

Characteristics of life-sustaining treatment decisions: National data analysis in South Korea

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Abstract

Although the Act on Decisions on Life-sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life was implemented in South Korea in 2018 to ensure the dignity of death for patients, adequate data are not available about whether patients' preferences are being reflected in end-of-life decisions. By using the data of 79,863 patients from the database of national institutions, this study examined the actual condition and characteristics of the life sustaining treatment decisions (LSTD) system since its implementation. The patients were divided into four groups according to the decision-making method (G1, G2, G3, and G4), and descriptive statistical analysis was performed. Logistic regression analysis was performed by dividing the patients into self-determining (G1, G2) and family-determining patients (G3, G4). The results revealed significant relationships between the variables; age, disease, and hospice use of patients showed differences in each group. Age was found to have a major impact on LSTD, and with increase in age, the family, and not the patient, made the LSTD. The LSTD method also differed depending on the disease. The self-determination rates of patients with circulatory or digestive diseases were somewhat lower than that of those with neoplastic diseases. Regarding the period from decision making to the implementation of the LSTD life judgment, the findings revealed hurried decision making and inadequate time for the patient to prepare for death. The findings highlights the need for ensuring that the patients are the subjects of their treatment decisions and for beginning LSTD consultation sooner.

Introduction

In 2018, the Act on Decisions on Life-sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life (LSTD Act) was enacted in South Korea to determine hospice-related medical treatment. This is the first law on end-of-life care respecting the patient's right to self-determination and ensuring their best interests regarding a dignified death (Article 1).[1]:

First, the LSTD Act documents the contents of advance care planning, which is based on patients' intention. The documents are categorized based on who makes the decision: the patient (Advance Directive [AD]) or the doctor (Physician Orders for Life-Sustaining Treatment [POLST]). Treatment preferences recorded in these forms go through verification procedures during the end-of-life, which is documented and reported to the national agency in South Korea. Second, only families of patients prescribed by civil law may be involved in treatment decisions. If the patient cannot directly confirm treatment preference, the family will state the patient's intention or obtain consent of the whole family. The decisions are determined on the patient's behalf by the authority granted by law. Third, the life-sustaining treatment decision (LSTD) process is divided into terminal-term and end-of-life. If a doctor diagnoses an end-of-life patient, he/she should write and register legal documents. Fourth, the LSTD system has a national supervisory and managing agency that establishes a database to manage legal forms, including POLST and AD, and guides and supervises matters related to LSTD. It also calculates monthly statistics on LSTD status.

As of January 2020, 85,076 cases have been implemented,[2] of which the number of decisions made through family statements or agreements (55,775) is nearly twice as high as that made using POLST or AD (29,301). The LSTD system is thus based on family decisions rather than on patients' preferences or wishes,[3-5] and a more accurate understanding of the decisions is needed. However, the national agency only provides simple figures of the cumulative number of implementation patients, and limitations exist in understanding the system's trends and characteristics. An international study used national death statistics on age of death, cause, and contents of forgoing treatment to identify the proportion and characteristics of patients forgoing treatment.[6-8] A South Korean study identified the types and related factors of life-sustaining treatment (LST) for geriatric patients, attitudes and characteristics of elderly patients to LST, and whether they wrote POLST.[9-11] However, these studies mostly considered data shared by a single or several medical institutions; as no data analysis was conducted using National Institute of Statistics data, there was limited information on the system's characteristics. Therefore, this study aims to analyze the national agency's data for two years after the LSTD system's implementation to identify the LSTD's status and characteristics according to patients' decision-making method.

Method

Design

This retrospective study analyzes data on legal forms prepared in South Korea's LSTD system and the characteristics of patients who implemented LSTD. The purpose is to analyze LSTD records collected and kept by a national agency and how much patient preferences are reflected in the decision-making and factors involved.

According to patients' LSTD forms, four types of decision-making groups exist (Figure 1) depending on the decision, decision maker, patient's condition, and timing of decision-making.

Group 1 (G1) involves determination by POLST, wherein a terminally ill or end-of-life patient asks the doctor for future medical decisions, and which documents the patient's condition and treatment options, hospice choices, type of forgoing treatment, and LSTD (Articles 10, 17.1).

Group 2 (G2) involves determination by AD, which lists LST preferences previously prepared by patients, and the doctor in charge reconfirms them with the patient to complete the patient's LSTD. If the patient does not have sufficient competency to verify the AD, the patient's decision can be respected by checking this document with a specialist (Article 17.2).

