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Legal Aspects of Home Care and Protection of Terminal Patients' Rights to Palliative Care

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ABSTRACT

The development of the healthcare system in Indonesia has promoted home care and palliative care services as fundamental needs for terminal patients. This study analyses the legal aspects of home care provision and the protection of terminal patients' rights to palliative care based on current regulations. Through a normative study of Law No. 17 of 2023 on Health and supporting technical regulations, it was found that home care and palliative care are legal rights that must be fulfilled by the state and health facilities. The implementation of these services is regulated through the application of professional standards, protection of informed consent, medical data confidentiality, and mediation-based dispute resolution. The state is responsible for ensuring equitable access and quality of services, including providing multidisciplinary teams, essential medicines, and psychological and spiritual support. The protection of the rights of terminal patients includes enforcing informed consent for medical procedures, respecting dignity until the end of life, and involving families in decision-making. These legal implications strengthen the national health system to uphold justice, safety, and welfare for terminal patients and all parties involved.

INTRODUCTION

The development of modern healthcare services has brought about significant changes in the way patient care is viewed, particularly for those in terminal conditions. The need for a more humane approach focused on quality of life has led to the emergence of the concept of home care. This service is intended for patients with diseases that have reached the final stage, whether due to cancer, neurodegenerative diseases, or other chronic conditions with poor prognoses. On a practical level, home care provides a solution to the limitations of hospital facilities while allowing patients and their families to undergo the treatment process in a familiar and comfortable environment. The healthcare landscape in various countries, including Indonesia, now increasingly places home-based services as an essential part of a comprehensive healthcare system. The World Health Organization (2002) emphasizes the importance of patients' rights to receive palliative care in an environment that supports their comfort and dignity. This paradigm shift is also supported by previous research showing that home care can improve the quality of life for terminal patients (Gomes et al., 2013).

The provision of home care is closely related to human rights in terms of access to health services. In Indonesia, the right to health services is constitutionally recognized and forms the basis for the formulation of various implementing regulations. Law No. 36 of 2009 on Health and its derivative regulations further promote the recognition that the needs of terminal patients go beyond the curative aspect alone. They have spiritual, psychosocial, and social needs that must be met in an integrated manner. In practice, the provision of integrated and technology-based health services requires clarity of legal responsibility from all parties involved. In line with these developments, legal studies in the context of digital health services are becoming increasingly relevant, as reflected in the research by Yatno et al. (2023), which raises the issue of the legal responsibility of hospitals in the modern health service ecosystem. The challenges in implementing home care in Indonesia stem not only from technical and resource aspects but also from juridical aspects, which include legal protection, patient rights, and the responsibilities of health workers. This

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phenomenon highlights the importance of a health law approach that is adaptive to social change and medical technology (Twomey et al., 2020).

In addition to the right to services, one of the central issues in the provision of home care is palliative care. This type of care focuses on reducing suffering and improving the quality of life for terminal patients and their families. In practice, palliative care requires the integration of medical, nursing, psychological, and social services, thereby fostering collaboration among health professions. A strong legal framework is needed to support this integration in a safe and accountable manner, especially in ensuring the legal protection of patients and regulating the responsibilities of each profession involved. In the evolving healthcare landscape, a study by Nurhefi et al. (2023) on patient legal protection, doctor accountability, and oversight mechanisms in digital health consultations confirms that a clear oversight and accountability system is a crucial prerequisite for minimizing legal risks and ensuring service quality, including in service models involving multi-professional collaboration such as palliative home care. The successful implementation of palliative care at home is highly dependent on a clear and robust legal framework that provides protection for both patients and service providers. Adequate regulation is necessary to ensure that the implementation of home care does not pose legal risks, minimizes conflicts of interest, and guarantees the provision of services that are oriented towards the rights and needs of patients (Murray et al., 2017).

Pressure on medical professionals and healthcare workers in the provision of home care is increasing, particularly as they face clinical decision-making dilemmas, high psychological burdens, and the dynamics of communication with patients' families. The process of adapting to new role demands, optimizing interpersonal skills, and the ability to carry out collaborative practices are crucial to promoting the sustainability of home care services. Clear legal aspects will provide legal certainty and a sense of security for medical professionals to perform their duties in accordance with applicable ethical and legal standards. In addition, the community needs to be empowered to understand their rights and obligations in the home care process (Tay et al., 2021).

