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Making Decisions for Unbefriended Patients on Life-Sustaining-Treatment in South Korea: Healthcare Providers' Experiences*,**

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Abstract

Purpose: This study attempts to clarify the difficulties faced by healthcare professionals in South Korea in making and implementing Life-Sustaining Treatment (LST) decisions for vulnerable patients who lack legally competent proxy decision-makers.

Materials and Methods: First, a keyword analysis was performed on the official responses of the National Health Agency of Korea to 750 questions from healthcare workers. Second, a survey probing the difficulties that healthcare professionals face in making LST decisions was administered to the ethics committee members of 246 medical institutions.

Results: From the keyword analysis, 139 keywords were categorized into ten subcategories. The survey had a 32.5% response rate, and of the respondents, 41.98% faced difficulties in making decisions for unrepresented patients because of the absence of family members or due to inadequate evidence. Among these patients, 82.35% did not have decision-making ability at the time of need and 85.29% had no family members to consult with.

Conclusion: Four categories of "unbefriended" patients were identified in this study. Additionally,

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in uncovering evidence on how LST decisions are implemented and creating a category of “unbefriended patients,” this study underscores the need to expand the scope of legal proxies under the LST Decisions Act.

Keywords
proxy, clinical ethics, decision making, end-of-life decision, Life-Sustaining Treatment Decision Act

I. Introduction

The “Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life” (hereafter, the LSTD Act) was legislated in South Korea in 2016 with the goal of “protecting the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination (Article 1).[1]” In this article, the “life-sustaining-treatment decision system” (hereafter, the LST decision system) refers to the general support for patients and healthcare professionals, including clinical decision-making processes as well as human resources. This system aims to improve the quality of care for patients with terminal illnesses through hospice-palliative care, solve the confusion around withdrawing/withholding futile treatment, and finally, establish the basis for patients to exercise self-determination[2,3]. According to a national report, the monthly utilization of this system gradually increased from 1,380 cases in February 2018 to 4,302 cases in April 2020, following the enforcement of this Act[4].

The LST decision system provides the authority to refuse or request the halting of medically inappropriate treatment, with appropriateness determined by two factors: the expected effectiveness of the treatment based on the patient’s condition and the patient’s expressed preference (Article 15). Patients can express their LST preferences with an “advance statement on life-sustaining treatment (usually referred to as an advance directive),” a verbal statement, or a “life-sustaining treatment plan (medical order written by the physician in charge)” with the expectation that their expressed preferences will be respected. The Act recognizes presumed will, as witnessed by family members, and substitutes decisions made in the best interest as agreed upon by all family members. Currently, 70% of LST decisions are made by families via presumed will or substitution.

The trend toward the majority of LST decisions being made by the family, not by the patients themselves, poses another problem for healthcare professionals when there are no legally competent individuals to make LST decisions[5], as is often the case for homeless people, orphaned minors, and older people living alone. Healthcare providers tend to avoid making LST decisions for these groups due to liability issues, ethical difficulties, and administrative reasons[6]. This tendency may lead to the infringement of the right to self-determination and even the right to treatment[7,8,9]. Therefore, it is necessary to estimate the occurrences and resolution of LST decision issues in medical practice to understand the considerations of healthcare professionals in the LST decision-making process for vulnerable groups by gathering and analyzing their experiences related to LST decisions.

II. Materials and Methods

The National Agency manages the LSTD Act for Management of Life-sustaining Treatment, which controls the decision-making and implementation of LST. Since the start of the LST decision system, the National Agency has been receiving questions on LST decisions from the general public and medical workers, including the Institution Ethics Committee (hereafter, IEC) staff members. The National Agency responds to these questions through the question-and-answer (Q&A) board of the National Agency's website and the Open API system[10]. Through these platforms, healthcare professionals obtain authoritative answers to issues in LST decisions of which they were uncertain. The questions reflect the legal considerations that healthcare professionals must consider. As of October 2019, under the law, 326 questions were registered on the Q&A board, and 434 queries on the open API, resulting in a total of 750 questions.

This study aims to understand the issues and their nature when LST decisions are made for individuals without family members to witness or substitute these decisions. The study is summarized in <Figure 1>.

