


Implementation Of Patient Autonomy Principle In End-Of-Life Decision-Making: A Case Study At KH. Daud Arif Regional General Hospital, Kuala Tungkal

Een Kurnaesih¹, Rahma Nasywa Sabilla², Syifa Fitriana Qurrotaayun³, Virgine Weby Anastasia⁴, Dian Mardiana Lestari⁵, Agisna Rafa Krismawanti⁶

Universitas Pembangunan Nasional "Veteran" Jakarta, Jalan Limo Raya No. 7, Cinere, Depok, Indonesia^{1,2,3,4,5}

Article Info	ABSTRACT
<p>Keywords: Medical Ethics Euthanasia Patient Autonomy Critical Care</p>	<p>The aim of this research is to explore and delve deeper into the reasons families request passive euthanasia, the illnesses and conditions that lead individuals to consider such actions, and how the principle of patient autonomy is applied in euthanasia practices at KH. Daud Arif Regional General Hospital, Kuala Tungkal. The research employs a qualitative approach through literature review studies. Data were collected from journals, books, and previous studies, focusing on the withdrawal of life-support measures and the ethical principle of autonomy. The collected information was analyzed to support the research. Based on the findings, decisions regarding euthanasia, particularly passive euthanasia, should ideally be made by patients when they are mentally capable. However, in critical conditions where the patient is incapacitated, the responsibility is transferred to the patient's family, who can make decisions on their behalf, including opting for passive euthanasia. While active euthanasia remains illegal in Indonesia, passive euthanasia, such as the cessation of life-support interventions, is permitted under certain legal frameworks, such as Ministry of Health Regulation No. 37 of 2014. This regulation also emphasizes the importance of therapeutic contracts between patients and healthcare providers. The reasons families or patients choose passive euthanasia at KH. Daud Arif Regional General Hospital, Kuala Tungkal, include prolonged physical suffering and a significant decline in quality of life. The illnesses or conditions considered for passive euthanasia include chronic, incurable diseases that cause ongoing suffering, such as heart disease, kidney failure, or illnesses with poor prognoses.</p>
<p>This is an open access article under the CC BY-NC license</p> 	<p>Corresponding Author: Een Kurnaesih Universitas Pembangunan Nasional "Veteran" Jakarta Jalan Limo Raya, No. 7, Cinere, Depok, Indonesia eenkurnaesih@upnvj.ac.id</p>

INTRODUCTION

Humans were created by God in perfection, endowed with reason, emotions, and will, which enable them to have the right to life. Human will serves as a tool to express choices and acts as a source of virtue and moral values for humanity. In Indonesia, the principle of regional autonomy is regulated under (Undang-Undang (UU) Nomor 23 Tahun 2014 Tentang

Pemerintahan Daerah, 2014) granting local governments the authority to manage governmental affairs in accordance with the mandate of the 1945 Constitution. One fundamental right guaranteed is health, as stated in Article 28H Paragraph (1) of the (Undang-Undang Dasar (UUD) Tahun 1945, 1945), which affirms that every individual has the right to access healthcare services. According to (Undang-Undang Nomor 36 Tahun 2009 Tentang Kesehatan, 2009), health is defined as a state of physical, mental, spiritual, and social well-being that enables individuals to live productively in social and economic contexts. For instance, (Kuuliala, 2021) describes physical health as a condition where bodily organs function properly without discomfort or visible illnesses.

However, dilemmas arise in certain medical situations, such as those encountered at KH. Daud Arif Regional General Hospital in Kuala Tungkal, where patients requiring ventilators to breathe decided to discontinue their use due to unbearable pain, even though their families had agreed to further treatment at another hospital. In another case, a patient experiencing respiratory and cardiac arrest was not given resuscitation treatment based on medical and ethical considerations, given the patient's poor prognosis. In bioethics, the principle of autonomy asserts that individuals have the right to determine their own fate, including making medical decisions. According to (Kalaja & Ruohotie-Lyhty, 2021) autonomy consists of three elements: agency, which refers to self-awareness of desires and intentions; independence, which involves the absence of external influences; and rationality in decision-making. These elements uphold the values of personal autonomy and self-determination (Akdeniz et al., 2021).

