

Opinion

Medicine General & Health Policy



For the Universal Right to Access Quality End-of-Life Care in Korea: Broadening Our Perspective After the 2018 Life-Sustaining Treatment Decisions Act

Hye Yoon Park ^{1,2} Min Sun Kim ^{2,3,4} Shin Hye Yoo ² Jung Lee ³
In Gyu Song ⁵ So Yeon Jeon ^{6,7} and Eun Kyung Choi ⁸



Received: Dec 31, 2023

Accepted: Mar 18, 2024

Published online: Mar 26, 2024

Address for Correspondence:

Hye Yoon Park, MD, PhD

Department of Psychiatry, Seoul National University Hospital, Seoul National University College of Medicine, 101 Daehak-ro, Jongno-gu, Seoul 03080, Korea.
Email: hypark@snu.ac.kr

© 2024 The Korean Academy of Medical Sciences.

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<https://creativecommons.org/licenses/by-nc/4.0/>) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.

ORCID iDs

Hye Yoon Park

<https://orcid.org/0000-0003-4114-5102>

Min Sun Kim

<https://orcid.org/0000-0001-5323-9857>

Shin Hye Yoo

<https://orcid.org/0000-0001-7473-1082>

Jung Lee

<https://orcid.org/0000-0001-8074-105X>

In Gyu Song

<https://orcid.org/0000-0002-3205-9942>

So Yeon Jeon

<https://orcid.org/0000-0002-3656-1593>

Eun Kyung Choi

<https://orcid.org/0000-0003-1448-1565>

¹Department of Psychiatry, Seoul National University Hospital, Seoul National University College of Medicine, Seoul, Korea

²Center for Palliative Care and Clinical Ethics, Seoul National University Hospital, Seoul, Korea

³Center for Integrative Care Hub, Seoul National University Hospital, Seoul, Korea

⁴Department of Pediatrics, Seoul National University Hospital, Seoul, Korea

⁵Department of Pediatrics, Yonsei University Severance Children's Hospital, Seoul, Korea

⁶Department of Psychiatry, Chungnam National University Hospital, Daejeon, Korea

⁷Department of Psychiatry, College of Medicine, Chungnam National University, Daejeon, Korea

⁸Department of Medical Humanities and Medical Education, School of Medicine, Kyungpook National University, Daegu, Korea

In a 2023 survey, 46.9% of the public and 77.2% of physicians disagreed that Korean people can die with dignity, citing the administration of life-sustaining treatment (LST) against patients' wishes as the main reason in one-third of both groups,¹ which is consistent with the results of the previous studies in Korea.^{2,3} Almost six years have elapsed since the enactment of "the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life" (LST Decisions Act) in 2018. Despite the remarkable development of medicine in Korea, people could not expect to have access to quality end-of-life (EoL) care. We will discuss this issue within the legal framework represented by the LST Decisions Act as the one of the major determinants for the EoL care pathway.⁴

Notably, EoL care requires an approach that is different from other medical care.⁵⁻⁷ In the early stages of a life-threatening illness, a patient and healthcare providers strive to cure or prolong life, sometimes using high-risk interventions. However, as the disease becomes incurable, treatment benefits diminish, leading to additional burdens from treatment itself, especially at the EoL. As care goals shift to minimizing suffering and maximizing comfort, the judicious avoidance of "futile" or "disproportionate" treatments becomes essential even if highly advanced interventions are available.⁸ Respecting a patient's EoL preferences becomes critical, as care needs vary with declining physical ability and the irreplaceable nature of this final phase. Also, terminal patients must have access to proper comfort care to reduce physical and mental suffering. Thus, the right to refuse burdensome treatments according to a patient's wishes and palliative care (PC) access at the EoL are critical.

To ensure them, many countries have their own legal frameworks and EoL care system, which have been implemented in Korea through the LST Decisions Act.⁹ The Act aims to protect human dignity and values by ensuring patients' best interests and respecting their self-determination.¹⁰ It encompasses two key frameworks: the LST decision-making process

Funding

This work was supported by the National Research Foundation of Korea (NRF) grant funded by the Korean government (Ministry of Science and ICT) (No. 2021R1F1A1060129).

