THE SLIPPERY SLOPE PARADOX: WHEN RESTRICTING AUTONOMY FUELS DEMANDS FOR PHYSICIAN-ASSISTED DYING

Claire Junga Kim¹

Abstract: Korea's system for end-of-life care and letting people die is quite rigid in the direction of maintaining life. The Life-sustaining Treatment Decision Act was enacted in 2016, but there was little opportunity for the breadth and depth of public discussion to develop before that. This paper aims to show the "concerns about the slippery slope" that some of the participants in the legislative debate had as one of the historical reasons for creating the conservative framework and detailed provisions of Korea's Life-sustaining Treatment Decision Act. Because of their arguments, the law was structured as a barricade to prevent slippery slopes. However, in 2022, the fifth year after the law took effect, a bill was proposed to legalize physician-assisted dying. This paper makes a worrisome prediction that this radical movement will continue unless it is possible to set treatment goals tailored to the patient's medical condition and values through the guarantee of the right to refuse treatment.

Keywords: self-determination, personal autonomy, assisted death, treatment refusals, refusal of treatment

¿ La paradoja de la pendiente resbaladiza: cuando restringir la autonomía alimenta las demandas de una muerte asistida por un médico

Resumen: El sistema coreano de cuidados paliativos y de abandono de la vida es bastante rígido en cuanto a la preservación de la vida. La Ley de Decisión sobre Tratamientos de Soporte Vital se promulgó en 2016, pero hubo pocas oportunidades para que el debate público se desarrollara con la amplitud y profundidad que se habían generado anteriormente. Este artículo pretende mostrar las preocupaciones sobre la pendiente resbaladiza que algunos participantes en el debate legislativo tuvieron como una de las razones históricas para crear el marco conservador y las disposiciones detalladas de la Ley de Decisión sobre Tratamientos de Soporte Vital de Corea. Debido a sus argumentos, la ley se estructuró como una barrera para evitar pendientes resbaladizas. Sin embargo, en 2022, cinco años después de su entrada en vigor, se propuso un proyecto de ley para legalizar la muerte asistida por un médico. Este artículo predice de forma preocupante que este movimiento radical continuará a menos que sea posible establecer objetivos de tratamiento adaptados a la condición médica y los valores del paciente mediante la garantía del derecho a rechazar el tratamiento.

Palabras clave: autodeterminación, autonomía personal, muerte asistida, rechazo al tratamiento, denegación del tratamiento

O paradoxo da inclinação escorregadia: quando restringir a autonomia alimenta as demandas de uma morte assistida por um médico

Resumo: O sistema coreano de cuidados paliativos e de deixarem as pessoas morrerem é bastante rígido no que diz respeito à manutenção da vida. A Lei de Decisão de Tratamento de Suporte à Vida foi promulgada em 2016 mas houve pouca oportunidade para que a amplitude e profundidade do debate público se desenvolvesse antes disso. Esse artigo objetiva demonstrar as "preocupações sobre a ladeira escorregadia" que alguns dos participantes na discussão legislativa tinham como uma das razões históricas para a criação do estrutura conservadora e das disposições detalhadas da Lei de Decisão de Tratamento de Suporte à Vida da Coréia. Devido aos seus argumentos, a lei foi estruturada para funcionar como uma barreira para evitar descaminhos. Entretanto, em 2022, o quinto ano após a lei entrar em vigor, foi proposto um projeto de lei para legalizar a morte assistida por médicos. Esse artigo faz uma previsão preocupante de que esse movimento radical continuará a menos que seja possível estabelecer metas de tratamento adaptadas à condição médica e valores do paciente por meio da garantia do direito de recusar tratamento.

Palavras-chave: autodeterminação, autonomia pessoal, morte assistida, recusa do tratamento, negação do tratamento

¹ Department of Medical Humanities, College of Medicine, Dong-A University, South Korea, clairejungakim@gmail.com, https://orcid.org/0000-0001-6889-5478

Introduction

South Korea's system for end-of-life care and letting people die is heavily weighted in favor of keeping people alive. Although the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life(1), AKA Life-Sustaining Treatment Decision Act, was enacted in 2016 with the purpose of "to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination(1)" and has been in force since 2018, the freedoms guaranteed by the Act are minimal. The law defines the time for refusal of treatment as the end-oflife process, "a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly(1)," and lists treatments that can and cannot be withdrawn at this point. The right to refuse treatment is nowhere explicitly declared in law or case law. This silence, when interpreted in conjunction with legal provisions regarding the scope of treatment withdrawal and withholding, would have likely limited the number of patients able to refuse aggressive treatments.

