

DISCLOSURE OF FINAL STADIUM PATIENTS' DIAGNOSIS REVIEW FROM LAW AND BIOETHICS IN INDONESIA

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Abstract: The relationship between doctor-patient rights and obligations, especially in hospitals, cannot be separated from conflicts or disagreements. These conflicts usually occur in special conditions that cause dilemmas in decision-making by doctors. Disclosure of the truth of the diagnosis in terminal patients or those suffering from the end-stage disease is an ethical and legal issue that often occurs in health services. Problems that occur, where on the one hand if the doctor tells the truth (reveals the truth) regarding the diagnosis/disease and on the other hand the doctor is worried that revealing the truth will have an impact that can worsen the patient's condition such as making the patient more depressed so that the patient can refuse further treatment. But on the other hand, patients have the right to know information related to their illness. This research was conducted with a normative review approach. The results of this study found that disclosure of the truth about end-stage disease can cause disturbances in psychological aspects and can potentially affect the patient's quality of life. The legal approach in disclosing the truth of end-stage disease through Law Number 36 of 2009 concerning health, Law Number 44 of 2009 concerning hospitals, and Law Number 29 of 2004 concerning medical practice is not fully the basis for the implementation of doctors in conveying the truth. Therefore, the bioethical aspect approach in this case through the principles of non-maleficence and respect for autonomy, truth disclosure can be done ethically and can minimize the negative impact of truth disclosure.

Keywords: Truth Disclosure; Final Stadium; Law; Bioethics; Indonesia

I. INTRODUCTION

The doctor-patient relationship is constantly changing and evolving with the changing times (Kaba & Sooriakumaran, 2007). The change from the application of paternalistic principles towards the principle of respecting the patient's decisions Paternalistic or often towards the will of the doctor, which always prioritizes goodness and non-maleficence/avoiding harm to patients without patient decisions (autonomy). On the other hand, the principle of respecting the patient's decision (autonomy) because it involves the patient in making treatment decisions or actions (Seshadri, 2020). From this relationship, the doctor-patient rights and obligations arise.

The relationship between doctor-patient rights and obligations, especially in hospitals, cannot be separated from conflicts or disagreements. These conflicts usually occur in special conditions that cause dilemmas in decision-making by doctors (Vizcarrondo, 2019). One of these special conditions is the correct diagnosis in terminal patients or those suffering from the end-stage disease. This

certainly creates a dilemma for a doctor where on the one hand if the doctor tells the truth regarding the diagnosis/disease and on the other hand, from a trusted doctor it has an impact that can improve the patient's condition so that it makes the patient depressed, may refuse further treatment (Mitchell, 1998). But on the other hand, patients have the right to know information related to their disease.

Confidentiality of information on the condition of patients with advanced disease is still a dominant practice in many countries (Surbone, 2006). Research conducted in Turkey (Buken, 2003) said that the truth in patients with terminal cancer requires an ethical and legal approach with due regard to ethical, social, and local cultural aspects. The same thing in research (Zhang & Min, 2020) is the truth and its implementation in terminal illness in patients who need careful consideration by looking at cultural aspects, understanding individual differences, and compliance with relevant laws and regulations.

In addition, according to the law Number 44 of 2009 concerning hospitals in article 29 it is stated that hospitals are obliged to provide true, clear, honest information about the rights and obligations of patients. It is also stated in article 52 of Law No. 29 of 2004 that patients have the right to get a complete explanation of medical actions in accordance with article 45 paragraph 3 (diagnosis and procedures for medical treatment, purpose of action, other alternative actions, risks and complications that may occur, prognosis). of the action taken). From the two things above that, the truth of the patient's disease has been regulated, but there are no specific rules for certainty in patients with special conditions such as end-stage cancer. This is certainly a consideration because the treatment that is believed to be in patients with terminal diseases and patients who do not suffer from terminal diseases is certainly different.

Researchers conduct reviews and related research related to the truth of the diagnosis of end-stage patients in terms of law and medical ethics with keywords (tell the truth, end-stage search patients, law, ethics) in Indonesia is still limited. Therefore, the research that will be carried out by researchers is relatively new and has not been carried out by other studies. From this, the researcher wants to conduct a normative review and research on the correctness of the diagnosis of end-stage patients in terms of household law in Indonesia.