Group 3 (G3) involves determination to confirm the patient's intention based on a family statement. This occurs when the patient cannot implement the above two decision-making methods and is not capable of decision-making. The presumed intent is recognized by the family's testimony that the patient did not want meaningless LST. The family statement is made by at least two members and must be consistent (Article 17, Paragraph 1, No. 3).

Group 4 (G4) involves decision-making by every patient’s family member. This decision is made if the patient does not have a document or witness for the LSTD. The family then ensures the decision is in the patient’s best interest. A proxy decision is made even if the patient is underage, when the legal representative is limited to the patient’s parental authority who may express the intention to make a life-long medical decision (Article 18).

G1 and G2 involve patients making decisions based on explicit preference expression, and they are classified as “self-determining patients.” Conversely, G3 and G4 include “family-determining patients” for whom proxy decisions are made based on family statement or agreement.

Population and data collection

The study subjects were patients registered in the LSTD system from March 2018 to January 2020. Data from the database of national institutions were used, which included the total number of registrations in the six main legal forms of the LSTD process for the presented period—POLST, AD reconfirm, witness by the family, consent of the family, end-of-life judgement, and implementation. Duplicate data were removed and as a result of merging based on the author of the implementation form, 84,422 patients were selected for analysis. Among them, 2,179 patients who were only registered with an implementation without end-of-life or decision-making documents (AD, POLST, witness by the family, and consent of the family) were excluded. Moreover, 579 patients without a registered decision-making document and 1,451 patients without end-of-life judgments were excluded. Finally, 80,213 subjects were extracted, who had a written end-of-life judgment, written statement of implementation, and at least one decision-making document. Among them, 79,863 were selected for the final analysis, excluding 350 with unclear decision-making methods because of two or more decision-making documents.

Ethics

In this retrospective study, data analysis was conducted after approval of deliberation exemption from the Institutional Ethics Committee of the researcher’s hospital (No: Y-2020-0008).

Data analysis

The patients were divided into four groups according to the decision-making method (Figure 1) and subjected to descriptive statistical analysis. Moreover, logistic regression analysis was performed by dividing them into self-determining and family-determining patients according to the decision-making method. For analysis, SAS ver. 9.4 was used. The data are described in Table 1.

Table 1 Data content by classification

Group	Written document	Contents
G1	Physician Orders for Life-Sustaining Treatment, end-of-life judgment, and implementation	Gender, age, patient status, diagnosis, type of medical institution, region of medical institution, AD status, status to use hospice, subject of specialist, contents of forgoing life-sustaining treatments, date
G2	Advance Directive (AD) confirmation, end-of-life judgment, and implementation	Gender, age, diagnosis, type of medical institution, region of medical institution, AD status, status to use hospice, subject of specialist, contents of forgoing life-sustaining treatments, and date
G3	Witness by the family, end-of-life judgment, implementation	
G4	Consent of the family, end-of-life judgment, and implementation	

Results

General characteristics of groups

Subjects were categorized into four groups according to the LST decision-making method. Each group's descriptive statistics show a significant relationship between the variables; particularly, age, disease, and hospice use of patients showed differences in each group (Table S1).

Characteristics of patients determined by POLST (G1)

G1 included patients who have written a POLST, an end-of-life judgment, and an implementation. They included 62.71% men and 37.29% women. Their average age was 66.86 years, with the majority in their 70s. The proportion of foreigners was 1.55%. There were 20 minors (0.07%) with average age of 14.3 years, and except for one person aged 18 years, a plan was prepared through agent confirmation. G1 mainly suffered neoplastic diseases (86.36%) and had terminal conditions (63.98%) when writing the POLST.

Medical institutions were mainly concentrated in the metropolitan areas of Seoul (37.22%) and Gyeong-gi (18.70%), and 55.69% were tertiary hospitals and 39.98% general hospitals. Specialists who judged patient's end-of-life mainly specialized in internal medicine (71.46%), followed by family medicine (10.17%).

Considering patient's LST-related characteristics, about 0.8% of ADs were written before POLST, and 12.21% used hospice-palliative care services. The content of forgoing LST mainly included cardiopulmonary resuscitation (97.80%), followed by ventilator (96.85%), hemodialysis (90.62%), and chemotherapy (74.54%). More than half of the patients (58.2%) wrote the end-of-life judgment, POLST,

and implementation on the same day. Moreover, 29.1% of patients wrote the POLST first and then later completed the end-of-life judgment and implementation on the same day.