Disclosure

The authors have no potential conflicts of interest to disclose.

Author Contributions

Conceptualization: Park HY, Kim MS, Yoo SH, Lee J, Song IG, Jeon SY, Choi EK. Formal analysis: Park HY. Investigation: Park HY. Validation: Park HY, Choi EK. Funding: Park HY. Writing - original draft: Park HY. Writing - review and editing: Park HY, Kim MS, Yoo SH, Lee J, Song IG, Jeon SY, Choi EK.

and PC provision.¹¹ Despite disagreements on consolidating these frameworks,¹² it reflects a social consensus that both are essential for preserving patient dignity and values. It has changed prevailing landscape of EoL care in Korea, allowing for avoiding LST following a patient's wishes and promoting nationwide PC.¹³⁻¹⁵ However, critical issues within the Act may still pose potential limitations to the right to optimal EoL care.

Restriction of the Right to Refuse Unwanted and Burdensome Treatments

Self-determination is a fundamental ethical principle in health care referring to a patient's right to accept or reject medical recommendations as an "informed consent".¹⁶ In Korea, this principle stems from the right to human dignity and the pursuit of happiness, as outlined in Article 10 of the Constitution as mentioned in the Supreme Court's Judgment for the Severance Hospital case.¹⁷ The LST Decisions Act marks a crucial step in acknowledging this constitutional right to self-determination in a medical context for the first time in Korea, and significant changes in respecting patient autonomy have been demonstrated after its enactment.¹⁸

It is reasonable to expect self-determination to extend to all individuals at the EoL unless a sensitive exception exists. Although such an exception should be carefully balanced with the right, the Act restricts it extensively regarding timing and intervention type. Forgoing LST is allowed only during the "dying process," distinct from the "terminal phase."¹² Originally intended as safeguards,¹¹ these restrictions narrow the window for patients to make decisions and they cannot benefit by avoiding disproportionate treatments. With the estimation of EoL patients that followed the process required by the Act only as 20–25%,⁹ several studies found that the use of intensive care unit hospitalization, ventilator, and cardiopulmonary resuscitation did not differ after legalization, suggesting that this restriction may lead to potential delays in avoiding LST.¹⁹⁻²¹ It may be an excessive violation of the rights of EoL patients who have not been judged as being actively dying despite the burden of treatment and goal of care at the terminal phase are not significantly different compared to the dying phase. Moreover, when a patient has a non-cancerous condition, such as organ failure or dementia, these limitations are more pronounced, as distinguishing the dying phase from the terminal phase is challenging.²²

Furthermore, the Act permits a patient's refusal of specific medical interventions (e.g., cardiopulmonary resuscitation, hemodialysis, anticancer chemotherapy, ventilator, transfusion, *extracorporeal membrane oxygenation* and vasopressors), excludes other therapeutic options like artificial feeding or antibiotics, and stipulates that nutrition and hydration should not be discontinued, ostensibly to uphold the right to life.¹² Consequently, it is difficult to decide on these interventions according to a patient's wishes or a specific benefit/risk analysis. This approach poses challenges especially in advanced dementia and persistent vegetative states, where a patient is unable to decide if their wishes and preferences can be assumed. Thus, a significant gap exists between patient autonomy and the current legal constraints. Moreover, as the family structures have changed and single-person household numbers have surged,²³ the limitation of allowing only immediate family members to be surrogate decision makers no longer consistently reflects a patient's will in cases of estranged or conflicting family relationship.

Limited Access to PC Based on Disease Type

The Act also provides the legal framework for hospice-PC,¹¹ which is defined as the comprehensive evaluation and provision of care in the physical, psychosocial, and spiritual domains, including symptom relief, for patients diagnosed with terminal diseases and their families.¹² Patients can express their willingness for PC and refuse LST through a LST plan.¹² Consequently, PC is gaining national prominence as a mandated service for terminally ill patients, accompanied by establishing a service system.