II. RESEARCH METHOD

This research method uses a normative juridical (Al-Fatih & Siboy, 2021) and bioethical method approach, where the focus of the study includes the rules and norms in positive law. Meanwhile, the aim of the research is to provide a systematic description of the rule of law and bioethics in revealing the truth of end-stage disease.

III. RESULTS AND DISCUSSION

Impact of Revealing the Truth of End-stage

Disease End-stage disease is a disease that is difficult to cure and its condition has spread, based on the Decree of the Minister of Health of the Republic of Indonesia Number: 812/Menkes/SK/VII/2007, increasing the number of patients with uncured diseases, both in adults and children, such as infectious diseases such as HIV. AIDS, degenerative diseases, lung diseases and one of them is cancer. Cancer is a disease that begins when abnormal cells are altered by genetic mutations of cellular DNA. These abnormal cells form clots and begin to proliferate abnormally. These cells infiltrate surrounding tissues and gain access to lymph and blood vessels, through these

vessels cells can be carried to other areas of the body for metastasis (spread of cancer) in other parts of the body (Irawan, 2013).

There are 4 stages or stages of malignancy of cancer, namely stages I, II, III, and IV. More specifically, the stages of cancer are divided into stages IA, IB, and IIA, which are called early invasive cancer stages, and stage IIB, stage IIIA-IIIIB, and stage IVA-IVB, or invasive cancer stages. In patients with late or advanced cancer, there is usually a delay in diagnosis or starting treatment at an advanced stage so it affects the poor prognosis of cancer patients (Polesel et al., 2017). Prognosis is a doctor's prediction where the patient's condition will develop and there will be a recovery process. The purpose of the prognosis is to communicate predictions of the patient's future condition with the disease he has suffered (Arifiyani & Purnami, 2020).

End-stage conditions in cancer patients generally cause impacts that can occur so that the patient's condition will continue to decline, psychological conditions in end-stage cancer patients also affect the state of their organs. Patients who are already in the final stage are usually easily discouraged and depressed, which causes the system in the body to decline. The dominant aspect of forming the quality of life of cancer patients is the psychological aspect, including spirituality, social support, and welfare (Carolina et al., 2021). In fact, the psychological aspect greatly determines the quality of life, sufferers gain strength and feel healthier without drugs, this is due to suggestions within the individual to stay healthy. Spiritual intelligence leads the sufferer to have self-acceptance of his illness. Patients experience spiritual improvement compared to before suffering from cancer (Anita, 2016). Sufferers feel closer to God and do not blame God, but consider it a gift from God. The love and comfort of social support provide motivation to heal and be strong in life. Finally, providing welfare that determines the patient's quality of life. However, in end-stage cancer patients, the level of depression and worry is usually increasing (Surbone, 2006).

Disclosure of Truth Judging from the Law

Disclosure of truth is defined in Indonesian law as the right of patients to obtain information about their health data. This is stated in Law Number 36 of 2009 concerning health, Number 44 of 2009 concerning hospitals, and Law Number 29 of 2004 concerning medical practice. Article 8 of Law Number 36 of 2009 states that everyone has the right to obtain information about their health data, including actions and treatments that have been given by health workers. Information on patient health data can be in the form of diagnostics and procedures for medical action, the purpose of the medical action taken, alternative actions and risks, and risks and complications that may occur. As well as the prognosis of the actions taken. This is stated in Law Number 29 of 2004 article 45. In addition, at the health service level, Law Number 44 of 2009 concerning Hospitals explains in article 29 that hospitals are obliged to provide correct, clear, and honest information regarding the rights and the obligations of the patient, and Article 32 states that the patient has the right to receive information which includes the diagnosis and procedure of medical action, the purpose of the medical action, alternative actions, risks and complications that may occur, and the prognosis of the action taken as well as the estimated cost of treatment.

From the articles relating to the provision of diagnostic information above, it can be said that how severe the diagnosis is and how bad the prognosis of a disease is, the patient needs to be informed of the condition of the disease correctly, clearly, and honestly. In addition, in the above rules, there is no separation of certain diagnoses in the delivery of information, so conveying bad news related to

certain diagnoses is considered the same as conveying related to other disease diagnoses that do not have a poor prognosis or severity of the disease.