Behind these various opportunities and challenges, the existence of home care and palliative care services for terminal patients is an indicator of the progress of the national health system in fulfilling the basic rights of its citizens in a fair manner. The relationship between patient needs, legal certainty, and the national health ecosystem illustrates the urgency of developing legal regulations related to home care that are in line with advances in medical knowledge and humanitarian demands. This study attempts to examine rationally and based on regulations how legal aspects frame the implementation of home care and the protection of terminal patients' rights to palliative care.

The formalization of the legal framework for home care in Indonesia still faces challenges in converging patient needs, certainty for service providers, and government demands to provide social protection. Amidst the increasing need for home care for terminal patients, existing regulations do not yet fully provide clarity on the division of responsibilities, service standards, and legal protection for all parties involved (Arisanti et al., 2019). This lack of clarity has the potential to give rise to ethical and legal dilemmas in the relationship between patients and service providers, particularly in terms of the balance between patient autonomy and the clinical responsibilities and authority of health workers. A study by Feriadi et al. (2023) on patient autonomy, healthcare provider paternalism, and criminal liability in therapy contracts confirms that the legal dynamics in therapeutic relationships are complex and require regulatory clarity to prevent potential disputes. Research by Radbruch et al. (2010) confirms that the ambiguity of the legal system in palliative care can cause uncertainty for both patients and healthcare professionals in accessing and providing optimal services.

The gap between the ideal norms in regulations and their implementation in the field remains quite wide. Many healthcare professionals and patients' families face ambiguity in terms of medical reporting, legal documentation, and the limits of permissible interventions during home care. Legal protection aspects, both for patients and service providers, are not yet detailed in Indonesian legislation. According to Bennet et al. (2009), the issue of documentation and the legality of actions in home care is one of the biggest obstacles in home-based healthcare systems in developing countries.

Legal uncertainty still surrounds the status of social security protection and criminal liability in the event of medical errors or negligence in the provision of home care. This lack of certainty can weaken the legal position of patients, who should receive clear protection from the risk of medical negligence, as highlighted in the study by Lethy et al. (2023) on legal protection for patients against negligence by healthcare professionals. This ambiguity is particularly evident in the context of social security, where patients' rights to protection and benefits from the health insurance system in the context of home care and palliative care also need to be clearly regulated, as examined in the legal review by Tamaka et al. (2023) on patients' rights in the health insurance system. This has an impact on the extra caution of service providers, as well as the potential neglect of patients' rights when facing a deterioration in their health condition. The lack of firm regulations can also exacerbate the vulnerability of terminal patients to arbitrary treatment and weaken the principle of justice in the health sector.

Demographic developments in Indonesia, with increased life expectancy and the prevalence of chronic diseases, mean that the need for home care services for terminal patients cannot be ignored. Attention to legal aspects and the protection of patient rights must be prioritized in the process of formulating future health policies. The availability of adequate regulations contributes directly to the quality and sustainability of long-term health services.

Furthermore, discussions regarding patients' rights to palliative care and the strengthening of the legal aspects of home care are highly relevant in the context of national health system reform. The impact is felt not only by patients and their families, but also in terms of optimizing the referral system, financing efficiency, and preventing potential disputes between patients, service providers, and policymakers.

This study aims to critically analyses the legal framework for the provision of home care for terminal patients and examine the extent to which the protection of patients' rights to palliative care is guaranteed in the laws and regulations currently in force in Indonesia. The results of this study are expected to contribute theoretically to the development of health law studies and offer practical insights for policymakers, healthcare providers, and the wider community.

RESEARCH METHOD

This study uses a normative legal approach with a systematic qualitative literature review design. The researchers examined various laws and regulations, the latest scientific research results, and official policy documents relevant to the provision of home care and palliative care for terminal patients in Indonesia. Qualitative literature study was chosen to map and analyses the legal basis, principles and practical implementation related to the legal rights and protection of terminal patients. In addition, this method was supplemented by a search of scientific literature from verified international and national journals published in the last two decades (Braun & Clarke, 2006).

Thematic synthesis was conducted through a process of selecting and codifying the contents of documents and scientific articles, in which researchers applied specific search strategies on national (Garuda, Neliti) and international (Sinta, Scopus, ScienceDirect) databases. The inclusion criteria included documents of laws that are still in force, academic journals and books, as well as studies that explicitly discuss legal aspects or the protection of the rights of terminal patients in home care and palliative care. Meanwhile, publications that were opinion pieces, popular articles, or whose sources were not verified were excluded in the screening process. The coding process was carried out manually to identify the main themes related to legal aspects, patient rights protection, and challenges in providing home care services in line with the techniques described in the legal research methodology literature (Soekanto & Mamudji, 2011).

