



# Hemodialysis as a life-sustaining treatment at the end of life

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The Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life came into effect on February 4th, 2018, in South Korea. Based on the Act, all Koreans over the age of 19 years can decide whether to refuse life-sustaining treatments at the end of life via advance directive or physician orders. Hemodialysis is one of the options designated in the Act as a life-sustaining treatment that can be withheld or withdrawn near death. However, hemodialysis has unique features. So, it is not easy to determine the best candidates for withholding/withdrawing hemodialysis at the end of life. Thus, it is necessary to investigate the meaning and implications of hemodialysis at the end of life with ethical consideration of futility and withholding or withdrawal of intervention.

**Keywords:** Hemodialysis, Life-sustaining treatment, Terminal care

## Introduction

The “Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life” (act no. 14013), commonly known as the well-dying law, was enacted in 2016. It came into effect on February 4, 2018, in South Korea. This legislation establishes a regulatory framework for care at a patient’s end of life (EoL).

According to the act, all Koreans over the age of 19 years are able to conduct advance care planning (ACP) to establish his or her wishes for EoL medical care and to doc-

ument their determination of acceptable life-sustaining treatments (i.e., advance directives or physician orders for life-sustaining treatment). Detailed definitions of terminology related to life-sustaining treatments at the EoL are described in Table 1 [1–5]. The act provides a legal basis for a patient’s autonomy in choosing medical interventions and hospice/palliative care at the EoL. To date, only four life-sustaining treatments including hemodialysis, chemotherapy, ventilator, and cardiopulmonary resuscitation (CPR) are included in the treatment options for dying patients. In comparison to levels of interest in ventilator care and CPR among dying patients, not much attention has been paid to hemodialysis. This may be the result of historic medical cases and circumstances in Korea. The aim of this review was to investigate the meaning and implications of hemodialysis as a life-sustaining treatment at patients’ EoL based on ethical considerations.

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**Table 1. Terminology related to life-sustaining treatments at patients' end of life**

Term	Definition
Advance care planning	The ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health care providers, and to record and review these preferences if appropriate [1]
Advance directive	A legal document in which a competent person makes provisions for medical and health care decisions in the event that she or he becomes mentally incompetent to make such decisions [2]
Futile treatment	A treatment which has no therapeutic purpose of any kind [3]
Palliative care	Multidisciplinary care to provide physical, psychosocial, religious, and spiritual support for terminally ill patients
Time-limited trial of dialysis	A goal-directed trial of renal replacement therapy restricted by predetermined outcomes that are assessed at planned intervals [4]
Withholding life-sustaining treatment	A decision/action not to initiate or escalate a life-sustaining intervention [5]
Withdrawal of life-sustaining treatment	A decision/action to actively quit a life-sustaining intervention that is presently provided [5]

### God committee: who should be selected for treatment and on what basis?

In the early 1960s in the United States, there was a shortage of dialysis machines for patients with end-stage renal disease (ESRD). The fact of these limited resources provoked ethical problems related to justice in terms of the proper allocation of resources to which patients. A committee was organized to decide who would be eligible for hemodialysis. The first committee consisted of seven members including a banker, a homemaker, a government official, a labor leader, a lawyer, a minister, and a surgeon. Later the committee came to be known as the "God committee" because the committee's selection of any given ESRD patient for hemodialysis meant that the patient had an opportunity to live longer. In contrast, if the committee decided not to give an ESRD patient a chance for hemodialysis, then that patient faced a terminal outcome.

The committee has been criticized along many lines, particularly in terms of its selection process for patients to receive hemodialysis. Without any guidelines, committee members made decisions based only on criteria such as age, sex, marital status, income, intelligence quotient, personality, vocational skills, criminal records, emotional stability, and the social value of a patient. The values and biases of the committee members were explicitly involved in decision-making processes. Under pressure from civilians, patients, and physician groups in 1972 to resolve the problem, the committee was dissolved with the decision of the United States Congress to estab-

lish universal funding for hemodialysis. Nevertheless, the committee played a key role in the development of modern bioethics. Its existence marked the first time that people without medical training made decisions on the allocation of medical resources. Until then, these types of decisions had been made entirely by physicians.