In medical practice, advances in science and technology present challenges, particularly in addressing ethical and legal dilemmas involving patients in critical conditions. One such issue is euthanasia, particularly the withdrawal of life-support devices in terminal patients. This practice, categorized as passive euthanasia, involves discontinuing therapies that are no longer effective in prolonging the patient's life. Although data on euthanasia cases in Indonesia are not officially available, discussions on the topic have begun to emerge. Some segments of society support euthanasia as a human right, including the right to determine the end of one's life. A survey conducted by Sajipto Rahardjo revealed that a portion of respondents agreed with the practice. Therefore, this study aims to explore the reasons families choose passive euthanasia, the medical conditions influencing such decisions, and the application of the principle of patient autonomy in euthanasia cases at KH. Daud Arif Regional General Hospital in Kuala Tungkal. The aim of this research is to explore and delve deeper into the reasons families request passive euthanasia, the illnesses and conditions that lead individuals to consider such actions, and how the principle of patient autonomy is applied in euthanasia practices at KH. Daud Arif Regional General Hospital, Kuala Tungkal.

METHODS

The research method employed in this scientific article is qualitative, conducted through a literature study or review. A literature study is a data collection technique that involves understanding and examining theories from various literature sources relevant to the research topic. The data collection process is carried out by searching for and organizing information

from multiple sources, such as journals, books, and previous studies (Adlini et al., 2022). The collected data and information are recorded and processed to serve as material for the research. The literature study examined in this scientific article focuses on the withdrawal of life-support systems and the ethical principle of autonomy.

The data analysis technique used in this study is descriptive qualitative, aiming to understand, interpret, and derive meaning from the data collected through a literature review. The process begins with data collection from various literature sources, including scientific journals, reference books, and previous research relevant to the topic of withdrawing life-support equipment and the ethical principle of autonomy. The gathered information is then classified into key categories, such as the concept of ethical autonomy, bioethical principles, the legality of withdrawing life-support equipment, and the medical conditions underlying such actions. Content analysis is employed to identify patterns, themes, or relationships within the data, ensuring consistency between theoretical frameworks and empirical findings from the literature. Subsequently, the identified patterns and themes are further analyzed and interpreted within the research context to understand the reasons families or patients choose passive euthanasia and how the principle of patient autonomy is applied in decision-making. The results of this analysis are presented in a structured narrative, providing a comprehensive and coherent explanation of the study's findings. Conclusions are drawn based on a synthesis of the analyzed data, highlighting key aspects related to the withdrawal of life-support equipment and the ethical principle of autonomy. This approach allows the research to contribute significantly to the academic discourse on the complex issues surrounding patient autonomy and ethical medical decision-making.

RESULTS AND DISCUSSION

Medical ethics issues have existed since the early development of the medical field and have always faced various dilemmas. To address these dilemmas, doctors are taught four principles: autonomy, beneficence, non-maleficence, and justice. Life-support equipment (APHP) is a form of passive euthanasia, which occurs when medical teams indirectly end a patient's life by discontinuing care or life-support systems necessary to prolong life, resulting in the patient's death (Cahyasabrina et al., 2023). The decision to perform euthanasia must be made by an individual in a sound mental state, capable of thinking and making their own decisions. If the patient loses this ability, such as in critical conditions, the decision can be delegated to the patient's family. Any decision made by the patient's legal guardian, including the choice for passive euthanasia or the termination of APHP, is considered valid. The reasons behind requests for euthanasia are not solely economic burdens for treatment costs but also compassion for the suffering patient and the minimal hope of recovery. Based on these reasons, families may decide to request passive euthanasia from medical personnel. A therapeutic contract is necessary to establish an agreement regarding medical treatment between the patient and the doctor (Gracia et al., 2022).

Research conducted at RSUD KH. Daud Arif Kuala Tungkal by (Nabila, 2019) recorded two cases of passive euthanasia in 2018. Chronic or incurable diseases that cause ongoing suffering, such as heart disease, kidney failure, or illnesses with poor prognoses, are examples

of reasons to consider passive euthanasia. In one case, a man with the initials F was in a coma for three days without significant improvement. Another case involved a woman with the initials N, who suffered from severe illnesses leading to her deteriorating health, including complications from diabetes, gout, glaucoma, and kidney failure. The reasons families or patients at RSUD KH. Daud Arif chose passive euthanasia included prolonged physical pain and a significant decline in quality of life. When Mr. F experienced respiratory and cardiac arrest, the neurologist and internist in charge did not perform resuscitation, and the resuscitation equipment was ultimately removed. This was done out of compassion for the patient, who had been in poor health for a long time with a poor prognosis, where the use of resuscitation equipment would only extend life for a few days or hours. In Mrs. N's case, the decision came from the patient herself, requesting the removal of the ventilator due to her unbearable pain, despite the family agreeing to continue treatment at another hospital.