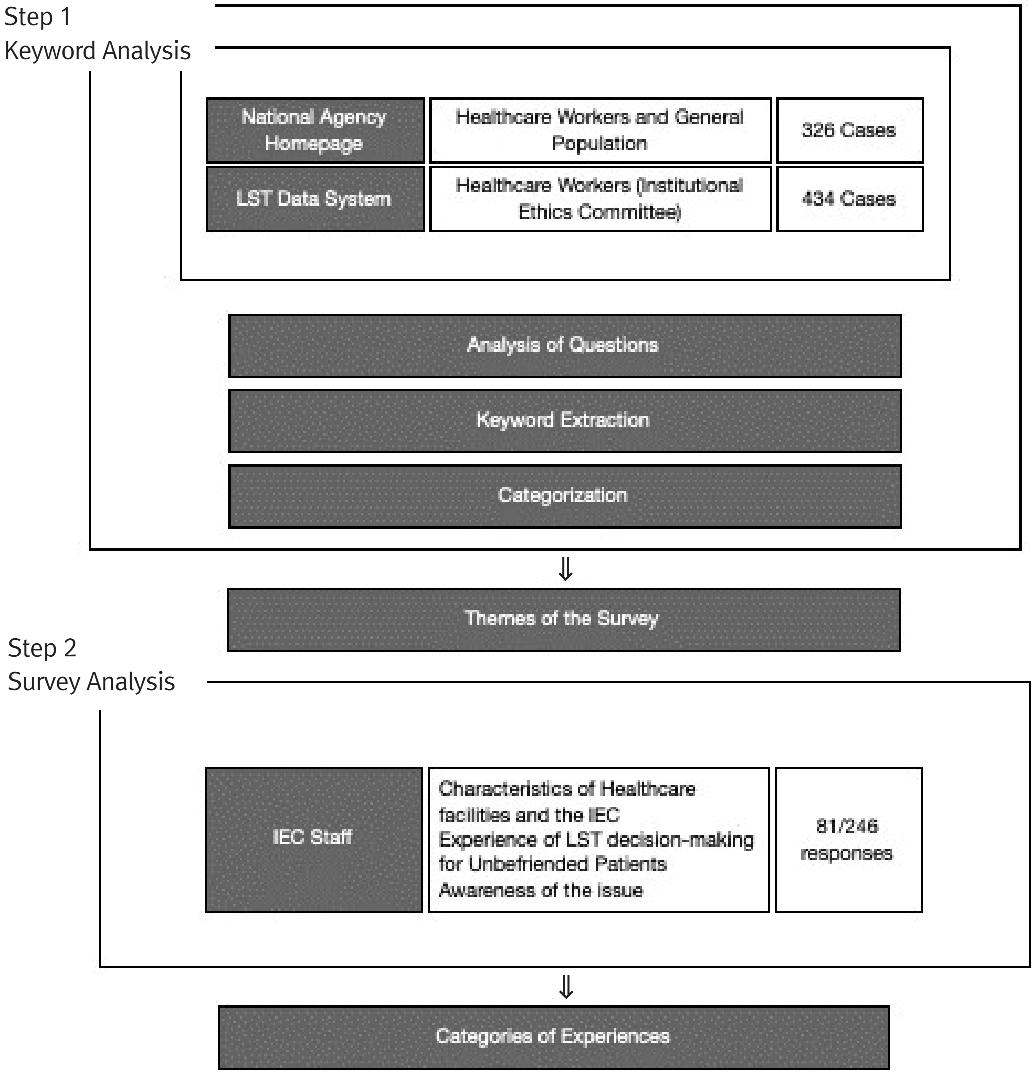
In step 1, questions from the general public (326 from the general Q&A board of the National Agency's website, 434 from IEC staff members) that requested authoritative interpretations of the law from the National Agency were gathered and analyzed to extract the themes of the survey. In step 2, the survey was administered to all institutional ethics committee staff members (81/246 responses) to gather and analyze the cases they had personally experienced.

1. Keyword Analysis

A keyword analysis was performed to identify the major issues related to LST decisions for unbefriended patients, as mentioned in previous studies, and verify whether such issues occur in clinical situations.

To minimize the research bias, two re-

〈Figure 1〉 Study flowchart



searchers read all the collected questions and extracted up to five main keywords for each question. In this process, they analyzed all of the questions, compared the results of their analysis, and reached a consensus by discussing the differences between their results. The extracted keywords were listed in the order of frequency of appearance, and those with similar keyword characteristics were categorized by grouping.