Historically, there have been relatively few cases in Korea on end-of-life care and dying or letting die compared to other countries. As a result, the breadth and depth of public discussion have had fewer opportunity to develop. Death has been medicalized, and as once-functional communities of family, lineage, belief, religion, and local neighborhoods have disappeared, many aspects of dying that were once managed by these communities have now become the responsibility of professionals. As a result, the process of dying has become a complex issue, understood by only a small group of healthcare professionals, to the extent that even doctors require detailed explanations to fully grasp it. Legislative discussions and draft laws were organized around experts and a few "representatives" without broad public awareness or participation, and transparent and efficient discussion structures to make this possible. In the absence of a social consensus, the outcome of the legislative discussion largely mirrored the structure of the previous judicial precedent(2), resulting in legislation that failed to recognize the right of patients to self-determination, the appointment of a surrogate, and the active role of hospital ethics committees(3).

Meanwhile, in 2022, five years after the law came into effect, a bill was proposed to legalize physician-assisted dying(4). Although the bill was proposed as an amendment to the Life-Sustaining Treatment Decisions Act(1), it diverged too much from the direction and scope of the current law, faced opposition from various groups, and ultimately was not passed. However, this should not be dismissed as an isolated incident. The conservative approach taken by the legislative debate, the unmet needs it leaves behind, and the limitations of the legislation could lead to similar demands in the future.

This paper examines the current state of South Korea's institutions concerning end-of-life care, with a particular focus on the "slippery slope" concerns expressed by some participants in the legislative discussions. These concerns are identified as one of the historical reasons for the conservative framework and detailed provisions of the Life-Sustaining Treatment Decisions Act. Due to these arguments, the law has been structured as a barricade against the slippery slope. It is crucial to assess whether the cautious approach they advocated was appropriate for Korean society. Additionally, given the government's lack of proactive commitment to improving end-of-life care and palliative care, the law may have inadvertently created significant risks, which are already becoming apparent. The following circumstances illustrate these risks: an increasing number of people being denied appropriate end-of-life care; patients enduring disproportionate suffering from harmful treatments to remain within the healthcare system and avoid abandonment; the profession being engaged in ethically questionable practices; and growing distrust in the patient-physician relationship. These risks are not inevitable; rather, they stem from the excessive fear of the consequences of a patient's right to refuse treatment, resulting in an extreme limitation of that right. In other words, in attempting to avoid the slippery slope, the law may be pushing people towards a far more extreme scenario—heading towards a cliff.

Historical Development of the Barricade Against the Slippery Slope

The discussion of this law in Korea has a relatively short history. The first case in which the termination of treatment drew public's attention was the Boramae Hospital case. This case occurred in 1997, and the Supreme Court ruled in 2004(5). Contrary to public and physician misconceptions at the time, this is not a case of patient refusal of treatment. This is a case where the patient's wife refused treatment and the patient was discharged from the hospital, resulting in the patient's death, in a situation where the patient had lost decisionmaking capacity and would have benefited from treatment. Since the Supreme Court ruling that sentenced doctors to prison, the medical community has continued to overtreat patients with no hope of recovery, out of fear of punishment. It was only after a 2009 Supreme Court ruling that allowed doctors to withdraw ventilator treatment on the presumption of wishes of a patient who "is considered to have entered the irreversible stage of death(2)" that the movement to enact legislation became apparent. Even after the Constitutional Court's decision, which indicated that the state was not obligated to legislate(6), and even though the majority opinion from the social consultative body established by the Ministry of Health and Welfare (7) was that legislation was unnecessary, discussions about the need to enact a special law continued. In response to these societal demands, the special committee of the National Bioethics Committee drafted a recommendation that would later evolve into a legislative proposal. The National Bioethics Committee then reviewed and approved this recommendation (8,9). Unlike the United States, which has accumulated more than 100 cases over the past 25 years from In re Quinlan to Cruzan v. Director, Missouri Department of Health (10,11,12), Korea has only had one case on refusal of life-sustaining treatment. The jurisprudence of the Supreme Court decision was not further elaborated or communicated understandably to professionals and the public, and public understanding of the issue did not deepen between 2009, when the Supreme Court decision was issued, and 2014 and 2015, when legislation was proposed. Refusal of treatment was often ambiguously described using terms like 'death with