Human Rights (HAM) are often associated with the right to life, peace, and so forth, but they do not explicitly include the right to die. Prohibitions against requesting or expecting death also encompass bans on seeking assistance from others to accelerate death. Requests for euthanasia, whether by the patient or their family, reflect desperation. As Dr. Eni noted regarding euthanasia, doctors may end a patient's suffering, which is often perceived as torment. Such actions may conflict with the principle of respecting patient autonomy. However, in the passive euthanasia cases at RSUD KH. Daud Arif, these actions were carried out with the agreement and request of the patient, their family, and the doctor. Considering the patients' challenges, such as Mr. F's respiratory and cardiac arrest, with significant suffering and a poor prognosis, and Mrs. N's case, these passive euthanasia actions were performed with mutual agreement and consideration. However, in cases like Mrs. Nurhayati's, where decisions were made under unstable emotional conditions, patients may lack competence or be unable to think rationally during decision-making. In such situations, healthcare providers need to involve the family in decision-making about ventilator installation or removal. The family acts as a representation of the patient's autonomy, as they are believed to understand the patient's wishes and values.

The principle of autonomy in medical ethics refers to the individual's right to make independent decisions about their care and health without unwanted external intervention. This principle places the patient in full control of their body and health, and medical decisions must be based on adequate information, guided by the patient's preferences and values (Akdeniz et al., 2021). In other words, autonomy demands respect for the patient's right to make free choices regarding their medical care, including the right to refuse or discontinue treatments no longer deemed beneficial (Bachri & Nurnaeni, 2022). In the context of passive euthanasia, respect for patient autonomy plays a significant role. Passive euthanasia allows patients to die naturally by discontinuing life-support equipment or medical therapies that extend life without prospects for recovery. Based on the principle of autonomy, such actions can be ethically justified if the patient or their legal representative has made a well-informed decision and understands the consequences (Emilia et al., 2023).

According to (Akdeniz et al., 2021) patient autonomy serves as the primary foundation in end-of-life care, including decisions to discontinue the use of life-support equipment, such

as ventilators, for critically ill patients. If the patient is unable to make their own decisions due to their critical condition, the patient's family can assume the role of representing the patient's autonomy. They are deemed most familiar with the patient's values and desires and are thus best positioned to make decisions aligned with the patient's wishes regarding end-of-life care. The study by (Bachri & Nurnaeni, 2022) further emphasizes that passive euthanasia does not violate the principle of autonomy; rather, it upholds the patient's right to refuse or discontinue treatments deemed futile or that merely prolong suffering. In Indonesia, while active euthanasia is prohibited, the cessation of futile medical treatments, including discontinuing life-support equipment, is legally and ethically recognized in specific circumstances. This is supported by (Peraturan Menteri Kesehatan Nomor 37 Tahun 2014 Tentang Penentuan Kematian Dan Pemanfaatan Organ Donor, 2014) (Suryo et al., 2023).

According to (Emilia et al., 2023) highlight that the principle of autonomy obliges healthcare providers to respect the patient's decisions, even when those decisions involve discontinuing prolonged treatment or interventions. This is particularly relevant for terminal or critically ill patients with no hope of recovery. If the patient is incompetent to make decisions, the family, who is presumed to understand the patient's preferences, has the right to represent them in making critical decisions, including the decision to discontinue life-support equipment. (Sofia J. A, 2021) in an article discussing ethical dilemmas in terminal patient care, also explains that the principle of autonomy provides moral and ethical justification for passive euthanasia, provided that the decision is made by the patient or their family representative based on adequate information. This approach allows patients to die peacefully without unnecessary prolongation of suffering.

In summary, the principle of autonomy supports passive euthanasia on the basis that patients have the right to refuse medical treatments that are no longer beneficial and only prolong suffering without the prospect of recovery. Within the context of ethics and law in Indonesia, the cessation of life-support equipment or ventilators for terminal patients can be morally and legally justified, provided the decision aligns with the patient's wishes or the representation of their autonomy by family members (Suryadi et al., 2021).

However, challenges may arise in implementing this approach. Family members experiencing grief, fear, anxiety, and stress over a loved one's severe illness may struggle to make decisions. If they are unaware of their loved one's preferences for end-of-life care, they may find it difficult to ensure their decision aligns with the patient's best interests. This situation may heighten family members' anxiety and stress. Additionally, family members may have differing preferences about care. While some may unequivocally insist that "everything possible" be done to keep their loved one alive, others may hesitate to limit care and might prefer that medical staff make the decision on their behalf. In such cases, doctors may find themselves in a difficult position. To address this, physicians and other healthcare professionals must possess patient-centered and family-oriented communication skills (Akdeniz et al., 2021).