2. Survey

To collect and categorize specific cases of life-sustaining care decisions identified through the question-and-answer analysis, a survey was conducted to gather healthcare workers' experiences on life-sustaining treatment decisions. The survey was administered to 246 medical institutions (as of December 4, 2019), specifically with the institutional ethics committees installed to enable the implementation of decisions, such as suspension of life-sustaining treatment[11].

The survey was conducted online after approval from the Institutional Review Board in the medical institution to which the researchers belong (approval number: Y-2019-0159). The survey period was from December 4 to 15, 2019, and the subjects were all employees of medical institution ethics committees. The questionnaire comprised a mixture of open and closed question types, depending on the content, and asked whether respondents had ever suffered difficulties due to an LST decision because there was no family member to consult or the patient had left no explicit instructions regarding preference. The respondents comprised administrative staff or members of the institutional ethics committee, and only one person per institution was guided to respond to the questionnaire. The questionnaire asked about the characteristics of the medical institution (location, number of beds, type), the status of the committee's activities (hosting meetings, providing counseling), the experience of making life-sustaining care decisions for the elderly (having related experiences and case descriptions), and the need for policies.

III. Results

1. Keyword Analysis

From the questions section, a total of 139 keywords were identified, among which an advanced statement on LST (5.61%), implementation report (5.20%), certificates of family relations (4.58%), and end-of-life process diagnosis documentation (4.13%) frequently appeared. This demonstrates the need for legal interpretation during decision-making and preparation of legal documents. In particular, questions related to family witnessing and surrogate decision-making [e.g., family's unanimous expression of agreement (4.01%), identical statement of witness (3.44%), and scope of family eligible to express (2.95%)] demonstrate the complicated nature of family involvement in decision-making. Other frequent keywords were competence (1.84%), minors, referring to persons under the age of 19 (1.80%), unconscious patients (1.72%), and foreigners (1.72%).

We categorized the 139 keywords into ten subcategories according to their contents: decision-maker, legal documents, LST decision-making process, healthcare facilities/medical practice, certificates, other facilities, related law, institutional ethics committees, advance statement registering agency, and brain death. In these categories, the decision-maker category includes the most keywords: family expression of agreement, family witness, terminal patient, decision-making capacity, minors, unconscious patient, and foreigner. This category also includes keywords such as minors, unconscious patient, foreigner, nationality, and person without identifiable/authoritative family member, legal representative, custodian, and order of decision power. These keywords demonstrate that identifying the decision-maker poses difficulties to healthcare providers.

In the "legal document" category, the LST plan document, advance statement on LST, and documentation on verification of advance statements appear. Keywords such as the power of the document and voice recording related to the legal power of documents also appear. In the "LST decision-making process" category, documents on the implementation of decisions, diagnosis of end-of-life process, withholding, registration, withdrawing, and revocation appear. In the "healthcare institute/medical practice" category, artificial ventilator, fee, physician-in-charge, cardiopulmonary resuscitation, and the emergency room appear; the results are summarized in <Table 1>.

〈Table 1〉 Results of keyword analysis

No.	Category (No. keywords)	Main keywords	Appearance	
1	Decision-maker (26)	Family expression of agreement, family witness, terminal patient, decision-making capacity, underage person, unconscious patient, foreigner	587	(24.02%)
2	Legal documents (18)	Advance Statement on LST, LST Plan Document, Preservation of Records, LST Data System, power of document, voice recording	545	(22.30%)
3	Decision-making process (22)	Documenting implementation report, certificate of end of life process diagnosis, withdrawing, withholding, revocation	459	(18.78%)
4	Healthcare institutes/medical practice (24)	Artificial ventilator, fee, physician-in-charge, cardiopulmonary resuscitation	313	(12.81%)
5	Certificate document (23)	Family relations certificate, resident registration number	253	(10.35%)
6	Other healthcare institutions (7)	Transfer, facilities without institutional ethics committee	114	(4.66%)
7	Institutional Ethics Committee (4)	Institutional ethics committee	104	(4.26%)
8	Related laws (10)	Punishment	58	(2.37%)
9	Advance statement registration agency (3)	-	6	(0.25%)
10	Brain death (2)	-	5	(0.2%)

2. Survey

There were 81 responses (32.5% response rate) to the survey, with a high proportion of respondents from Seoul (23.75%), Gyeonggi (17.50%), and Incheon (12.5%). Regarding the size of the medical institutions, the largest proportion had 500 to 999 beds (40.74%), and general hospital workers were the most common respondents (46.91%). More than half of the medical institutions had established institutional ethics committees in 2018 when the Life-Sustaining Treatment Decision Act was enforced (64.20%). After establishing the ethics committees, an average of 3.06 (SD 4.48) institutional ethics committee meetings were held to deliberate and discuss LST decisions and other ethical issues. The average number of counseling sessions regarding LST issues with patients, family members of patients, and clinical staff in the last two years was 248.70.