However, the legal scope of PC is currently limited to specific five diseases namely cancer, human immunodeficiency virus infection, chronic obstructive pulmonary disease, chronic liver failure, and chronic respiratory failure, with the potential for expansion through sub-regulatory changes.¹² Despite the legislation, only around 10% of patients with terminal illnesses in 2022 received PC in Korea.²⁴ Service utilization still focuses on patients with cancer, as was true of over 99% in 19,228 people who registered hospice in 2021. Yet, only 23.2% of cancer patients accessed PC before death, with a gradual increase for the last decades.¹⁵ A number of PC beds increased only slightly after legalization (1,461 in 2017; 1,601 beds in 2022) far from the 2,500 beds estimated to be required by the European Association for Palliative Care's standards.²⁵ Consequently, a considerable number of Koreans do not have equal access to PC, with only a fortunate few receiving it before death.

Globally, PC is recognized as a medical service that alleviates suffering and enhances the quality of life for patients and families dealing with life-threatening illnesses.²⁶ The World Health Organization states that various conditions necessitate PC, encompassing cardiovascular diseases, cancer, chronic respiratory diseases, acquired immune deficiency syndrome, diabetes, kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, and children with congenital anomalies and genetic conditions, especially in the neonatal period.²⁶ Accordingly, many countries provide access to PC for patients with serious illnesses regardless of disease type²⁷⁻³⁰; still, PC provision for non-cancer patients remains limited,³¹ with an example being that only 15.2% of specialized PC facilities have admitted them in Japan.³² Therefore, global approach in recent years has been to reduce access barriers and extend it to individuals with serious health-related suffering across all ages.^{33,34} However, Korean patients with cardiovascular disease and dementia, now major causes of death,³⁵ and other serious illnesses are not eligible for PC under the Act. The takeaway here is that Korea could gradually extend PC according to symptom burden and care resources for all those who need it.

Conclusion: Ensuring the Right to Quality EoL Care for Everyone in Korea

According to Huffman and Harmer, EoL is “a stage in the process of living, which all people will eventually face,” marking its uniqueness and irreplaceability.³⁶ Despite some improvements in the respect to patient autonomy and the PC system, the LST Decisions Act still substantially restricts patient rights to have quality EoL care and a good death. The current legal framework should be revised to respect patients' wishes and values across the continuum of care and facilitate sensitive medical decision-making to accommodate complexities in individual EoL scenarios. A revised framework should allow EoL patients to make decisions through patient-doctor communication with removing the criteria of “dying process” and to choose their proxy decision-maker.

It is time to advance this fundamental right for every individual to receive appropriate care and choose their own treatments. The Korean government must address the critical issues of improving EoL care and respond the widespread despair of Koreans at their last stage of life. Finally, while this article raises concerns about the Act from the perspective of human rights, financial support and implementable policies to enhance shared decision-making and strengthen supportive care networks are crucial beyond legal revisions.³⁷