Healthcare professionals play a crucial role in ensuring that the patient's family receives the necessary information and adequate emotional support to reduce conflict and confusion. Effective communication between healthcare providers and the family is essential in helping

make the best decision for the patient's interest, while respecting the patient's autonomy within the given context. For instance, at RSUD KH. Daud Arif Kuala Tungkal, the medical staff explained to the patient's family why mechanical ventilation was necessary, providing recommendations and explaining the potential impacts. Several factors need to be considered before the installation of mechanical ventilation, including: (a) the family must understand the patient's condition and its severity, (b) the patient or their family must comprehend the reasons behind the recommendation for ventilation, (c) while in the ICU, both the family and the patient need to be aware of what is and is not allowed, (d) the patient or family has the right to receive information about the patient's care process and possible outcomes, and (e) if the family decides they do not want to cause further suffering to the terminally ill patient, they have the right to stop the procedure.

The issue of withdrawing life-sustaining support (LSS) often presents an ethical dilemma, particularly in the context of passive euthanasia. The decision to cease treatment must consider the principles of autonomy, beneficence, non-maleficence, and justice. In this context, the principle of patient autonomy is crucial, as the decision to stop life support should be made by the patient, if mentally capable, or by the family representing the patient when they are no longer able to make rational decisions. In Indonesia, the withdrawal of LSS is regulated by (Peraturan Menteri Kesehatan Nomor 37 Tahun 2014 Tentang Penentuan Kematian Dan Pemanfaatan Organ Donor, 2014), which provides legal protection for patients and families in making end-of-life decisions in accordance with the patient's wishes. Research by (Tungkagi et al., 2023) indicates that the withdrawal of LSS from patients declared brain dead by medical teams is permitted with the consent of the family, ensuring that the decision is made ethically, reflecting the patient's and family's wishes.

However, the practice of passive euthanasia in Indonesia remains a legal and ethical dilemma. The principle of autonomy supports the patient's right to make decisions about their life, including choosing to stop treatment that is no longer beneficial. However, in the context of human rights, Article 28I paragraph (1) of the 1945 Constitution emphasizes that the right to life is a fundamental right that cannot be diminished under any circumstances. Islamic law also views euthanasia as contradictory to religious teachings, as it is considered a form of suicide, which goes against the principles of *tawakal* (trust in God) and acceptance of God's will. Legally, the withdrawal of LSS remains in a gray area, as both the Criminal Code (KUHP) and Law No. 39 of 1999 on Human Rights reject any form of action that ends life, even at the request of the patient or family. Nonetheless, some studies suggest that passive euthanasia can be ethically justified if it aligns with the principle of autonomy, provided the patient or family fully understands the consequences of such a decision. However, the legal system in Indonesia still considers both active and passive euthanasia to be violations of the fundamental right to life, which cannot be infringed upon (Cahyasabrina et al., 2023).

CONCLUSION

Legal protection for patients aims to safeguard all of their rights, including the right to medical information and informed consent, the right to medical confidentiality, the right to refuse treatment and medical procedures, the right to seek a second opinion, and the right to access

medical records. Overall, the principle of autonomy supports passive euthanasia based on the belief that patients have the right to reject medical care that is ineffective and merely prolongs suffering without the hope of recovery. The reasons given by patients or their families for opting for passive euthanasia at RSUD KH. Daud Arif Kuala Tungkal include prolonged physical pain and significantly diminished quality of life. Conditions such as chronic diseases that cannot be cured and cause continuous suffering, including heart disease, kidney failure, or illnesses with a poor prognosis, are often considered when making this decision. In cases where the patient is unconscious, consent for medical procedures is granted by the family, in accordance with the Ministry of Health Regulation No. 290 of 2008 regarding Medical Action Consent. Therefore, it is essential to have patient-centered and family-oriented communication to address ethical dilemmas in critical care, especially those related to the cessation of life support.