The law above implies that health workers or health providers are obligated to provide information related to the patient's diagnosis. The obligation relates to sanctions if there is a failure in the delivery of information. The sanctions in Law Number 44 of 2009 concerning hospitals article 29 are in the form of reprimands, verbal warnings, fines, and revocation of hospital permits. Meanwhile, Law number 29 of 2004 concerning medical practice describes disciplinary sanctions in the form of written warnings, recommendations for revocation of practice, and the obligation to attend training or education provided by the Indonesian Medical Discipline Honorary Council.

The existence of sanctions for failure to deliver this information has the potential to make medical personnel in delivering information not consider the impact on their patients. Submission of information in this case conveying the truth related to bad or negative news (late-stage disease diagnosis) can certainly change patients' views about their future (Buckman, 1984). This is where it is necessary to pay attention to the impact of truth disclosure, where from the legal aspect there is no difference in the treatment of truth disclosure related to the final stage of diagnosis. Therefore, the law is not sufficient as an approach as a solution to reveal the truth regarding patients with end-stage diagnoses

Disclosure of Truth Seen from Bioethics

Bioethics is defined by UNESCO (The United Nations Educational Scientific and Cultural Organization) as the analysis of ethical issues arising from the life sciences, applications of technology, and regulations in the fields of medicine and health. There are several ethical concepts that are considered when making ethical decisions, namely autonomy, nonmaleficence, beneficence, justice, loyalty, and truth (Wijaya et al., 2022). If there are contradictions between these ethical concepts, the process of making ethical decisions will be a challenge.

Respect for autonomy is defined as respect for autonomous decisions made by a competent person (patient, research subject, or legal representative) in the field of health and research. Nonmaleficence is defined as an obligation not to cause harm and an obligation not to expose a person to potential harm. Beneficence is an act that is mandatory to do good and provide benefits to others. While justice is defined as distributive justice, procedural justice, retributive justice, and restorative justice (Childress & Beauchamp, 2022).

The process of openness in the diagnosis of cancer involves two parties, the doctor and the patient, usually, the third party is a spouse or close relative. The patient's openness to cancer has several factors to consider and there are several things that a doctor considers not disclosing the disease to patients. Among them are caused by:

- 1) Fear of causing psychological morbidity in patients. Research findings related to truth-telling regarding the end-stage disease of patients have been widely carried out, but this has changed. Some studies do not support the concealment of the truth of the diagnosis or prognosis of the disease, especially in patients with end-stage disease. This is because patients will seek the truth themselves and raise suspicions through intensive care or the side effects of drugs that patients get. This can potentially cause psychiatric disorders (Atesci et al., 2004).
- 2) The patient has no curiosity about his illness. Patients are not interested in knowing about their disease, it is assumed from the perspective of cultural background, but some studies say that patients prefer to be informed about the diagnosis of their disease. However, some studies

have found that groups of patients are reluctant to be fully informed about their diagnosis or prognosis. This study emphasizes that in providing disease information, patients can consider individual preferences regardless of the patient's background (Fallowfield et al., 2002).

3) The doctor's personal psychological interest in revealing the truth Communication between doctors and patients about cancer diagnosis and prognosis is difficult, not only for patients as recipients of information but also for doctors who bear the psychological pressure of presenting bad news. Research has shown that doctors don't feel comfortable taking too many expectations from patients. Medical students experience more stress when they have to reveal cancer diagnoses and terminal prognoses to patients compared to students who hide the truth (Panagopoulou et al., 2008).

4) Requests from the patient's family not to reveal the truth Family is the strongest factor in revealing the truth of the diagnosis not to tell the patient, in order to protect his psychology. Many reports reveal that not informing the patient about his illness is a way of psychologically protecting the patient. Some cultures are concerned with revealing that withholding information or not revealing the truth is ethical behavior because it is motivated by an element of kindness to do good (Smajdor et al., 2021).