Characteristics of patients determined by AD (G2)

G2 included patients who prepared AD, reaffirmed the contents through the confirmation form, and completed the end-of-life judgment and implementation. They included 60.56% men and 39.55% women. Their average age was 74.13 years, and they were mainly in their 70s (37.23%) and 80s or older (34.50%). G1 subjects mostly had neoplasms (65.50%) and respiratory disease (12.31%).

Medical institutions were mainly concentrated in the metropolitan area of Seoul (36.40%) and Gyeong-gi (26.52%), with 51.37% tertiary hospitals and 42.63% general hospitals. Specialists who judged patient's end-of-life were mainly specialized in internal medicine (66.64%), followed by family medicine (8.66%).

A total of 14.59% used hospice-palliative care services. The content of forgoing LST mainly included cardiopulmonary resuscitation (96.12%), followed by ventilator (90.88%), hemodialysis (87.77%), and chemotherapy (76.06%). In G2, 79.7% of patients reconfirmed the AD content, end-of-life judgment, and implementation the same day. It took an average of 157.25 (standard deviation [SD]: 151) days after writing the AD to reconfirm it.

Characteristics of patients determined by witness by the family (G3)

G3 included patients whose wishes were confirmed through family statements and who had prepared an end-of-life judgment and implementation. They included 56.71% men and 43.29% women. Their average age was 75.24 years, with mainly those over 80 years (42.58%) and 70 years (30.13%). The diseases included neoplasms (46.58%), respiratory diseases (20.04%), and circulatory diseases (12.68%).

Medical institutions were located mostly in Seoul (33.74%), Gyeong-gi (15.59%), and Dae-gu (10.03%), with 63.71% tertiary hospitals and 32.46% general hospitals. Most specialists who judged patients' end-of-life specialized in internal medicine (78.25%).

Among the patients, 0.22% had previously written AD and 2.37% used hospice-palliative care services. The content of forgoing LST included mainly cardiopulmonary resuscitation (97.52%), followed by ventilator (83.35%), hemodialysis (80.81%), and chemotherapy (56.92%). In G3, 83.4% of patients confirmed through the family with an end-of-life judgment and implementation on the same day. The average number of family member participating was 2.1 (SD 0.48), and the statements were mostly made by the son, daughter, and spouse, in order.

Characteristics of patients determined by consent of family (G4)

G4 included patients who completed the consent of family, end-of-life judgment, and implementation forms. They included 60.14% men and 39.86% women. Their average age was 70.46 years, and they were mainly over 80 years (31.35%) and 70 years (29.76%). The diseases included neoplasms (41.13%), respiratory diseases (19.47%), and circulatory diseases (16.87%).

Medical institutions were located mostly in Seoul (36.31%) and Gyeong-gi (16.81%), with 66.35% tertiary hospitals and 32.16% general hospitals. Most specialists who judged patients' end-of-life specialized in internal medicine (71.37%).

Moreover, 0.12% of patients had previously written AD, and 1.02% had used hospice-palliative care. The content of forgoing LST mainly included cardiopulmonary resuscitation (97.40%), followed by hemodialysis (74.94%), ventilator (72.91%), and chemotherapy (49.48%). In G4, 78.9% of patients had consent of the family with an end-of-life judgment and implementation on the same day. The average number of family members participating in decision-making was 3.42 (SD 1.58), with consent given by the son, daughter, and spouse, in order.

Characteristics of self-decision-making

This study also conducted a regression analysis to determine the characteristics of patients' self-determination of withdrawal and withholding of LST. Significant differences existed between self-determined and family-determined according to age, type of medical institution, region, whether AD was prepared, and refusal of some medical treatment (see Table S2).

Self-determination rate of patients in their 40s was 5.685 times higher than that of patients in their 80s. The self-determination rate for patients with circulatory disorders was 0.246 times lower than that of patients with neoplasms; this rate for patients with gastrointestinal disorders was 0.552 times lower than that of patients with neoplasms.

The rate of self-determination of general hospital inpatients was 0.021 times lower than that of those in tertiary hospitals. Regarding subjects of specialists, the self-determination rate of patients with end-of-life judgments by family medicine specialists was 3.460 times higher than that of patients with judgments by internal medicine specialists.

