Patient autonomy and family-centered decision-making

Respecting patients' rights in decision-making requires acknowledging their autonomy and ensuring they are adequately informed about their condition.⁶ Nevertheless, despite recognizing this ethical obligation, healthcare professionals often perceive end-of-life decision-making as a source of significant emotional distress for patients. Patients receiving end-of-life care undergo continuous assessment, feedback, and management, enabling healthcare professionals to develop and implement care plans collaboratively and to ensure that patients' values, rights, expectations, and care preferences are respected.⁷ However, within the Pakistani sociocultural context, integrating patient autonomy remains challenging, as family-centered decision-making frequently surpasses patients' autonomous wishes, resulting in surrogate decisions being

prioritized over individual patient preferences.⁷ In addition, in Western countries, patient autonomy is highly respected in end-of-life care decisions, while in many Asian countries, family decision-making is given greater importance.⁸

The concept of paternalism reflects the belief that family decisions may take precedence over individual preferences, particularly within collectivist societies. In this context, there is a critical need to address cultural blindness and its influence on healthcare decision-making, especially in situations involving survival and end-of-life care. Every individual has the fundamental right to make informed decisions regarding their treatment based on adequate disclosure of relevant clinical information.⁴ However, patient inclusiveness in decision-making is often diminished during the end-of-life stage, as families may assume that the patient lacks decision-making capacity, while healthcare professionals may remain limited in advocating for patient autonomy. A multidisciplinary healthcare team is intended to promote collaborative care involving patients and their families; nevertheless, in many cases, family authority exerts greater influence over the direction of patient care and treatment decisions. This underscores the importance of carefully determining surrogate decision-makers for incapacitated patients. Importantly, the selection of a surrogate decision-maker should remain the patient's sole prerogative. Furthermore, advance directives provide an essential framework for guiding healthcare decisions when patients are no longer able to express their preferences. An advance directive is defined as a legal document prepared by an individual to guide healthcare professionals and family members in making treatment decisions in accordance with the patient's wishes when the individual loses decision-making capacity.⁹

Within many societies, individuals are deeply influenced by family and social relationships, and healthcare decisions often become institutionalized within these collective structures. Consequently, patient autonomy may be suppressed when individuals are in fragile, vulnerable conditions, particularly at the end of life, where their preferences may be overridden by family-centered decision-making.

Ethical Conflicts

Care decisions made by patients regarding their treatment can generate conflict among patients,

families, and healthcare professionals. Furthermore, patients' autonomous decisions concerning end-of-life care may also contribute to disagreements between patients and their family members.¹⁰ Such conflicts raise important ethical concerns regarding why tension emerges when individuals exercise their right to make decisions about their own care. In many cases, families who are unaware of or disagree with the patient's decisions may reject those choices due to concerns about cultural beliefs, emotional perspectives, or long-term financial stability. Consequently, family members may refuse to support or remain involved in the patient's care when they perceive themselves as lacking decision-making authority, potentially leaving the patient without adequate social or financial support. Healthcare professionals have an essential responsibility to provide equal and equitable healthcare services to all patients.¹¹ In situations where healthcare professionals continue aggressive treatment despite recognizing a guarded prognosis, ethical tensions may arise between the principles of equality and equity in care provision. Professionals must therefore prioritize patients' needs and clinical conditions to deliver appropriate and patient-centered care.¹² In such circumstances, patients may benefit more from palliative and comfort-focused care rather than life-sustaining interventions, requiring clinicians to carefully evaluate the appropriateness of ongoing treatment strategies.

Recommendations

Clinicians should adopt structured communication to ensure that patients and families clearly understand treatment options and prognosis. In addition, ethics committees should be involved early in cases of uncertainty about decision-making capacity or disagreement between patient and family preferences. Furthermore, nurses should advocate for patients by supporting reassessment of capacity and ensuring their involvement in care discussions. Similarly, advance care planning should be routinely integrated into practice to document patient values before loss of capacity. Moreover, end-of-life discussions should balance cultural sensitivity with respect for patient autonomy. At the institutional level, ICU policies should be strengthened to guide capacity assessment, shared decision-making, and documentation of patient preferences. Finally, ongoing professional ethics training should be provided to ICU staff to enhance their ability to manage ethically complex situations.

Conclusion

Respect for patient autonomy is a fundamental ethical principle in end-of-life care. This case highlights the challenges that arise when family-centered decision-making overrides the preferences of a potentially competent patient. It underscores the importance of timely reassessment of decision-making capacity and direct patient involvement in treatment discussions. Overreliance on surrogate decision-makers may result in ethically complex care decisions. Strengthening capacity assessment practices, promoting advance care planning, and establishing clear institutional and legal frameworks can help clinicians balance cultural values with patient-centered ethical care at the end of life.

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