REFERENCES

1. The Seoul Shinmun. <https://www.seoul.co.kr/news/newsView.php?id=20230711500198>. Updated 2023. Accessed December 10, 2023.
2. Yun YH, Han KH, Park S, Park BW, Cho CH, Kim S, et al. Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients. *CMAJ* 2011;183(10):E673-9. [PUBMED](#) | [CROSSREF](#)
3. Yun YH, Kim KN, Sim JA, Yoo SH, Kim M, Kim YA, et al. Comparison of attitudes towards five end-of-life care interventions (active pain control, withdrawal of futile life-sustaining treatment, passive euthanasia, active euthanasia and physician-assisted suicide): a multicentred cross-sectional survey of Korean patients with cancer, their family caregivers, physicians and the general Korean population. *BMJ Open* 2018;8(9):e020519. [PUBMED](#) | [CROSSREF](#)
4. Meisel A, Snyder L, Quill T; American College of Physicians--American Society of Internal Medicine End-of-Life Care Consensus Panel. Seven legal barriers to end-of-life care: myths, realities, and grains of truth. *JAMA* 2000;284(19):2495-501. [PUBMED](#) | [CROSSREF](#)
5. Crawford GB, Dzierzanowski T, Hauser K, Larkin P, Luque-Blanco AI, Murphy I, et al. Care of the adult cancer patient at the end of life: ESMO Clinical Practice Guidelines. *ESMO Open* 2021;6(4):100225. [PUBMED](#) | [CROSSREF](#)
6. National Institute on Aging. Providing care and comfort at the end of life. <https://www.nia.nih.gov/health/end-life/providing-care-and-comfort-end-life>. Updated 2022. Accessed December 10, 2023.
7. Berlinger N, Jennings B, Wolf SM. *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life. Revised and Expanded Second Edition*. New York, NY, USA: Oxford University Press; 2013.
8. Kang J, Choi EK, Seo M, Ahn GS, Park HY, Hong J, et al. Care for critically and terminally ill patients and moral distress of physicians and nurses in tertiary hospitals in South Korea: a qualitative study. *PLoS One* 2021;16(12):e0260343. [PUBMED](#) | [CROSSREF](#)
9. Heo DS, Yoo SH, Keam B, Yoo SH, Koh Y. Problems related to the act on decisions on life-sustaining treatment and directions for improvement. *J Hosp Palliat Care* 2022;25(1):1-11. [PUBMED](#) | [CROSSREF](#)
10. National Law Information Center. Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or the End-of-life. <https://law.go.kr>. Updated 2016. Accessed December 10, 2023.
11. Lee I. South Korea's End-of-Life Care Decisions Act: Law for Better End-of-Life Care. In: Cheung D, Dunn M, editors. *Advance Directives Across Asia: A Comparative Socio-Legal Analysis*. Cambridge, UK: Cambridge University Press; 2023:57-74.
12. Kim M. The problems and the improvement plan of the hospice/palliative care and dying patient's decisions on Life-Sustaining Treatment Act. *Korean J Hosp Palliat Care* 2018;21(1):1-8. [CROSSREF](#)
13. National Agency for Management of Life-sustaining Treatment; Ministry of Health and Welfare. 2022 annual report: national agency for life-sustaining treatment decisions. <https://www.lst.go.kr>. Updated 2023. Accessed December 10, 2023.
14. Kim K, Park B, Gu B, Nam EJ, Kye SH, Choi JY. The National Hospice and Palliative Care registry in Korea. *Epidemiol Health* 2022;44:e2022079. [PUBMED](#) | [CROSSREF](#)
15. National Hospice Center; Ministry of Health and Welfare. Hospice & palliative care in Korea: facts & figures 2022. <https://hospice.go.kr>. Updated 2023. Accessed December 10, 2023.
16. Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. New York, NY, USA: MacMillan Publishing Co.; 2015.
17. Supreme Court of Korea. Supreme Court Decision 2009Da17417 decided May 21, 2009. <https://glaw.scourt.go.kr>. Updated 2009. Accessed December 10, 2023.
18. Kim H, Im HS, Lee KO, Min YJ, Jo JC, Choi Y, et al. Changes in decision-making process for life-sustaining treatment in patients with advanced cancer after the life-sustaining treatment decisions-making act. *BMC Palliat Care* 2021;20(1):63. [PUBMED](#) | [CROSSREF](#)

