EXPERT OPINION

Ethical and Legal Issues at the End of Life for Critically Ill Patients

Ibrahim NA[a], Mat Nor MB[b]

[a]Department of Anaesthesiology and Intensive Care, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia
[b]Department of Anaesthesiology and Intensive Care, Kulliyyah of Medicine, International Islamic University Malaysia.

CASE VIGNETTE

Mr. A, a 68-year-old man with advanced metastatic colon cancer, was admitted to the intensive care unit following respiratory failure. Despite maximal ventilatory support, his prognosis was poor, with no realistic chance of recovery. His oncologist had previously discussed about palliative care, but the family insisted on "doing everything possible" in the hospital. After two weeks of mechanical ventilation, Mr. A remained sedated, dependent on artificial nutrition, and developed recurrent infections. The treating team faced a dilemma: should life-sustaining treatment be withdrawn to allow a natural death, or should it be continued in deference to the wishes of the family?

This case illustrates the ethical and legal complexities of end-of-life the (EOL) care, where cultural expectations, religious beliefs, and legal uncertainties converge.

INTRODUCTION

Medical progress has transformed the natural course of illness and death. Life-sustaining technologies such as ventilators, dialysis and artificial nutrition can extend the physiological function of critically ill patients long after the body's natural capacity has waned.[1] While these life-prolonging interventions save lives, they also create ethical and legal dilemmas when applied to patients with no realistic prospect of recovery. Clinicians in Malaysia, face uncertainty due to limited legislation, diverse cultural expectations, and strong religious influences. This article provides an expert opinion on ethical and legal issues at the EOL, contextualised within Malaysian practice but informed by global discourse.[2]

MORALS, ETHICS, AND LAW

EOL decision-making is shaped by three overlapping domains: morals, ethics, and law. Morals represent the personal values and convictions of individuals, often deeply influenced by religion, culture, and social norms. Ethics refers to the professional codes that guide medical conduct, such as the Malaysian Medical Association's *Code of Ethics* and the Malaysian Medical Council's *Code of Professional Conduct*.[3] These codes provide a framework for acceptable practice, though they are not legally binding. Law differs in that it comprises statutory rules enforced by government institutions, carrying penalties for any violation. At the bedside in hospital wards, these domains frequently intersect: a physician may feel morally compelled to continue treatment, ethically bound to respect patient autonomy, and legally constrained by the absence of clear provisions on withdrawal of treatment. The conflict between these spheres creates the crucible in which EOL dilemmas must be resolved. [5]

ETHICAL FRAMEWORKS

The four principles of biomedical ethics articulated by Beauchamp and Childress, namely autonomy, beneficence, non-maleficence, and justice, remain central to EOL care. Autonomy requires respect for patient choice, beneficence obliges physicians to act in the best interests of patients, non-maleficence demands the avoidance of harm including futile interventions, and justice calls for fair allocation of resources. These principles are not hierarchical and may be in conflict, requiring nuanced judgment and sensitive communication.

ETHICAL ISSUES IN END-OF-LIFE CARE

Decisions at the EOL often involve whether to continue life, withhold, or withdraw treatment. Ethically, withdrawal and withholding are considered equivalent, yet they carry different emotional weight. Families may perceive withdrawal as an active step of "giving up" or

abandoning care, which makes the process more emotionally problematic and can lead to conflict.

Artificial hydration and nutrition are frequently regarded as basic care rather than medical intervention, and their withdrawal is often resisted even when it prolongs suffering without meaningful benefit. Terminal sedation, when used to relieve intractable symptoms, is ethically defensible under the principle of double effect, provided the intent is comfort rather than hastening death.[4,5]

In Malaysia, euthanasia and physician-assisted suicide are not legally permitted. Physicians, therefore, focus on ethically sound alternatives, particularly comprehensive palliative care, to relieve suffering and uphold the dignity of the patients. The actual challenge lies in balancing beneficence and non-maleficence by providing interventions that genuinely benefit the patient while avoiding harm through futile or burdensome treatments. Ultimately, ethical decision-making at the end of life requires sensitive communication, respect for patient autonomy, and recognition of the emotional complexities faced by family members. Structured approaches such as planning for advance care and family conferences can help bridge these gaps, ensuring that decisions about patient care reflect both ethical principles and patient values.

RELIGIOUS AND CULTURAL PERSPECTIVES

Malaysia's plural society adds complexity to this conundrum. Islamic jurisprudence emphasises regarding the sanctity of life but permits withdrawal of medically inappropriate treatments.[6] Christian and Buddhist traditions emphasise compassion and dignity. Cultural norms often prioritise family-centred decision-making, sometimes overshadowing patient autonomy. Clinicians in charge must navigate these sensitivities by engaging in dialogue with family members and religious authorities to ensure that care aligns with the patient's values.[7]

SURROGATE DECISION-MAKING IN END-OF-LIFE CARE

Surrogate decision-making is a defining feature of EOL care in Malaysia, where family members frequently assume responsibility when patients are incapacitated. This practice reflects cultural expectations of filial duty and collective decision-making; however, this also raises ethical concerns when surrogates' preferences diverge from those of the patient.