dignity,' 'euthanasia,' and sometimes even 'suicide.' The right to refuse treatment was rarely asserted by patients or the public.

In this situation, the legislative discussions were limited to a small number of 'representatives' and 'experts.' After the Supreme Court's ruling, the group that recommended the special law and drew up the core framework for the later drafting was the social consultative body established by the Ministry of Health and Welfare(7). It was comprised of 18 members including the former deputy minister of health and welfare and representatives from the religious, medical, legal, civil society, and legislative sectors. After meeting seven times in seven months, the consultative body announced the results of its discussions on which patients may be withdrawn from life-sustaining treatment and the scope of life-sustaining treatment that could be withdrawn. The minutes of the discussions were not publicly available at the time and have not been released since. A year and a half after the announcement, the National Bioethics Committee formed a special committee to discuss the institutionalization of futile life-sustaining treatment withdrawal for six months and established the results as recommendations for end-of-life decisions(9,13). The committee had 11 members, including six who had participated in the previous social consultative body. Same as in the previous consultative body, the members were not elected and their deliberations were not publicized in real time.

It is noteworthy that in this discussion structure, participants representing the religious community gained significant influence. Of the 18 members of the council, there were four representatives from the religious community, representing Protestants, Catholics, Buddhists, and Won-Buddhists, respectively. It is also noteworthy that people who are unable to form any organized social group—for example, those who are nonreligious or atheists—were not eligible to nominate representatives, and that some of the civil society representatives who did not represent a religion also had an affinity with a particular religion. Representatives from both the Catholic and Protestant churches appear to have had strong opinions on narrowing the scope of withdrawal of treatment(14). Specifically, they insisted on the

exclusion of PVS patients from treatment withdrawal and the designation of only terminally ill patients as eligible for treatment withdrawal. They also rejected the presumption of patient wishes to withdraw treatment and the designation of proxy. This position persisted in subsequent discussions, resulting in the final law limiting treatment withdrawal or withholding to the time period of the end-of-life process and not providing the option of designating a surrogate. Given the strong Catholic and Protestant opposition to the arbitrary termination of human life, it is unlikely that full recognition of the right to refuse treatment was discussed at the meetings.

As the minutes of the meeting are not publicly available, there is no way to know what the discussions within the meeting consisted of and what arguments were made. However, based on the context, it is possible to speculate on the origin of the arguments for limiting the scope of treatment refusal or the restriction on surrogate decision making. First of all, it is unlikely that it came from representatives of the medical community. In the first place, the medical community was asking for legislation for use in practice and for physicians to be free from the risk of legal penalties. Given that the previous guideline(15) developed by medical professional organizations, including medical associations, before this meeting included treatment withdrawal for PVS patients, it is unlikely that the medical community intended to severely limit the scope of treatment withdrawal.

On the other hand, the arguments of the Catholic and Protestant representatives on the Council are articulated in several of their own publications. They argue that a patient's right to self-determination cannot be absolute, and that the risks of self-determination can be real. Notably, they both cautioned against refusal of treatment based on self-determination, citing the "slippery slope(16)" or "slippery ladder theory(17)." Kyo Hun Chin, who represents the Catholic community, is even wary of self-determination being used as a basis for withdrawing life-sustaining treatment, saying "I would like to discuss the problem of the patient's right to self-determination in the legislating withdrawal of life-sustaining treatment. It is because once the decision to withdraw life-sustaining treatment is based on the patient's right to self-determination, what will follow is the risk that this will later be inferred and expanded to include the patient's right to arbitrarily refuse certain treatments and to decide on their own death. If the right to self-determination is used to determine human life and death, this could lead to the permissibility of euthanasia and suicide(17)." Here he is concerned that the right to self-determination is used as a basis for "arbitrarily refusing" medical treatment that is not life-sustaining treatment—what he calls "certain treatments"—and that this could lead to the permissibility of euthanasia and suicide.