To the best of our knowledge, there was no such committee in Korea. Although it would be meaningful work to explore how proper allocation of hemodialysis machines was managed before this medical equipment was sufficiently provided in Korea, it is beyond the purpose of this review.

### Ethical concerns for the withholding or withdrawal of hemodialysis

Traditionally, the aim of medicine is to save and prolong life as much as possible. However, it is impossible to save all patients with life-threatening disease. Thus there should be room in medicine for discussion with patients and permission for patients to die in a proper way with dignity according to their own wishes.

#### *Futility*

The concept of futility of treatment is very important in EoL care. The aim of medicine to preserve life at any cost is not always justifiable. If a treatment has no therapeutic purpose of any kind, that treatment may be considered futile [3]. In this sense, maintenance of life-sustaining treatments simply to prolong life without any real possi-

bility of curing—or at least relieving—a critical condition may be futile. Such treatments can be lawfully withheld or withdrawn according to the rights of a patient.

#### *Life-saving versus life-sustaining treatments*

There are various terms that describe treatment to prevent someone from dying, including life-saving and life-sustaining treatments. It is not always easy to distinguish life-saving treatment from life-sustaining treatment [6]. This ambiguity in terminology leads to misunderstanding and conflict between patients/patient surrogates and health care professionals. In fact, an identical intervention can be regarded as life-saving or life-sustaining treatment based on the situation. Life-saving treatment is a broader concept. It includes life-sustaining treatment. If chances are high for a patient to recover body function from illness or disease with the support of treatment, then the treatment may be considered life-saving treatment. If a treatment prolongs a person's life without any hope or possibility for the patient to regain body function, then the treatment is considered life-sustaining. In comparison to other life-sustaining interventions, dialysis is more positively perceived. Dialysis usually begins as an elective treatment in chronic kidney disease (CKD) patients who progressively become patients with ESRD [7].

#### *Withholding or withdrawal of life-sustaining treatments*

Withholding life-sustaining treatment is defined as the decision not to initiate or escalate a life-sustaining intervention. Withdrawal of life-sustaining treatment is defined as the decision to actively quit a life-sustaining intervention that is presently being provided to a critically ill patient [5].

According to traditional views in medical ethics and in the law, withdrawal of life-sustaining treatment is logically similar to withholding intervention [8]. Both the withholding and withdrawal of life-sustaining treatment allows a patient to die from his/her underlying disease, as opposed to the notion that withholding or withdrawing treatment actively causes patient death. Some experts have criticized the traditional view, however, arguing that contrary to the omission of withholding treatment, the withdrawal of life-sustaining treatment is an active cause

of death, or a causal consequence [9,10]. Furthermore, the opposition insists that there is no distinction between the withdrawal of life-sustaining treatment, assisted dying, and euthanasia.

A World Congress Ethics Round Table Conference was held to identify the main position of physicians of intensive and critical care medicine about the withholding/withdrawal of life-sustaining treatment [11]. Most respondents at the conference stated that there was no difference between withholding and withdrawing life-sustaining treatment in patients with terminal disease. Although almost all life support guidelines consider withholding or withdrawing life-sustaining treatment to be ethically, legally, and/or philosophically equivalent in critical patient care [12], health care professionals certainly have a greater psychological burden and difficulty in withdrawing life-sustaining treatment than in withholding it [11,13].