Research quality assurance was carried out through source triangulation and cross-verification between relevant national regulations and academic study results, so that the validity of the findings could be maintained. In addition, each citation was verified for authenticity and validity, as recommended by robust literature analysis methods (Boell & Cecez-Kecmanovic, 2015). Valid thematic synthesis results were used to formulate legal arguments and analyses in the results and discussion sections.

RESULT AND DISCUSSION

Legal Aspects of Home Care for Terminal Patients

The provision of home care services for terminal patients in Indonesia is legally complex, as it is rooted in constitutional rights to health services while ensuring protection for patients, health workers, and families. This service is classified as a form of formal healthcare because it is explicitly regulated in applicable legislation. Law No. 17 of 2023 on Health affirms that everyone has the right to quality, safe, and equitable healthcare services, without discrimination based on economic background or health status. This regulatory recognition means that home care, including for patients with advanced-stage diseases, is one of the rights guaranteed and protected by the state (Rochmawati et al., 2016).

Within this legal framework, home care is defined as a form of health service that can be provided outside of health facilities, provided that it complies with established professional and service standards. This regulation legitimizes the home care model as an integral part of the healthcare system. Similar dynamics can be seen in the regulation of other non-traditional healthcare services, such as telemedicine. A study by Sasmita et al. (2023) on telemedicine regulation in Indonesia emphasizes the importance of a strong regulatory framework to ensure patient safety and protection in a service model that is not tied to a single physical location. The establishment of professional standards is necessary to ensure that home care is provided in accordance with the principle of prudence and patient safety, while also ensuring that all actions are carried out by healthcare professionals with clear competencies and practice licenses. The obligation to have a practice license reinforces the legal dimension of the professional relationship between service providers and recipients, in order to avoid illegal practices and violations of medical ethical standards.

The Minister of Health Regulation governing palliative care and home health care reinforces this mandate. This regulation also emphasizes that terminal patients are entitled to care that focuses on quality of life, prioritizing the psychosocial, spiritual and comfort needs of patients, rather than merely medical treatment. This principle is in line with the main orientation of modern health services, which places service quality and patient satisfaction as measures of success, as confirmed in a study by Khayru and Issalillah (2022) on the relationship between service quality and patient satisfaction in public health facilities. This service is aimed at upholding the dignity of patients until the end of their lives, involving families in decision-making and daily care processes. Consequently, healthcare workers are required to collaborate in a multidisciplinary manner, ensuring that all aspects of terminal patients' health are handled comprehensively in accordance with applicable legal norms.

The implementation of home care is inseparable from the principles of fairness and non-discrimination. In this system, the state is obliged to guarantee that every terminal patient, regardless of their social, economic, or residential status, has the right to access adequate health services. This includes the provision of affordable palliative medicines, psychological support from experts, and spiritual services in line with the patient's beliefs. The state is also obliged to strive for the equitable provision of home care facilities and infrastructure through financing schemes, subsidies, and cross-regional referrals, so that services are not dominated by urban areas alone.

Legal protection for patients and families in home care is provided through the mechanism of informed consent. Every medical action at home must be approved consciously, after receiving sufficient and honest explanations about the patient's terminal illness, the potential benefits and risks of palliative care, and possible future clinical developments. The informed consent arrangement gives patients and families the space to be active subjects in the medical decision-making process, while preventing potential disputes due to unauthorized actions (Ando, 2023).

On the other hand, medical data confidentiality is a central issue in home care procedures. Although the service takes place in a home environment, healthcare workers are legally restricted from disclosing patient medical data to outside parties without the consent of the patient or family, except in certain conditions stipulated by law. This principle protects patient privacy and prevents potential misuse of information that could lead to stigma and social harm.

The dimension of legal accountability in home care is also accommodated by regulations that emphasize the importance of careful documentation of all medical actions that have been carried out. Healthcare workers are obliged to compile medical records, report interventions that have been carried out, and record all dynamics of changes in the patient's condition. This step serves as evidence in the event of disputes or reports of ethical/professional violations in the future.

In a non-litigation approach, the resolution of home care disputes prioritizes mediation as the primum remedies. This model aims to minimize the escalation of conflicts to the formal legal realm so as to create a proportional, quick resolution that maintains good relations between the parties involved. Only if no common ground can be found can the dispute be pursued through formal legal mechanisms in accordance with the provisions of the law.