Similarly, Lee Sang-won, a representative of the Protestant community, seeks to correct the understanding of his fellow scholars to distinguish between withdrawal of futile medical treatment and passive euthanasia, and his premise is that only when there is a combination of "not artificially terminating life but allowing death to come naturally" and the patient's explicit expression of wishes to do so —which he defines as withdrawal of futile medical treatment and which Korean current law defines as withdrawal of life-sustaining therapy — is it justifiable (14). This is consistent with his opposition to the institutionalization of withdrawal of life-sustaining treatment, stating that "human life belongs to God and is not a matter of human nature(18,19)." In response to this opinion of some members of the consultative body, the scope of the right to self-determination was limited in the subsequent drafting process. Subsequently, the Special Committee of the National Bioethics Committee(13) revised the term 'terminal patient' to 'end-of-life' or 'dying process' to avoid broad interpretations, and explicitly excluded patients in a persistent vegetative state (PVS). After reviewing the recommendations of this Special Committee, the National Bioethics Committee stated that the scope of self-determination should be specifically defined in the context of life-sustaining treatment decisions (13), and did not discuss the general rights of self-determination regarding any treatment.

This position of the religious community, especially the Catholic Church, was reiterated at a public hearing on the draft law by parliamentarian Kim Jae-won who received the draft of the National Bioethics Committee, and presented as the "Draft

Law on Decisions on Life-Sustaining Treatment for Patients at the End of Life(20)." Father Jung Jae-woo, who participated as a panelist, recommended postponing the enactment of the law until the laws and policies on hospice and palliative care are sufficiently developed, and not providing advance directives that can be written without a conversation with a doctor, even in the absence of illness. Instead, he recommended to provide a Life-Sustaining Treatment Plans, equivalent to Physician Orders for Life-Sustaining Treatment (POLST), only. The reason he made such a claim was likely due to his concern that the passing of the bill could "deepen a culture of devaluing life, or a culture of death(21)."

In a pluralistic society, it is natural to have differing opinions about what good can be achieved at the end of human life, what support should be provided by those at the bedside and by the medical profession, what are the expected consequences of institutionalizing and implementing such support, and how to evaluate those consequences. The question is how supporters of "incompatible yet reasonable comprehensive doctrines(22)" can come together to reach a consensus on direction and terms and translate that consensus into law. Unfortunately, the legislative discussions aimed at creating end-of-life legislation in South Korea have demonstrated that, at least in matters of human life and death, individuals with differing belief systems cannot achieve the ideal of "overlapping consensus(22)". Instead, what emerged was a negotiated compromise. When evaluating the actual process of consensus, it is important to remember that both the Protestant and Catholic representatives who participated in each stage of the legislative discussion were also opposed to the legislation itself(18,21). In other words, while some participants opposed the very existence of a legal framework for end-of-life care, others sought to persuade them to enact the first legislation allowing for the withdrawal of life-sustaining treatment, regardless of its scope. As a result, the point of overlap became the most conservative position among the various opinions, as those advocating for withdrawal of life-sustaining treatment ultimately accepted the most conservative criteria set by those opposed to having any legal framework for end-of-life care.

Signs of people heading towards a cliff

Since the enactment of the first laws addressing end-of-life and death, the public debate has slowly deepened. After some initial confusing reports about the law enabling "death with dignity," over time, there has been a growing body of reporting(23-28), popular books(29-31), public communication content(32,33), and academic researches (34-37) that has focused on the unmet needs at the end of life that the law leaves behind. The consensus has been that the current Life-Sustaining Treatment Decision Act is not sufficient to improve end-of-life care in our society. Individual studies and opinions have their own strengths and point to important issues. However, in a context where death has already been medicalized, it was challenging to cut to the heart of this holistic issue, to identify appropriate responses, and, most importantly, to build societal understanding and consensus around it (38). The government, in particular, was unable to play a role in educating the public about its limitations and building consensus for the next steps, preoccupied with implementing the new law. Moreover, the issue has not been elevated to the forefront of the debate, at least not in the eyes of the general public. This is a far cry from the experience in the United States, where sensationalized and misleading language such as "death panels" has pushed the issue of end-of-life care and costs up the political agenda(9,40). Although the limitations of the current law were discussed, there was little analysis on where those limitations came from. While it was fortunate that the debate did not get heated, it did not get a chance to revisit in the public eye whether the arguments made during the last legislative discussion, including concerns about the "slippery slope," were valid.