Moreover, the self-determination rate in Gwang-ju was 0.082 times lower than that in Seoul, and that in Gyeongbuk was 0.084 times lower than that in Seoul. Compared with Seoul, the rate was 1.934 times higher in Ulsan, 2.471 times higher in Gyeong-gi, 1.597 times higher in Chung-buk, and 1.987 times higher in Je-ju.

The self-determination rate of patients who had previously prepared AD was 117.475 times higher than that of those who did not.

This rate for patients who decided to withdraw or withhold a ventilator was 5.300 times higher than that of patients who did not, and the rate for patients who decided to withdraw or withhold hemodialysis was 2.120 times higher than that of patients who did not.

Discussion

This study found differences in the LSTD method according to patients' age and specific disease when the LSTD was made at an impending time of death for the patient.

Difference in LSTD method according to age

As age increases, the family, not the patient, makes the LSTD. Considering that the average age of G1 is 66.86, G3 is 75.24, and G4 is 70.46,[1] age has a major impact on LSTD. Patients in their 80s or older are dominant in G3 and G4, compared with G1, which has the largest proportion of patients in their 60s and 70s, and G2, which has the largest proportion in their 70s.

These results are confirmed by the logistic regression analysis, according to which the self-determination rate of patients in their 40s was 5 times higher than that of patients in their 80s. Thus, elderly patients' families generally make LSTDs as major proxy decision-makers. Family-centered decision-making is common in Asian countries as a characteristic of Asian cultures.[12,13] This is in line with previous research that interviewed doctors in intensive-care units to find that family-led decisions to withdraw and withhold patient treatment were more prevalent than patients' own decisions.[14] Particularly, for elderly patients, the family did not deliberately inform the patient of the medical condition, fearing patients' lack of understanding and weakening of willingness to fight the disease.[15,16]

Families play a major role in determining patient treatment as they have key information about patient preferences and values. However, elderly cancer patients showed the attitude of preparing for and accepting death in physical, psychological, social, and spiritual aspects if they had knowledge of LST. [17,18]

This means that even if the patient is older, has less understanding, and has a protective family, it is necessary to seriously reconsider the family's decision to exclude the patient. The LSTD Act was implemented to protect patients' right to self-determination in treatment choices. To realize this, it is fundamental to give patients the opportunity to decide.

Difference in LSTD method according to disease

According to the results of this study, we found that the LSTD method differs depending on the disease. In G1, 86.36% of patients had neoplasms, and G2 patients also showed the highest proportion of neoplasms. Comparing the groups, the proportion of neoplastic diseases decreased in the order of G1-G2-G3-G4, and the proportion of respiratory and circulatory diseases increased in reverse order. This can be

explained in the same context that the self-determination rates of patients with circulatory or digestive diseases were somewhat lower than that of those with neoplastic diseases.

Neoplastic diseases' progression is relatively predictable,[19] while in chronic diseases, it is generally difficult to distinguish between terminal and end-of-life stages. For cardiopulmonary diseases, it is generally difficult to determine the treatment direction because the patient repeatedly improves and worsens. These characteristics are confirmed by existing studies.[20,21]

In G1, which accounts for a large proportion of neoplastic patients, LSTD was mainly made in the terminal stage. This means that changes in the disease's progress are related to LSTD's timing. However, the more difficulty chronic patients experience in their daily lives, the more they hope to receive terminal diagnosis and information from their doctors.[22] Therefore, information and opportunities for LSTD must be given equally to all patients regardless of the type of disease and change in disease status.

Period from decision-making to implementation for LST

POLST can be created in the terminal stage, and additional forms are required at the end-of-life and transition periods. However, in only 29.1% of cases was POLST prepared in the terminal stage and then judged and implemented at the end-of-life. More than half (58.2%) of patients who made LSTD by POLST simultaneously received end-of-life judgment and implementation on the same day.

This was similar for patients who wrote AD (G2). The doctors reconfirmed the AD content, judged the end-of-life, and implemented it in one day (79.7%). Even if the patient's family made a proxy decision (G3 and G4), witnessed by the family or with consent of the family, end-of-life judgment and implementation all occurred in one day. In previous studies, most patients were found to withdraw or withhold treatment just before their death.[16] In conclusion, the LSTDs in this study seem to have been made in a hurry during the end-of-life period, and the patient was not given enough time to prepare for death.