#### *Withholding or withdrawal of hemodialysis*

Currently, hemodialysis is one of the most popular medical processes for ESRD patients with sufficient financial support via national insurance in developed countries. The current dilemma around hemodialysis is not which patients are the most appropriate to receive hemodialysis upon diagnosis of ESRD, but rather, which patients are candidates for withholding/withdrawing hemodialysis at the EoL. If hemodialysis has become a maintenance therapy for ESRD patients, then omitting dialysis therapy can be considered the withholding or withdrawal of treatment. Because hemodialysis is periodically provided on an ongoing basis, skipping an upcoming turn may be justifiable as an omission rather than an active act of withdrawal [8]. Criteria for the withdrawal of hemodialysis have not been standardized yet. The main reasons that patients forgo dialysis are physical burdens and perceived social burdens associated with treatment [14,15]. In fact, the withdrawal of dialysis is one of the common causes of death in dialysis patients, including cardiovascular disease and infection [16–20].

Based on the Act on Decisions on Life-Sustaining Treatment in Korea, hemodialysis is one life-sustaining treatment that a dying patient has the right to decide to refuse at the EoL. If a patient does not want to undergo hemodialysis, the patient should express this opinion

through an advance directive when they approach the EoL. Unfortunately, the decision to withhold or withdraw hemodialysis is not usually made by patients due to a lack of decision-making capacity at the time near death [21]. Moreover, most dialysis patients have not previously discussed end-of-life care with their families, surrogates, or health care professionals. Thus no ACP has been established [22]. Conversations about dialysis withdrawal can be an emotional burden for all involved [23].

### Respect for autonomy versus sanctity of life

The core of the principle of the sanctity of life is the prohibition of intentional killing. The notion is deeply rooted in religion, including the Judeo-Christian tradition in Western thought and Buddhism in Eastern thought. The sanctity of life was considered the most important principle in medical ethics until the mid-twentieth century. With the overturn of the prohibition on abortion in 1967 in the United Kingdom, followed by similar legislation in many other Western countries such as the United States in 1973 and Canada in 1988, notions on the inviolability of life have changed. The principle of the sanctity of life, which had been absolute in medical practice, has been gradually abandoned by legislatures directly impacting the field of health care [24]. Based on modern ideas that the principle of the sanctity of life does not mean the preservation of life at all costs, respect for patient autonomy and quality of life has been incorporated as the single most important ethical approach to the evaluation of human life on the part of intensive care physicians.

### Advance care planning and renal palliative care

Most dialysis patients want their physicians to determine EoL care related to life-sustaining treatments on their behalf [25]. Initiating a discussion about ACP is challenging for patients and family members as well as for health care providers [7,22]. Optimal timing and appropriate ways of communicating in ACP discussions are difficult to discern. According to a large survey of stage 4 and 5 CKD patients, more than 80% of patients indicated the importance of being informed about withdrawing dialysis as an EoL care option and of preparing a plan in case of death [22]. Opinions about the proper time to address EoL varied. For example, 39% of patients wanted

to have this conversation when they became critically ill, while 24% wanted to undertake the conversation at a time upon their explicit request. Four percent of patients wanted to have the conversation prior to starting dialysis, while 10% wanted to have the conversation after commencing dialysis but before becoming ill. There is concern that when the conversation is initiated too early, patients may be unprepared. On the other hand, if the conversion is initiated too late, patients are unable to clearly express their own opinions [26]. These findings emphasize the importance of patient-centric approaches when nephrologists consider discussing EoL care with dialysis patients. Nevertheless, an insufficient number of nephrologists has been shown to discuss EoL care with their dialysis patients. Fewer than 10% of dialysis patients indicated that they had discussed EoL care with their nephrologist in the past 12 months [22]. Most patients did not consider advance directives as an essential requirement for proper EoL care [27]. This thinking on the part of patients impedes shared decision-making related to EoL treatments.