Without any subsequent groundbreaking case law or intense politicized debate, a fairly radical change was proposed in an amendment bill in 2022(4). The amendment, which introduced the concept of "assisted death with dignity," was proposed to amend the existing Life-Sustaining Treatment Decision Act(1) and was dubbed the "Assisted Death with Dignity" Bill by its proponents. The essence of this bill is to legalize physician-assisted dying by allowing it under the condition that it has received approval from a government committee. The pro-

posal was based on a survey of 1,000 citizens that showed a 76.4% favorable opinion of euthanasia or physician-assisted suicide (EAS)(41). This was interpreted as a significant increase compared to a similar survey conducted by the same corresponding author in 2016, which showed only 41.4% in favor of active euthanasia and 35.9% in favor of physician-assisted suicide(42).

The bill faced stiff opposition from the Ministry of Health and Welfare, various medical professional organizations including the Korean Medical Association, and related societies and organizations such as the Korean Society for Hospice & Palliative Care and the Korean Society for Medical Ethics(43). The bill was automatically discarded due to the expiration of the parliamentary session. However, it would be naïve to consider this legislative attempt as a mere isolated incident and to assume that future attempts of this nature can be consistently prevented. Representative Ahn Kyuback, who had previously introduced the amendment, successfully retained his seat in the next parliamentary session and has now proposed a new piece of legislation aimed at addressing physicianassisted dying through a completely new law, not merely as an amendment (44). Moreover, by the end of 2023, a lawsuit was filed arguing that the failure to enact specific legislation permitting physician-assisted dying and the existing laws criminalizing aiding and abetting suicide were unconstitutional (45).

Except for a few fortunate individuals, the majority of patients do not receive adequate care at the end of life. While much attention has been given to hospice utilization, which primarily serves cancer patients, and the insufficient resources available for hospice care (46), a more fundamental issue remains unresolved: whether patient-defined goals of care can be prioritized over aggressive treatments. This issue stems from the Korean legal system's lack of explicit recognition of the right to refuse treatment based on self-determination. This lack of recognition originated from excessive concerns about self-determination and the potential for a slippery slope, which dominated past legislative discussions. Paradoxically, by closing off the more moderate option of treatment refusal, which would have benefited a larger number of people had such a law been in place, attention has shifted to the more radical option of physician-assisted dying, which affects a smaller percentage of patients (47).

Conclusion

The legislative discussion surrounding the enactment of Korea's Life-Sustaining Treatment Decision Act was marked by excessive concerns, and the barricade erected by those expressing these concerns to prevent a "slippery slope" has created significant unmet needs in end-of-life care in Korea, leading to paradoxical outcomes. A topic that had lacked sufficient public discourse was then shaped by the assertions of a specific group of representatives, and even within that process, there was a failure to provide a forum for broad societal learning, participation, and discussion. The radical movement advocating for physician-assisted dying will persist unless it becomes possible to establish treatment goals that are tailored to the patient's medical condition and values, supported by the guarantee of the right to refuse treatment. Now, nearly 15 years after the legislative discussion, it is crucial to assess whether Korean society is prepared to establish legal frameworks that protect the "dignity and value of human beings(1)" at the end of life through a more robust social deliberation process. Without increased social engagement aimed at improving the structure of past legislative discussions, it will be impossible to move toward better alternatives. There is a need for democratic deliberation—a structure that effectively communicates specialized content to the public, facilitates their reflection, enables them to express their views and engage in discussion, and ultimately reaches a consensus. Korean society must not ignore the urgent concerns of citizens heading toward a cliff but instead increase its investment in public discourse.

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