Knowing the treatment, patients generally wish to reduce the burden on surrogate decision-makers.[23] In particular, advanced care planning, which is a way for patients to identify their preferences in advance and document them, is a major method of end-of-life treatment. Advance care planning is not just an expression of the patient's intention, but a result of active communication between patients and medical staff, and decisions tend to reduce the burden on the patient and agent.[24,25]

Summary, contributions, and limitations

Based on the research results and discussion, this study argues the following. First, in making LSTDs, patients must be the subjects of their treatment decisions. Particularly, even if patients are old or have poor medical understanding, they should be given the opportunity to make their own decisions. Second, patients' LSTD consultation should begin earlier than it is now. If it is determined that the patient has

reached the terminal stage, the medical staff should be able to think about the quality of death the patient will face and discuss it with the patient and family.

This empirical study examined the actual condition and characteristics of the LSTD system by analyzing data of patients who have used the system since its implementation. It is a significant research that identifies the characteristics of patients' end-of-life care decision-making process and objectively shows the current state of self-determination. Unlike previous studies that analyzed a single form, this is the first study to objectively examine the trends of patients' life-sustaining treatment decisions by identifying their characteristics throughout the LSTD process.

However, some data had missing values and this study only confirmed the system's trends and characteristics, but could not identify specific problems related to the phenomenon. In order to suggest effective improvement plans, further empirical studies will be needed to identify the cause of the significant difference in variables.

[1] For G4, whose LSTD was made through patient family agreement, the average age was somewhat lower than that of other groups, likely because 474 underage patients were included.

Conclusion

In South Korea, decisions are made about the discontinuation of treatment for patients at the end-of-life through the LSTD system. Despite the introduction of this system to protect the dignity of the dead, LSTDs for elderly and chronically ill patients are made by their families rather than by self-determination. Moreover, the time for decision-making to stop LST is tight. This does not satisfy the purpose of the law, which confirms the patient's right to self-determination and best interest. Thus, efforts to protect this law are needed.

This is the first study to empirically confirm and grasp the current status of the LSTD system in South Korea. The results can guide future directions of this system and can be a cornerstone for developing better policies and systems for end-of-life patients.

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Figures

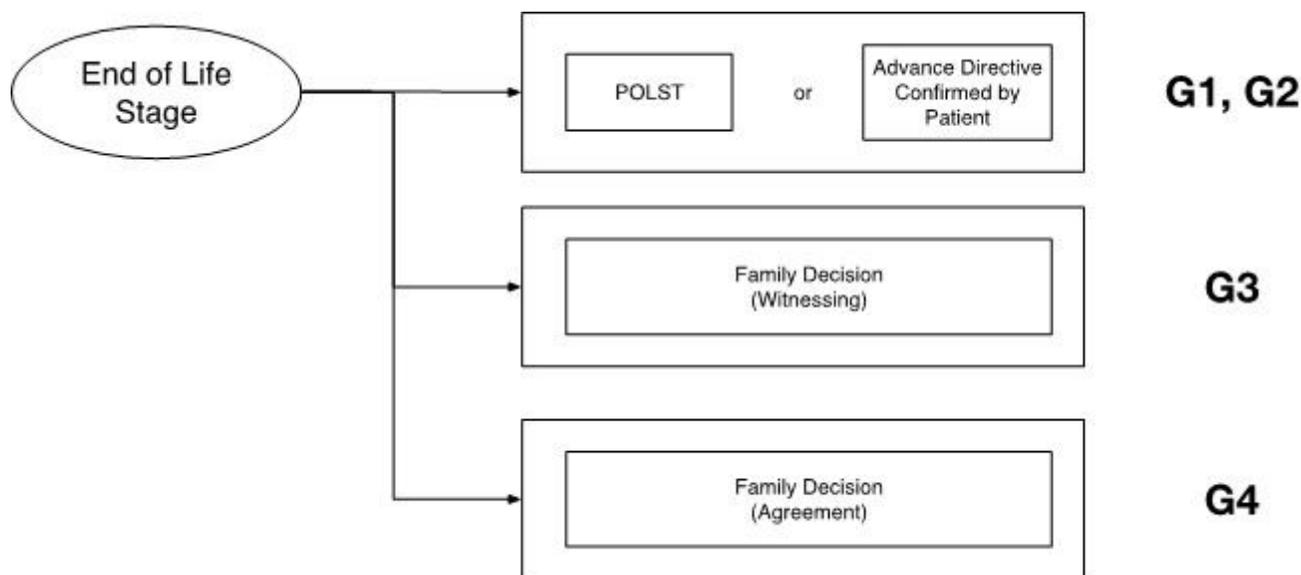


Figure 1

Classification of groups according to the life-sustaining treatment decision form. POLST: Physician Orders for Life-Sustaining Treatment. G: group.