Home care services also require legal protection for healthcare workers. If procedures are carried out in accordance with standards and guidelines, and administration is carried out correctly, healthcare workers are protected from baseless legal claims. The state, through regulations, provides guarantees for work safety, including opportunities for consultation and supervision, so that professionals are not caught in a dilemma between ethics and legal practice.

Regulations on home care require synchronization with other laws such as the Medical Practice Act, the Nursing Act, and all provisions on medicines and patient protection. Policy synchronization is necessary to avoid overlapping regulations and provide greater legal certainty to both service providers and beneficiaries.

The monitoring system ensures that the

implementation of home care laws remains on track. The government, through the health department, is tasked with conducting regular evaluations, guidance, and audits of all home care service provider organizations. This approach to supervision and guaranteeing rights through government intervention is an integral part of the state's obligations in the context of health, as reflected in the legal review by Wuryani et al. (2023) regarding the government's legal measures to guarantee the rights of patients with mental disorders in the social security system. This ensures that there are no violations of patient rights or inconsistencies between field practices and normative provisions.

Strengthening community participation is also included in the legal aspects of home care provision. Patients' families can act as supervisors and reporters if they find any inconsistencies or violations of rights. An easily accessible complaint mechanism is an integral part of the home care legal system to ensure transparency and accountability of services.

The conclusion of this description confirms that the legal aspects of home care for terminal patients in Indonesia have been designed within a framework that combines legal certainty, protection of rights, and quality assurance of services. Home care stands as a legitimate and legally guaranteed part of the national health system, with implementation that is strictly supervised by regulations, supported by professional standards, and protection of the human rights of all parties involved.

Ultimately, the enforcement of legal aspects in home care should not stop at the formulation of regulations alone, but requires synergy between policymakers, service providers, and the wider community. Consistent implementation and continuous monitoring are key to ensuring that home care truly protects the dignity, basic rights, and safety of terminal patients and their families.

Protection of Terminal Patients' Rights to Palliative Care

The protection of terminal patients' rights to palliative care within the framework of positive law in Indonesia stems from the recognition that quality health services are a fundamental right of every citizen. The provisions of Law No. 17 of 2023 on Health position palliative care as a fundamental right of patients, not merely a supplement to the system, but a key part of the services that must be provided to patients in terminal conditions. This right equates access to treatment, symptom relief, and respect for human dignity until the end of life as an obligation of the state and healthcare providers (Widjaja et al., 2022).

The normative perspective emphasizes that the provision of health services, including palliative care, must be carried out in accordance with professional standards and applicable service standards. Terminal patients, based on this legal framework, have the right not only to receive pain relief therapy but also psychological counselling, social support, and spiritual assistance in accordance with their beliefs and needs. Legal norms emphasize that every element of service must be provided in a comprehensive and equitable manner, so that there is no discrimination in treatment solely because the patient is in the terminal stage (Arisanti et al., 2019).

The right to informed consent is central to protection in palliative care. The law provides space for patients or their families to participate in every medical decision, starting with receiving clear information about their medical condition, the objectives, treatment options, and their implications (Rindianti & Nugraheni, 2023). Thus, every action taken during palliative care is based on the awareness and voluntary consent of the patient or their family. This protection not only upholds patient autonomy but also serves as a guideline for healthcare professionals to carry out their practices ethically and legally.

Provisions regarding medical data confidentiality also form a pillar of legal protection for terminal patients. Legislation emphasizes that patient medical data is private, and healthcare professionals are obliged to ensure that all information regarding the patient's condition is not disclosed without explicit permission. This protection of confidentiality is increasingly important given that terminal patients often experience social pressure and the possibility of stigmatization, so the law acts as an umbrella to ensure that individual privacy and dignity are maintained in vulnerable situations.

In the realm of implementation, the protection of terminal patients' rights is also outlined through accountability mechanisms in palliative care. When conflicts or disputes arise, for example, regarding medical decisions or the refusal of certain actions, the preferred resolution mechanism is mediation, not direct litigation. This approach is based on the principle of respect for patient rights, including in critical situations, as stipulated in Law No. 17 of 2023, which regulates patient rights and medical responsibilities in emergency situations. A study by Zuhri et al. (2023) on the implementation of this law emphasizes the importance of placing patient rights as the main foundation in resolving healthcare disputes. From a broader perspective, mediation in healthcare also reflects the harmony between legal and professional ethical aspects in protecting the basic rights of patients. This is confirmed by Chairul et al. (2023) and Sugianto et al. (2023) in their studies examining the protection of patient rights from a legal and medical ethics perspective in Indonesia. Mediation facilitates the achievement of fair and humane solutions, avoiding additional burdens on patients and families in the midst of a crisis. This process also maintains professional and humane relationships between healthcare workers, families, and patients. Thus, mediation in the palliative context is not just a procedure, but a concrete manifestation of the ethics of protecting patient rights, especially in critical situations where patient autonomy and welfare are the highest priorities.