A total of 41.98% of the respondents responded “yes” to the questionnaire item regarding whether there was any difficulty in making decisions for incompetent patients because their families were not available, or the evidence was insufficient or lacking. Additional questionnaire items were administered to respondents who answered “yes” to this item, and 82.35% said they did not have the decision-making ability when they needed to make a decision, while 85.29% also had no family to consult. In 61.76% of cases, end-of-life judgment was made on behalf of the patient, but in most cases, even when the judgment and form were filled out, the implementation report was not reported to the National Agency. The survey results are summarized in <Table 2>.

〈Table 2〉 Survey results

Difficulties	No.		Percent (%)
Patient’s Competence	Yes	6	17.65
	No	28	82.35
Availability of Family for Consultation	Yes	5	14.71
	No	29	85.29
Existence of Diagnosis of End-of-life stage	Yes	21	61.76
	No	13	38.24
Report to Agency	Yes	3	8.82
	No	31	91.18

IV. Discussion

This is the first study to be conducted based on questions received from an official government platform and a subsequent survey to understand healthcare institutions' experiences related to LST decision-making[12,13]. The questions were related to the difficult decisions that healthcare institutions must make and represented the problems that lie outside the current legal system[14,15].

The purpose of advance care planning, or advance directives, is to guarantee that the patient's autonomous decisions be respected when they are at the end-of-life stage. In many cases, the family executes a power of attorney as witnesses or as substitute decision-makers[16]. Under the current legal system, the patient's best interest is protected under the following conditions. First, a medical judgement on the end-of-life must be made in advance. This medical judgement means that treatment aimed at recovery may no longer be effective. Second, patients with prior medical judgement may be protected in their best interests by (1) the patient's explicit expression of LST preference, (2) a presumed decision based on the [legal] family as a witness, and (3) a substitute decision made by unanimous agreement. Our study demonstrated that 41.98% of healthcare institutions experienced issues related to patients with no records of an LST decision. These issues, related to these un-represented patients, are the areas that require systematic improvement.

As illustrated in <Table 1>, the most frequent category was "decision-makers," with keywords related to decisions. We found questions related to difficulties due to the lack of evidence for groups such as minors and foreigners. We also identified areas that the current law does not address, such as legal custodianship. Likewise, healthcare providers faced difficulties related to the administration of legal documents, particularly with regard to administrative processing. The collection period of the questions was during the early stages of the system's implementation, and these difficulties were caused by a lack of understanding of the system, which were gradually addressed through education and experiences

In the survey, 41.98% of respondents reported difficulties in decision-making for patients without evidence of preferences or proxy decision-makers. In these situations, the healthcare institutions attempted to comply with the requirements of the LSTD Act but had to finalize the situation without reporting the decision to the Agency, and these patients received medical assistance until their death. However, there were difficult cases when the patient was competent or the family was contactable. These were related to conflict between family members or a lack of legal status for the proxy decision-makers.

Situations where the proxy was available but unable or unwilling to exercise their power of attorney, were the most concerning.

Patients in this condition were referred to as "adult orphans," "unbefriended," or "unrepresented," and were defined as "incompetent and without a proxy to decide for him/herself.[17]" We can classify these "unbefriended patients" in the South Korean legal system as illustrated in <Table 3> below.

The multidisciplinary institutional ethics committee can substitute for the treatment decision-maker role[18], but this does not resolve the problem[19].

〈Table 3〉 Classification of "unbefriended patients" in the South Korean legal system

1) Absence of proxy: patients with no family or foster children
2) No legally recognized family member accessible.
3) Patients with a family who are available but who cannot be contacted for consultation.
4) Patients with family members who are available but are unwilling to serve as a proxy.

