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# Ensuring Patients' Well-Deserved Right to Refuse Treatment, Not Jumping to an “Assisted Death With Dignity”

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Last year, a revision was proposed to the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End-of-Life,<sup>1</sup> hereinafter referred to as the Life-Sustaining Treatment Act, to include clauses legalizing medical aid in dying (MAID). The proposed revision was based on a survey of 1,000 citizens, the majority of whom expressed a positive view of euthanasia.<sup>2</sup> The revision is also known as the Bill on Assisted Death with Dignity. Diverse professional and academic organizations, including the Korean Medical Association, Korean Academy of Medical Sciences, and Korean Society for Medical Ethics, have voiced their concerns about the bill,<sup>3</sup> and the revision was not considered during the National Assembly's plenary session. However, the proposed revision has indeed communicated that the existing Life-Sustaining Treatment Act fails to provide adequate assurance to those requiring end-of-life care. In other words, the proposed revision and social discussion triggered by it show that many people fear not receiving adequate care, being left to suffer pain, or becoming a burdensome concern for those around them during the dying process. Considering that the possibility of such unfulfilled needs has been consistently identified through various studies<sup>4-7</sup> and revealed in the most recent survey of the general public, physicians, and national assembly members,<sup>8</sup> it is not too much to say that people wish to escape such multifaceted fear through the most extreme measure of dying. Given the genuine and practical concerns expressed, contemplating whether the medical community should remain complacent about the quality and structure of current medical care and continue to reiterate its position of opposing physician-assisted suicide or euthanasia is worthwhile.

However, calling for physician-assisted suicide or MAID is not what this article aims to do. Such a radical leap may not be required if there is an alternative solution viewed as more acceptable across various members of society. Instead, this article aims to demonstrate that an explicit guarantee of a patient's right to refuse treatment can be a reasonable alternative. Treatment refusal or right to refuse treatment is “the guaranteed right of mentally competent adults to decline medical, psychological, or psychiatric treatment and to express their end-of-life treatment preferences with an advance healthcare directive and appointment of a healthcare proxy decision-maker should they be unable to make their own healthcare decision.”<sup>9</sup> According to the World Medical Association, “competent patients have the right to refuse treatment, even when the refusal will result in disability or death.”<sup>10</sup> This right is based on patient autonomy, the core value of modern medicine, and the Life-Sustaining Treatment Act, and it is widely recognized as already implied in informed consent.<sup>11</sup> Although many other countries stipulate competent patients' right to refuse treatment,<sup>12-17</sup> it is not clearly stated in Korea's legal framework.

This article does not wish to introduce abstract principles or consistencies within a legal framework to assert the need for the right to refuse treatment. Instead, some concrete yet practical benefits will be listed, which can be experienced by the patients and physicians if the right to refuse treatment is guaranteed. This argument also implies that medicine is only partially successful at achieving its various goals when such rights are not guaranteed.

The right to refuse treatment is a fundamental component for patients to be respected as autonomous human beings and pursue their best interest in treatment. Granting that this is so in terms of autonomy, some may find it puzzling that it serves as an essential baseline for protecting patients' best interests. To them, exercising such a right may seem like deviating the patient from receiving treatment, seemingly in the patient's interest. However, barriers that hamper a patient's best interests can be eliminated by explicitly guaranteeing their right to refuse treatment. First, the right to refuse treatment enables meaningful advance care planning (ACP). Despite recent academic and clinical efforts to facilitate ACP,<sup>18,19</sup> its adoption has been very slow. One reason for this is that the Life-Sustaining Treatment Act excessively restricts what can be covered in ACP, making it less meaningful for the physician to initiate early conversations with the patient on decisions related to end-of-life care. For instance, even if the patient sets a treatment goal to alleviate pain, withdrawing from treatment before entering the end-of-life process will not be allowed according to a rigid interpretation of the law if the refusal of treatment is likely to result in death. Here, we confirmed that the right to refuse treatment is a prerequisite for ACP at the terminal stage owing to the nature of end-of-life care during terminal stages. At the terminal stage, the ACP should include the choice to invest one's time and resources elsewhere instead of receiving certain treatments that could only postpone death. Additionally, the patient's right to approve the doctor's action following this choice and the doctor's right to act according to the patient's choice should be guaranteed. However, for now, medical choices that can be detailed with the ACP are narrow and often unclear, which reduces the motivation to facilitate active discussions with patients in advance. If there is explicit recognition that a patient with decision-making capacity has the fundamental right to forgo any unwanted treatment, the ACP could become an essential means of fully understanding one's illness and aligning future decisions based on personal values.