Mr. A's case illustrates this dilemma vividly. Although his prognosis was poor and his oncologist had previously discussed regarding palliative care, his family members insisted on "doing everything possible." Their role as surrogate decision-makers effectively overrode the patient's earlier openness to comfort-focused care, resulting in prolonged interventions that may not have aligned with his wishes.

A study conducted in Malaysia in 2022 highlighted this issue. The findings revealed that chronic haemodialysis patients were generally more receptive to limiting aggressive interventions, whereas family members tended to favour continuation of treatment. This divergence underscores the risk that surrogate decision-makers may unintentionally override patient autonomy, perpetuating interventions that the patient might not have desired.[8]

International evidence reinforces this concern. Shalowitz and colleagues, in their systematic review of surrogate decision-making accuracy, found that surrogates correctly predicted patients' treatment preferences only about two-thirds of the time, with accuracy declining further in complex scenarios involving life-sustaining treatment. Their work demonstrates that even in societies where family involvement is deeply valued, surrogate decision-making is inherently limited and prone to error.[9]

These findings highlight the importance of Advance Care Planning (ACP**)** in Malaysia. ACP provides a structured process for patients to articulate their values, preferences, and goals of care before they become incapacitated. By documenting these preferences, ACP reduces reliance on surrogate interpretation and ensures that medical decisions reflect the voice of the patients. In a plural society like Malaysia, ACP also facilitates dialogue between patients,

family members, and healthcare providers, bridging cultural expectations with ethical safeguards. Institutionalising ACP within hospitals and dialysis units would help mitigate conflicts, reduce moral distress among clinicians, and align care more closely with patient autonomy.

EVIDENCE FROM ETHICUS TRIALS AND MALAYSIAN CONTEXT

The Ethicus I trial (2003), conducted across 37 European intensive care units (ICU), revealed that nearly half of ICU deaths involved some limitation of treatment, either withholding or withdrawing life-sustaining interventions. Importantly, the study highlighted striking regional differences: clinicians in Northern Europe were more likely to withdraw treatment, while those in Southern Europe tended to withhold treatment rather than withdraw, reflecting cultural and religious influences on medical decision-making.[10]

Nearly two decades later, the Ethicus II trial (2021) demonstrated a significant evolution in decision-making. Physicians reported greater acceptance of treatment withdrawal, more structured communication with families, and increased patient involvement in decision-making. The trial concluded that EOL practices had become more standardised across Europe, with clearer institutional protocols and reduced variability between regions.[11]

For Malaysia, these findings are highly relevant. Local ICU audits, such as those conducted at Universiti Malaya Medical Centre and Hospital Kuala Lumpur, suggest that decisions to limit treatment remain relatively uncommon compared to those in Europe. Malaysian intensivists often favour withholding rather than withdrawing interventions, echoing the Southern European pattern seen in Ethicus I. This reluctance is driven by cultural sensitivities, strong family involvement, and fear of litigation. Physicians have reported moral distress when continuing intervention, which they considered futile, but felt constrained by family expectations and legal uncertainty.[12,13]

Taken together, the Ethicus trials and Malaysian studies highlight the importance of structured communication and documentation of patient preferences. Ethicus II showed that family engagement, when guided by clear institutional protocols, reduces conflict and aligns decisions with patient values. In the Malaysian context, the absence of such structures means that family surrogates often exert dominant influence over end-of-life decision-making, which can perpetuate overtreatment. Institutionalising advance care planning and family conferences could help ensure that patient voices remain central, even when they are incapacitated, while balancing cultural sensitivities and family expectations.[10,11, 12,13]

LEGAL CONSIDERATIONS IN MALAYSIA

In Malaysia, the absence of clear legislation on end-of-life care creates significant uncertainty, often resulting in overtreatment as healthcare professionals seek to avoid potential legal repercussions. While this legal vacuum poses challenges, it should not prevent clinicians from acting in accordance with ethical standards. The Malaysian Medical Association (MMA) Code of Ethics 2023 provides a crucial framework, emphasising that ethical duties remain paramount even in the absence of statutory support. Healthcare teams must therefore strive for consensus in their decision-making, ensuring that choices are both ethically defensible and clinically appropriate. Once a unified position is reached, it should be communicated transparently and compassionately to the patient's family, allowing for family concurrence and alignment with the care plan. This approach not only safeguards professional integrity but also fosters trust between healthcare providers and families, bridging the gap left by the lack of legislative clarity.[2,3,14,15]

INSTITUTIONAL CHALLENGES

Hospitals in Malaysia face systemic challenges, including a lack of standardised protocols, limited palliative care resources, inadequate ethics training, and physicians' fear of litigation. These challenges contribute to inconsistent practices and moral distress among healthcare providers.