5) Other factors The lack of legal and ethical guidelines regarding the delivery of bad news, as well as communication training, emotional skills, and inexperience, have contributed to the confusion of doctors about what to do in dealing with dilemma cases related to disclosing the truth of a terminal patient's diagnosis (Sarafis et al., 2013). The lack of sufficient time to communicate between doctor-patients causes the patient's diagnosis not to be conveyed properly (Sarafis et al., 2013).

In revealing the truth, medical personnel, in this case doctors, must consider aspects of the principles of bioethics, which in this case the principle of nonmaleficence as *prima facie*. *Prima facie* is an obligation that intuitively just appears but in subsequent developments it can change if there are other obligations that are more fundamental. Aspects of the principle of nonmaleficence in revealing the truth, looking at the impact whether it is negative or potentially causing "harm" or having a positive impact on the patient, so it is necessary to first ascertain the patient's characteristics and prepare communication techniques in conveying the truth of bad news related to the diagnosis and prognosis of end-stage disease (Prawiroharjo et al., 2020).

In the management of conveying the truth regarding the late-stage diagnosis, of course, it is necessary to pay attention to the characteristics of the individual or patient. The character between one individual and another is certainly different and cannot be generalized. This is influenced by a person's background which is different from many aspects such as age, gender, culture, ethnicity, religion, education, and so on (Fallowfield et al., 2002). *Prima facie*, the application of the principle of nonmaleficence must be ensured that it does not cause harm, so that further disclosure of the truth can be carried out by applying respect for autonomy to the patient, in which case the doctor explains the diagnosis, examination plan, treatment plan to prognosis which is carried out with open discussion with the patient, and so on. recognize the forms of hope that patients want in the face of serious or end-stage disease (Clayton et al., 2008).

IV. CONCLUSION

Disclosure of the truth about end-stage patients is an ethical issue that needs attention. The truth-telling approach can not only be viewed from one aspect, but many factors need to be considered. Handling the management of revealing the truth of end-stage disease cannot be separated from human characters that are different from one another. Therefore, the approach of generalizing a policy certainly cannot be used as a guide. The policy of disclosing the truth of the diagnosis in dealing with issues, especially in the late-stage diagnosis, is required to complement the principles of bioethics as a solution in the implementation of the disclosure of the diagnosis, especially in late-stage disease.

REFERENCES

- Al-Fatih, S., & Siboy, A. (2021). *Menulis Artikel Karya Ilmiah Hukum di Jurnal Nasional dan Internasional Bereputasi*. Inteligencia Media.
- Anita, A. (2016). Perawatan Paliatif dan Kualitas Hidup Penderita Kanker. *Jurnal Kesehatan*, 7(3), 508. <https://doi.org/10.26630/jk.v7i3.237>
- Arifiyani, N., & Purnami, S. W. (2020). Indeks Prognostik Pada Pasien Kanker Serviks di RSUD dr. Soetomo Surabaya Menggunakan Model Regresi Cox Extended. *Inferensi*, 3(1), 37. <https://doi.org/10.12962/j27213862.v3i1.6880>
- Atesci, F. C., Baltarli, B., Oguzhanoglu, N. K., Karadag, F., Ozdel, O., & Karagoz, N. (2004). Psychiatric morbidity among cancer patients and awareness of illness. *Supportive Care in Cancer*, 12(3), 161–167. <https://doi.org/10.1007/s00520-003-0585-y>
- Buckman, R. (1984). Breaking bad news: why is it still so difficult? *British Medical Journal (Clinical Research Ed.)*, 288(6430), 1597 LP – 1599. <https://doi.org/10.1136/bmj.288.6430.1597>
- Buken, N. O. (2003). *Truth-telling information and communication with cancer patients in Turkey*.
- Carolina, P., Hermanto, H., & Katimenta, K. S. Y. (2021). Hubungan Pemenuhan Kebutuhan Spiritual dengan Kualitas Hidup Pasien Kanker. *Jurnal Surya Medika*, 7(1), 140–145. <https://doi.org/10.33084/jsm.v7i1.2112>
- Childress, J. F., & Beauchamp, T. L. (2022). Common Morality Principles in Biomedical Ethics: Responses to Critics. *Cambridge Quarterly of Healthcare Ethics*, 31(2), 164–176. <https://doi.org/10.1017/S0963180121000566>
- Clayton, J. M., Hancock, K., Parker, S., Butow, P. N., Walder, S., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., Olver, I. N., & Tattersall, M. H. N. (2008). Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology*, 17(7), 641–659. <https://doi.org/10.1002/pon.1288>
- Fallowfield, L. J., Jenkins, V. A., & Beveridge, H. A. (2002). Truth may hurt but deceit hurts more: communication in palliative care. *Palliative Medicine*, 16(4), 297–303. <https://doi.org/10.1191/0269216302pm575oa>
- Irawan, E. (2013). Pengaruh perawatan paliatif terhadap pasien kanker stadium akhir (literature review). *Jurnal Keperawatan BSI*, 1(1). <https://doi.org/https://doi.org/10.31311.v1i1.84>
- Kaba, R., & Sooriakumaran, P. (2007). The evolution of the doctor-patient relationship. *International Journal of Surgery*, 5(1), 57–65. <https://doi.org/10.1016/j.ijsu.2006.01.005>