Second, ensuring the right to refuse treatment prevents patients from being denied appropriate healthcare based on the legal classification of health conditions. The Life-Sustaining Treatment Act consists of two distinguishable parts: withholding or withdrawing life-sustaining treatment provided at the end-of-life process, and the hospice and palliative care provided to patients in the terminal stage. Conceptually, these two stages link seamlessly after one another, and the end-of-life process follows the terminal stage. However, in reality, the timeline of the medical diagnosis is unique to each stage; therefore, it may not occur sequentially, contrary to this concept. Specific timeframes or signs aid physicians in determining the terminal stage; however, not all illnesses exhibit distinct symptoms on a specific timeframe. Similarly, the diagnosis of end-of-life processes varies with diseases, with specific symptoms and timeframes aiding physicians in their determination. Moreover, as receiving a medical diagnosis of being in the terminal stage or end-of-life process is a prerequisite for a patient to receive a particular type of care, this prerequisite becomes a barrier to care, meaning that patients at the borderline of such a legal classification will be denied appropriate care. Guaranteeing the right to refuse treatment across legally defined stages will, in turn, allow patients to receive the most appropriate care they need in their specific conditions, which may not always strictly fall under the categorization set forth by the law.

On the other hand, explicit recognition of the patient's right to refuse treatment will allow physicians to implement more medically reasonable practices. First, physicians can deliver optimal patient care by assessing the benefit-to-harm ratio of treatment considering the various benefits and potential harms. This approach differs from a categorization-based approach that emphasizes determining whether a patient is in the end-of-life process. Treatment based on benefit-to-harm ratio is a fundamental principle in medical practice. Accordingly, physicians can exercise their clinical reasoning skills when providing end-of-life care as they do in all other care settings. Second, physicians are no longer pressured to provide probably unprofitable treatments. In a social environment in which a person's right to life is emphasized more than the right to self-determination, physicians are often pushed to continue providing medical interventions that may be more harmful than beneficial for the patient, in fear of potential medical lawsuits. An explicit guarantee of the patient's right to refuse treatment will allow physicians to exercise their discretion in forgoing any treatment considered harmful by both the physician and the patient. Third, building on the first and second points described above, more sensible and receptive education on end-of-life patient care can be provided to current and future physicians if the right to refuse treatment is ensured. End-of-life care is one area in which huge discrepancies lie between medical practice in Korea and medical textbook guidelines, which is the basis of international practice. The current law mandates that physicians follow practices that may not align with their natural way of thinking, i.e., clinical reasoning. Moreover, the law fails to include what medical textbooks describe as choices in its scope, which is the required course of action resulting from the physician's clinical reasoning. Hence, ensuring the right to refuse treatment is a prerequisite to administering meaningful education for physicians on end-of-life care, guiding them to focus on the treatment goal setting with the patient, staying at the dying patient's bedside and not leaving him or her when the person is not in "the stage" described by the law, and being freed from a fear of potential litigation.

The *assistance* or *aid* of the so-called assisted death with dignity or MAID may not be something that a large majority of patients actually need. Therefore, medical communities may not be obliged to provide the assistance. However, the right to refuse treatment is crucial for most or all patients and should be presented and guaranteed in a more explicit and extensive form. Guaranteeing the right to refuse treatment will eventually transform current medical practice in Korea into a more sensible and patient-centered state, fulfilling the ultimate goal of medicine. Given that granting the patients such rights cannot be unilaterally performed and achieved by those in the medical community alone, social consensus and institutionalization are required to achieve this end. Of course, everyone is a stakeholder in matters of death. Anyone should have the opportunity to participate in discussions and eventually reach social consensus. Inviting people to this discussion will require providing accurate and understandable information, constantly confronting different standpoints, often disclosing the weakest points of the medical system and community, and, most importantly, making sincere efforts to solve one of the largest and most complicated social problems of life. Now is the time for medical professionals equipped with knowledge and hands-on experience to exert wisdom to form such a social consensus and facilitate legislation in support of end-of-life care.

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