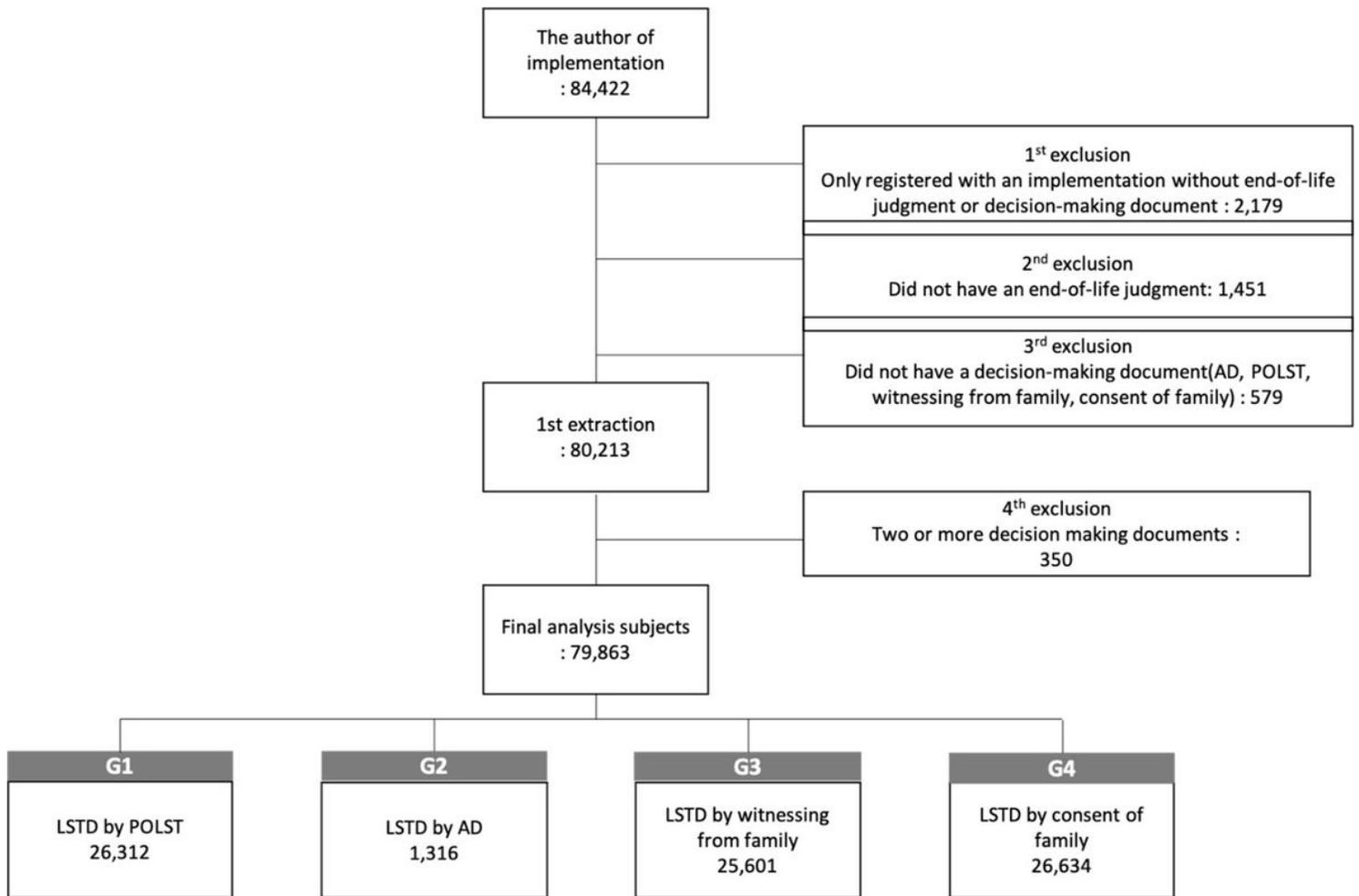


Figure 2

Process of subjects' extraction for data analysis. G: group; LSTD: life-sustaining treatment decision; POLST: Physician Orders for Life-Sustaining Treatment; AD: Advance Directive.

Supplementary Files

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