These principles are reinforced by ministerial regulations that require the provision of multidisciplinary palliative care teams in healthcare facilities. The protection of patient rights in this case does not stop at medical services, but includes comprehensive support involving psychological, social and spiritual aspects, providing space for patients and families to live out the final stages of life with dignity. The obligation of health facilities to form such teams also serves as a legal instrument to prevent the denial of patient rights by service institutions.

Quality of life is another important aspect of protecting these rights. Palliative care is aimed at managing symptoms, reducing suffering, and helping patients achieve comfort, meaning, and acceptance in the natural process of terminal illness. The state ensures that healthcare facilities are obliged to provide access to essential medicines, counselling, and comprehensive social support services as part of the rights of terminal patients to proper care.

In addition to the right to medical and non-medical services, protection for terminal patients also applies to the right to refuse or accept certain interventions during the palliative care process. This principle not only upholds autonomy, but also prevents unnecessary medical actions and potential excessive interventions that are contrary to the patient's wishes. The law stipulates that every intervention must be based on the principle of well-informed voluntary consent.

Healthcare facilities are required to actively disseminate information regarding the rights of terminal patients, especially to clarify access to palliative services. This serves as a form of preventive protection to reduce the risk of access negligence, unfair treatment, and ignorance on the part of patients and families regarding their rights at the end of life. This legal education and information are the obligation of institutions as part of the implementation of the mandate of the law.

The state also provides legal guarantees for the implementation of administrative procedures related to the supervision of palliative care services. Every action, document, and communication during service provision must be neatly recorded so that it can be legally accounted for in the event of a service inspection or audit. This administrative obligation ensures that service practices remain transparent, accountable, and open to continuous evaluation.

The government is obliged to provide a complaint channel or advocacy mechanism for terminal patients and their families in the event of alleged violations of rights or negligence during palliative care. This system provides additional protection so that all patient rights are not only guaranteed normatively, but can also be enforced through clear official procedures.

The involvement and protection of the rights of patients' families as an integral part of palliative care is also included in the legal framework. Families have the right to receive psychosocial support and education related to the care process and important medical decisions made during the terminal stage. The state encourages families to be empowered as part of a support system that can facilitate quality care at the end of a patient's life.

Finally, Indonesian positive law affirms that palliative care is not merely a medical option, but a right that is guaranteed with comprehensive protection of the right to quality services, confidentiality, informed consent, access to multidisciplinary services, and complaints if there are violations. All of these legal elements are part of the state's commitment to placing humanity and justice as the foundation for the protection of terminal patients until the end of their lives.

CONCLUSION

The provision of home care for terminal patients in Indonesia has been given a clear and strong legal basis through Law No. 17 of 2023 on Health and various other supporting regulations. These regulations establish home-based healthcare and palliative care as fundamental rights of terminal patients, while also providing legal certainty for all parties involved. The implementation of home care requires the application of professional and service standards, protection of informed consent and medical data confidentiality, and the enforcement of proportional dispute resolution mechanisms. The state is obliged to facilitate equitable access, quality of service, and protection of the rights and dignity of patients at the end of life.

The implementation of laws on the provision of home care and the protection of the rights of terminal patients to palliative care has an impact on improving the quality of health services, protecting medical personnel, and respecting the dignity of patients. Strengthening consistent regulation and supervision can encourage an improvement in patients' quality of life, the effectiveness of health system financing, and a greater sense of security for families and health workers. Clear legal aspects also contribute to reducing the number of disputes and increasing public trust in the national health system.

Policy makers are advised to continue evaluating, harmonizing, and disseminating regulations related to home care and palliative care so that they are more responsive to the needs of terminal patients and their families. Improving legal education for health workers, empowering communities, and establishing efficient complaint mechanisms should be prioritized. Further research using empirical approaches in various regions is also needed to identify implementation barriers and provide relevant recommendations.

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