- Mitchell, J. L. (1998). Cross-Cultural Issues in the Disclosure of Cancer. *Cancer Practice*, 6(3), 153–160. <https://doi.org/10.1046/j.1523-5394.1998.006003153.x>
- Panagopoulou, E., Mintziori, G., Montgomery, A., Kapoukranidou, D., & Benos, A. (2008). Concealment of Information in Clinical Practice: Is Lying Less Stressful Than Telling the Truth? *Journal of Clinical Oncology*, 26(7), 1175–1177. <https://doi.org/10.1200/JCO.2007.12.8751>
- Polesel, J., Furlan, C., Birri, S., Giacomarra, V., Vaccher, E., Grando, G., Gobitti, C., Navarria, F., Schioppa, O., Minatel, E., Bidoli, E., Barzan, L., & Franchin, G. (2017). The impact of time to treatment initiation on survival from head and neck cancer in north-eastern Italy. *Oral Oncology*, 67, 175–182. <https://doi.org/10.1016/j.oraloncology.2017.02.009>
- Prawiroharjo, P., Meilia, P. D. I., & Hatta, G. F. (2020). Etika Menyampaikan Informasi Diagnosis Penyakit Terminal kepada Pasien sesuai Konteks Budaya Indonesia. *Jurnal Etika Kedokteran Indonesia*, 4(1), 13. <https://doi.org/10.26880/jeki.v4i1.41>
- Sarafis, P., Tsounis, A., Malliarou, M., & Lahana, E. (2013). Disclosing the truth: a dilemma between instilling hope and respecting patient autonomy in everyday clinical practice. *Global Journal of Health Science*, 6(2), 128–137. <https://doi.org/10.5539/gjhs.v6n2p128>
- Seshadri, K. (2020). Doctor–Patient Communication. In *Effective Medical Communication* (pp. 49–61). Springer Singapore. https://doi.org/10.1007/978-981-15-3409-6_5
- Smajdor, A., Herring, J., & Wheeler, R. (2021). *Oxford Handbook of Medical Ethics and Law*. Oxford University Press.
- Surbone, A. (2006). Telling the truth to patients with cancer: what is the truth? *The Lancet Oncology*, 7(11), 944–950. [https://doi.org/10.1016/S1470-2045\(06\)70941-X](https://doi.org/10.1016/S1470-2045(06)70941-X)
- Vizcarrondo, F. E. (2019). Medical Futility in Pediatric Care. *The National Catholic Bioethics Quarterly*, 19(1), 105–120. <https://doi.org/10.5840/ncbq20191919>
- Wijaya, Y. A., Yudhawati, N. L. P. S., & Andriana, K. R. F. (2022). *The Role Of Nurses In Ethical Decision Making: In Literature Review Perspective*. <https://doi.org/https://doi.org/10.31219/osf.io/rs8pa>
- Zhang, Z., & Min, X. (2020). The Ethical Dilemma of Truth-Telling in Healthcare in China. *Journal of Bioethical Inquiry*, 17(3), 337–344. <https://doi.org/10.1007/s11673-020-09979-6>