1. Absence of proxy: patients with no family or foster children

According to the Act on Funeral Services, Etc. in Korea, an unrelated person is a person who does not have a spouse, direct descendants, or siblings. In South Korea, this could be a religious person, an older person living alone, or a homeless person with no family members (hereafter referred to as unrelated persons) to represent them. In the cases collected in the survey, such patients had not documented their intention to discontinue life-sustaining treatment and did not have any family to make this decision; therefore, the unrelated persons eventually died after receiving life-sustaining treatments, including cardiopulmonary resuscitation. Some of these had revealed their intentions to acquaintances whom they visited and who were the guardians of the patient. As these acquaintances had been communicating with the patient for a long period, they knew the patient's preferences better than anyone else. However, while this proximity had allowed them to attain sufficient statements of will, they were not recognized as legal representatives of the patient and could not, therefore, make the decision. For these cases, the medical staff felt pressurized to continue providing life-sustaining treatment even though informed through the guardians of the patient's wishes. This meant that, in most cases, they were unable to stop life-sustaining treatments. Therefore, the respondents who had had this experience emphasized the necessity for an attorney system or ethics committee to facilitate the withdrawal of life-sustaining treatments.

The scope of unrelated persons includes minors who live in child protection consignment facilities. They do not have lineal ancestors who can exercise proxy decision-maker roles, so they do not have the right to decide to stop life-sustaining treatment. In the cases collected through the survey, many related to the life-sustaining treatment decisions of minors. Most facility managers' requests to stop life-sustaining treatment are not granted.

2. No legally recognized family member accessible

There were cases in which the patient had a common-law spouse or a direct family member who was not registered in the family register. Despite maintaining a strong relationship with the patient during their lifetime and understanding the patient's intentions better than anyone else, such persons do not have the authority to stop life-sustaining treatment because they cannot be legally recognized as a family member. In this situation, there are no legally stipulated family members such as immediate family members or siblings, but relatives such as cousins or nephews have served as long-term main guardians and have borne witness to the patient's intention during their lifetime; however, there are many cases in which this cannot be applied[20].

If the patient who could not discuss the life-sustaining plan due to unconsciousness was a foreigner living alone in South Korea, healthcare providers had difficulties proving family relations. In such a case, to stop the patient's life-sustaining treatment, a person in charge of the healthcare institution must visit the foreigner's embassy to prove the patient's relationship with the family in the home country. There is also a need to contact that family to obtain a certificate reflecting that relationship and their consent to stop the LST. As this process takes a considerable amount of time, the patient's life-sustaining treatment also continues for a long time[21].

3. Patients with a family who are available but who cannot be contacted for consultation

In the process of withdrawing or withholding life-sustaining treatment by family agreement, there are cases where direct relatives, subordinates, or some of the siblings cannot be contacted for decision-making. In the LSTD Act, the family member's agreement is excluded only if the person is missing or unconscious. Therefore, if there is a family member who has lost contact, it is difficult to decide whether to suspend the patient's life-sustaining treatment or not[22]. For example, if a family member has been out of contact for a long time simply due to family discord or personal circumstances, the decision to stop life-sustaining treatment might be delayed. To find the patient's relevant family member in such a situation, other family members may have to discover their whereabouts or the hospital staff might have to locate such a family member; this significantly delays the consent process, and the patient has no choice but to continue meaningless treatment.

4. Patients with family members who are available but are not willing to serve as a proxy

As described above, when there is a decision to withhold/withdraw LST through a family agreement, some families refuse to make the decision for personal reasons. In particular, family members who have not met for a long time due to family discord such as separation or divorce are representative of such cases. However, it is not sufficient to suddenly recognize the critical condition of the patient, and such a person may feel greatly burdened by the fact that the patient will die as a result of their decision and will therefore refuse to make the decision. Buchanan and Brock argued that family members usually understand the patient's personal interests, values, and preferences best, and also care the most for the patient's well-being; therefore, family members can be the proxy decision-makers[23]. However, as described above, in the case of a family who cannot fulfill the criteria to make a decision on behalf of the patient due to their lack of information on the patient's personal history, it is difficult to say whether they would act in the best interests of the patient.

The United States' Patient Self-Determination Act (1990) allows the appointment of a continuous medical representative through advanced medical directives. These are persons who have been legally granted the authority to make medical decisions on behalf of the patient[24,25]. These persons, in most cases, are family members, but not always. In Germany, through the "Third Amendment to the Act on Adult Guardianship (Drittes Gesetz zur Änderung des Betreuungsrechts)," medical treatment through a guardian is possible. The guardian is a person designated by the patient, even if they are not a family member[26].