19. Won YW, Kim HJ, Kwon JH, Lee HY, Baek SK, Kim YJ, et al. Life-sustaining treatment states in Korean cancer patients after enforcement of act on decisions on life-sustaining treatment for patients at the end of life. *Cancer Res Treat* 2021;53(4):908-16. [PUBMED](#) | [CROSSREF](#)
20. Kim D, Yoo SH, Seo S, Lee HJ, Kim MS, Shin SJ, et al. Analysis of cancer patient decision-making and health service utilization after enforcement of the Life-Sustaining Treatment Decision-Making Act in Korea. *Cancer Res Treat* 2022;54(1):20-9. [PUBMED](#) | [CROSSREF](#)
21. Im H, Choe HW, Oh SY, Ryu HG, Lee H. Changes in the incidence of cardiopulmonary resuscitation before and after implementation of the Life-Sustaining Treatment Decisions Act. *Acute Crit Care* 2022;37(2):237-46. [PUBMED](#) | [CROSSREF](#)
22. Quinn KL, Wegier P, Stukel TA, Huang A, Bell CM, Tanuseputro P. Comparison of palliative care delivery in the last year of life between adults with terminal noncancer illness or cancer. *JAMA Netw Open* 2021;4(3):e210677. [PUBMED](#) | [CROSSREF](#)
23. Statistics Korea. Korean Social Trends 2023. <http://sri.kostat.go.kr>. Updated 2023. Accessed February 15, 2023.
24. Heo DS. The role of hospice in Korean's end-of-life. NECA (National Evidence-based Healthcare Collaborating Agency) Newsletter. <https://blog.naver.com/necahta/222908913128>. Updated 2022. Accessed December 15, 2023.
25. Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 2. *Eur J Palliat Care* 2010;17(1):22-33.
26. World Health Organization. Planning and implementing palliative care services: a guide for programme managers. <https://www.who.int>. Updated 2016. Accessed December 15, 2023.
27. National Hospice and Palliative Care Organization. What is palliative care? <https://www.caringinfo.org/types-of-care/what-is-the-difference-between-palliative-care-and-hospice-care/>. Updated 2023. Accessed February 15, 2023.
28. NHS England. Specialist palliative and end of life services. <https://www.england.nhs.uk/wp-content/uploads/2023/01/B1674-specialist-palliative-and-end-of-life-care-services-adult-service-specification.pdf>. Updated 2023. Accessed February 15, 2023.
29. Government of Canada. Palliative care: overview. <https://www.canada.ca/en/health-canada/services/health-services-benefits/palliative-care.html>. Updated 2023. Accessed February 15, 2023.
30. Department of Health. Australian Government. National Palliative Care Strategy 2018. <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. Updated 2019. Accessed February 15, 2023.
31. Cagle JG, Lee J, Ornstein KA, Guralnik JM. Hospice utilization in the United States: a prospective cohort study comparing cancer and noncancer Deaths. *J Am Geriatr Soc* 2020;68(4):783-93. [PUBMED](#) | [CROSSREF](#)
32. Hamano J, Shima Y, Kizawa Y. Current situation and support need for non-cancer patients' admission to inpatient hospices/palliative care units in Japan: a nationwide multicenter survey. *Ann Palliat Med* 2023;12(1):81-9. [PUBMED](#) | [CROSSREF](#)
33. Tobin J, Rogers A, Winterburn I, Tullie S, Kalyanasundaram A, Kuhn I, et al. Hospice care access inequalities: a systematic review and narrative synthesis. *BMJ Support Palliat Care* 2022;12(2):142-51. [PUBMED](#) | [CROSSREF](#)
34. Radbruch L, De Lima L, Knaut F, Wenk R, Ali Z, Bhatnagar S, et al. Redefining palliative care – a new consensus-based definition. *J Pain Symptom Manage* 2020;60(4):754-64. [PUBMED](#) | [CROSSREF](#)
35. Statistic Korea. Statistical Database Korea: Statistic Korea, 2023. <https://kosis.kr>. Updated 2023. Accessed December 15, 2023.
36. Huffman JL, Harmer B. End-of-life care. <https://www.ncbi.nlm.nih.gov/books/NBK544276>. Updated 2023. Accessed December 15, 2023.
37. Heo DS, Yoo SH, Keam B, Yoo K, Choi I, Kim MJ. Hospice-palliative medicine as a model of value-based healthcare. *J Korean Med Sci* 2022;37(15):e111. [PUBMED](#) | [CROSSREF](#)