ACKNOWLEDGEMENT

The authors would like to acknowledge the insights shared by Nabila Vina (2019), for her invaluable research and interviews with the medical staff at RSUD KH. Daud Arif Kuala Tungkal, which have provided critical insights and data for this study. The author express their deepest gratitude, especially to the supervisors directly involved and to those indirectly involved in helping to publish this scientific paper. The writing team acknowledges that there are many shortcomings in this scientific paper, therefore constructive criticism and suggestion are expected to improve future scientific writings

REFERENCE

- Adlini, M. N., Dinda, A. H., Yulinda, S., Chotimah, O., & Merliyana, S. J. (2022). Metode Penelitian Kualitatif Studi Pustaka. *Edumaspul: Jurnal Pendidikan*, 6(1), 974–980. <https://doi.org/10.33487/edumaspul.v6i1.3394>
- Akdeniz, M., Yardımcı, B., & Kavukcu, E. (2021). Ethical considerations at the end-of-life care. *SAGE Open Medicine*, 9, 20503121211000918. <https://doi.org/10.1177/20503121211000918>
- Bachri, S., & Nurnaeni, N. (2022). Literature Review—Etika Dan Hukum Kesehatan. *Jurnal Berita Kesehatan*, 14(2). <https://doi.org/10.58294/jbk.v14i2.67>
- Cahyasabrina, G. T., Abidahsari, I., Geraldine, M. A. R., Purba, H. A., & Bakhtiar, H. S. (2023). Pengambilan Keputusan Euthanasia Pasif dalam Kehidupan Akhir Pasien: Tinjauan Hak Asasi Manusia. *Jurnal Panorama Hukum*, 8(2), Article 2. <https://doi.org/10.21067/jph.v8i2.9388>
- Emilia, N. L., Samutri, E., Mu'awanah, Sarman, J. N. R., Nurfitriani, Purnomo, H., Tampake, R., Brune Indah Yulitasari, Pont, A. V., Pesak, E., Hesty, Erlin, F., Silfia, A., Puswati, D., & Daryanto. (2023). *Bunga Rampai Etika Dan Hukum Kesehatan*. Media Pustaka Indo.
- Gracia, G., Ramadhan, D. A., & Matheus, J. (2022). Implementasi Konsep Euthanasia: Supremasi Hak Asasi Manusia dan Progresivitas Hukum di Indonesia. *Ikatan Penulis Mahasiswa Hukum Indonesia Law Journal*, 2(1), Article 1. <https://doi.org/10.15294/ipmhi.v2i1.53730>

- Kalaja, P., & Ruohotie-Lyhty, M. (2021). Autonomy and Agency. In *The Routledge Handbook of the Psychology of Language Learning and Teaching*. Routledge.
- Kuuliala, J. (2021). *Chapter 9 Physical Disability and Bodily Difference*. Brill.
https://doi.org/10.1163/9789004468498_011
- Nabila, V. (2019). *Tindakan Pencegahan Euthanasia (Studi di RSUD KH. Daud Arif Kuala Tungkal)* [Universitas Islam Negerisulthan Thaha Saifuddin Jambi].
<https://core.ac.uk/reader/480777114>
- Peraturan Menteri Kesehatan Nomor 37 Tahun 2014 Tentang Penentuan Kematian Dan Pemanfaatan Organ Donor, Pub. L. No. 37 (2014).
- Sofia J. A. (2021). Kajian Penerapan Etika Dokter Pada Pemberian Pelayanan Kesehatan Di Era Pandemi Covid-19. *Jurnal Hukum dan Pembangunan Ekonomi*, 9(1), Article 1.
<https://doi.org/10.20961/hpe.v9i1.52592>
- Suryadi, T., A'la, N., & Kulsum. (2021). Pengetahuan, Sikap, Kesadaran dan Harapan Pegawai Terhadap Eksistensi Komite Etik dan Hukum di RSUD Dr.Zainoel Abidin Banda Aceh. *Journal of Medical Science*, 2(2), Article 2. <https://doi.org/10.55572/jms.v2i2.43>
- Suryo, A. P., Dewi, T. N., & Dhanardhono, T. (2023). Pelindungan Hukum bagi Dokter atas Tindakan Penghentian atau Penundaan Terapi Bantuan Hidup yang Sia-Sia (Futile) pada Pasien Terminal. *Soeptra Jurnal Hukum Kesehatan*, 9(2), Article 2.
<https://doi.org/10.24167/sjkh.v9i2.7156>
- Tungkagi, K., Bawole, H. Y. A., & Lumunon, T. H. W. (2023). Perlindungan Terhadap Pasien Mati Otak Dari Pencabutan Alat Penunjang Hidup Ditinjau Dari Hukum Di Indonesia. *LEX ADMINISTRATUM*, 11(4), Article 4.
<https://ejournal.unsrat.ac.id/v3/index.php/administratum/article/view/48551>
- Undang-Undang Dasar (UUD) Tahun 1945 (1945).
- Undang-Undang Nomor 36 Tahun 2009 Tentang Kesehatan, Pub. L. No. 36 (2009).
- Undang-Undang (UU) Nomor 23 Tahun 2014 Tentang Pemerintahan Daerah, Pub. L. No. 23 (2014).