RECOMMENDATIONS

Authorities in Malaysia's medical sector should consider legislative reform to clarify the legality of withdrawing futile treatment and to protect physicians who act ethically. Strengthening palliative care services nationwide would ensure that patients receive holistic support addressing physical, psychological, social, and spiritual needs while improving the quality of those dying and reducing unnecessary interventions. Education in ethics should be expanded to train clinicians in communication and cultural competence. Hospitals should adopt clear institutional protocols for EOL decisions, and structured family engagement should be prioritised to align expectations and reduce conflict.

Equally important is the institutionalisation of Advance Care Planning (ACP). ACP allows patients to articulate their values and preferences before they become incapacitated, reducing reliance on surrogate interpretation and minimising conflict between families and clinicians. In Malaysia's plural society, ACP provides a culturally sensitive framework for dialogue between patients, families, and healthcare providers. Incorporating ACP into routine practice, particularly in dialysis units, oncology clinics, and intensive care settings, would ensure that patient autonomy is respected, decisions are guided by documented preferences, and care at the EOL reflects the values and wishes of individuals rather than being driven solely by surrogate interpretation or institutional uncertainty.

REFERENCES

1. Beauchamp TL, Childress JF. Principles of biomedical ethics. 7th ed. New York: Oxford University Press; 2013.
2. Malaysian Medical Association, Handbook of Medical Ethics, 2023 Edition.
3. Malaysian Medical Council. Code of Professional Conduct. 2019 Edition. Kuala Lumpur: Malaysian Medical Council;2019.
4. Boyle J. Medical ethics and double effect: the case of terminal sedation. Theor Med Bioeth. 2003;24(1):17-36.
5. Arima H. Double-effect sedation: do physicians not intend a decrease in consciousness when it is caused by drugs that can also reduce specific symptoms? J Med Ethics. 2020;46(9):601-5.
6. Hehsan MR, Wan Muhd Shukeri WF. Protocols and fatwa in Malaysia on withholding and withdrawal of life-sustaining treatment in intensive care units: an overview. Malays J Syariah Law. 2021;9(2):1-18. Doi:10.33102/mjsl.vol9no2.296
7. Muishout G, El Amraoui A, Wiegers GA, van Laarhoven HWM. Muslim jurisprudence on withdrawing treatment from incurable patients: a directed content analysis of the papers of the Islamic Fiqh Council of the Muslim World League. J Relig Health. 2022;63:1230-67.
8. Azahar, A., & Ibrahim, N. A. Differences in attitude towards end-of-life care among haemodialysis patients and their family members in two Malaysian hospitals. IIUM Med J Malaysia. 2022;21(2):45-52.
9. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166(5):493-7.
10. Sprung CL, Cohen SL, Sjokvist P, Baras M, Bulow HH, Hovilehto S, et al. End-of-life practices in European intensive care units: the Ethicus Study. JAMA. 2003;290(6):790-7.
11. Sprung CL, Ricou B, Hartog CS, Maia P, Mentzelopoulos SD, Weiss M, et al. Changes in end-of-life practices in European intensive care units from 1999 to 2016: the Ethicus II Study. Intensive Care Med. 2019;45(3):311-20.
12. Goh CH, Wong YL, Lim TK. End of life care practices in the intensive care unit: An audit at Universiti Malaya Medical Centre. Malays J Med Health Sci. 2018;14(2):45 52.
13. Tan CS, Ibrahim N, Hassan H. End of life decision making in the ICU: An audit of practices at Hospital Kuala Lumpur. Med J Malaysia. 2019;74(4):289 95.
14. Alias F, Jahn Kassim PN. Legal aspects of end-of-life care in Malaysia. Malayan Law J. 2021;2:xxxiii.
15. Kaur S, Tan THW, Yau JKY, Lim RBL. The law and practice of advance directives and end-of-life care in Malaysia. In: Cheung D, Dunn M, editors.

Advance directives across Asia. Cambridge: Cambridge University Press; 2023. p. 185-204.

Dr. Noor Airini Ibrahim
Senior Lecturer and Consultant Intensivist,
Department of Anaesthesiology and Intensive Care,
Faculty of Medicine and Health Sciences,
Universiti Putra Malaysia

Former, National Coordinator,
EOL Care Workshop and Training,
Malaysian Society of Intensive Care,
2015 to 2025

Prof . Dato' Dr. Mohd Basri Mat Nor
Consultant Intensivist,
Department of Anaesthesiology and Intensive Care,
Kulliyyah of Medicine,
International Islamic University Malaysia