The category of patients who cannot make decisions is similarly described in existing studies, but some differences can be attributed to the proxy system that exists in overseas legal systems but not in the domestic LSTD Act. Pope's study on "Legal Unbefriended Patient" or "Unbefriended Patient without treatment decision authority" corresponds to the "unrelated persons" including "non-legal family" and minors among the categories of this study. However, there are differences in content in the case of "unrelated persons" and "disconnected families," which correspond most closely to the scope of "permanent unbefriended patient." Pope's study included patients whose agent refused to make decisions, whereas the "disconnected family" of this study deals with cases of a family's refusal to make decisions. Also, in the case of the "existence of a family outside the law," there is no corresponding category because the domestic LSTD Act does not have an agent system.

The restricted scope of a legal proxy in the LSTD Act has resulted in difficulties in determining and implementing life-sustaining treatment decisions. This is a barrier that prevents the patient's self-determination and best interests from being guaranteed. According to the ruling in the grandma Kim case of Severance, which served as the legislative basis for the life-sustaining treatment decision system, the continuation of meaningless life-sustaining treatment was seen as an infringement of basic rights based on the right to pursue dignity, value, and happiness as a human being[27]. It is necessary to prepare a life-sustaining treatment decision procedure for patients who cannot make decisions due to lack of family or evidence to ensure the dignity of patients' death and equity of care at the end of their life.

V. Conclusion

This study confirmed the difficulties in the clinical field in the life-sustaining treatment decision process of patients who cannot make a decision because there is no family or evidence and has proposed a countermeasure. To this end, in this study, a question-and-answer analysis and questionnaire surveys of the National Agency were conducted to determine the problems in the life-sustaining treatment of patients who could not make decisions due to lack of evidence or family members as prescribed by law. As a limitation, the results cannot be generalized as the survey response rate was from less than half of the healthcare institutions established by the Medical Institution Ethics Committee. However, the results are still effective as this is the first research that has empirically analyzed the limitation problem of a legal proxy, which has been criticized since the enactment of the LSTD Act. Additionally, by creating a category of "unbefriended patients in Korea" and comparing them with the existing international literature, the problems of the domestic system have been reconfirmed. This study can be expected to improve the quality of care for more terminally ill patients by identifying the blind spots of the law and presenting a proxy system as a measure to fill this gap. However, the proxy system presented in this study is only one supplementary alternative considering the legal purpose enacted to reflect the patient's own intention. Therefore, in order to truly realize the purpose of the LST system, advanced research on influencing factors and countermeasures should be given priority so that patients can express their intentions in a timely manner.◎

Conflict of Interest

There are no potential conflicts of interest relevant to this article.

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연명의료결정법에 의해 연명의료결정을 내릴 수 없는 환자에 관한 연구:
보건의료제공자의 경험을 중심으로*,**

최지연[1], 전희정[2], 이일학[3]

요약

본 연구는 한국의 연명의료결정법에 의하여 연명의료중단등 결정을 내리기 어려운 환자들에 관한 연구로써, 해당 환자들의 현황을 살펴보고 그 범위를 확인함으로써 보건의료제공자가 직면하는 어려움을 명확하게 하는 것에 목적을 두고 있다. 본 연구에서는 각 의료기관의 보건의료제공자들이 국립연명의료관리기관에 질의한 내용을 수집하여 키워드로 분석하였으며, 의료기관 윤리위원회 설치 의료기관 내 담당자에게 연명의료결정과정에서 어려움을 겪은 경험에 대한 설문조사를 시행하였다. 그 결과 국립연명의료관리기관 질의사항을 바탕으로 진행한 키워드 분석에서는 139개의 키워드와 10개의 범주를 추출하였다. 또한 설문조사의 경우 응답자 중 41.98%가 연명의료결정법 18조에서 제시하는 의사확인 요건을 충족할 수 없는 환자로 인하여 어려움을 겪은 경험이 있음을 응답하였다. 이 환자들은 연명의료중단등 결정의 시기에 환자가 의사결정능력이 없었으며(82.35%), 의사결정을 내릴 가족이 없었던(85.29%) 경우였다고 답하였다. 본 연구는 위의 연구결과를 토대로 한국의 연명의료결정법에 의하여 의사결정을 내릴 수 없는 환자를 총 4가지 범주로 나누었다. 이는 연명의료결정제도가 포섭하지 못하는 환자들의 유형을 실제적으로 구성하였다는 부분에 의의를 둘 수 있으며, 향후 제도가 갖추어야 할 법적 대리인의 지정 및 의사결정자 범위 확장의 필요성을 제시하였다.

색인어

대리인, 임상윤리, 의사결정, 연명의료결정, 연명의료결정법

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