The purpose of ACP is to respect a patient's autonomy and identify his/her wishes for future medical care, including life-sustaining treatments [28,29]. Racial and ethnic differences have been well documented in the approaches of patients to ACP, as well as stark differences in marital, parental, educational, and socioeconomic status [30]. Asians were 58% less likely to have EoL discussions, but were 56% more likely to have living wills in comparison to white patients. Asians showed a tendency to rely on formal documents. They did not want to actively discuss dying [31]. One of the most difficult situations for nephrologists in trying to respect patient ACP wishes were cases of disagreement between patients and family members [32]. Encouraging patients to discuss their ACP wishes with key family members to inform and prepare them for EoL care is essential [29]. Cultural acceptance of ACP is necessary in the field of nephrology to properly implement ACP for dialysis patients [32]. Any personal and professional vulnerabilities experienced by physicians should be addressed to improve professional confidence [32].

Withdrawal of dialysis has been reported to be the cause of death in 18% of patients treated with renal replacement therapy in the United Kingdom and in 25% of renal replacement therapy patients in the United States

**Table 2. Possible indications of withholding hemodialysis and factors associated with withdrawal from hemodialysis**

Possible indications for withholding hemodialysis [36]	Risk factors for hemodialysis withdrawal [14,18,37–40]
Severe hypotension	Increasing age [14,37–40]
Very poor prognostic conditions	Female sex [14,37,38,40]
Far advanced dementia	White race [14,38,40]
Age > 75 years with a high comorbidity score and significantly impaired functional status	Prior cerebrovascular disease [37]
	Chronic or progressive diseases [38]
	Diabetes mellitus [40]
	Multiple medical problems with a recent deterioration [14,39,40]
	Late referral to nephrologist [40]
	Severe medical complications and/or cachexia [18]

[20,33]. We emphasize that treatment withdrawal is not the ignoring of a patient. Appropriate hospice and palliative care should be followed by a decision to withhold or withdraw dialysis. In spite of high annual mortality rates in dialysis patients, hospice services have not been properly provided to dialysis patients in comparison to patients with other diagnoses [34]. Adequate education of ESRD patients on their prognosis with more thorough and frequent discussions of ACP with well-trained nephrologists is necessary to improve the utilization of hospice services and palliative care [35]. Shared decision-making is the key element for proper ACP and palliative care. According to guidelines developed by the Renal Physicians Association [36], dialysis could be withheld if a patient has very poor prognostic conditions, such as severe hypotension, far advanced dementia, and age > 75 years with a high comorbidity score and significantly impaired functional status (Table 2). Even though several risk factors for dialysis withdrawal have been revealed [14,18,37–40], research on withdrawal and associated factors is still scarce (Table 2). Study results are inconclusive because of a lack of consistency in the definition of terms and selection bias [41], but the withholding or withdrawal of hemodialysis has been more commonly conducted in elderly patients. According to reports from the Insan Memorial Dialysis Registry in Korea, the mean age of hemodialysis patients periodically increases (62.3 years old in the 2016–2017 registry vs. 55.2 years old in the 2005–2006 registry) [42,43]. Moreover, excess mortality was revealed among ESRD patients compared to the general population in Korea [44]. Considering the recent “Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life”, nephrologists should pay greater attention to withhold-

ing or withdrawing hemodialysis in elderly patients in Korea.

If there is any uncertainty in prognosis and no consensus is reached related to dialysis, then a time-limited trial of dialysis may be provided [4]. Palliative care should be considered for patients suffering from disease complications at any EoL stage [45]. A multidisciplinary care team is necessary to provide physical, psychosocial, religious, and spiritual support for ESRD patients who opt out of or refuse dialysis. Unfortunately, hospice and palliative care for ESRD patients are not well established as part of EoL care in Korea. Further studies are needed to develop and implement an appropriate palliative care model to improve the quality of EoL care for ESRD patients.

## Conclusion

Nephrologists should pay greater attention to EoL care for ESRD patients. A shared decision-making approach is essential to resolve conflicts and achieve proper goals between health care professionals and patients, as well as family members and patient surrogates. An appropriate and novel model for hospice and palliative care should be developed and implemented through a multidisciplinary approach to improve the quality of EoL care for ESRD patients in Korea.

## Conflicts of interest

The author has no conflicts of interest to declare.

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