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Geriatric Nursing

journal homepage: www.gnjournal.com

Preferences of older inpatients and their family caregivers for life-sustaining treatments in South Korea

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ARTICLE INFO

Article history:

Received 12 September 2017

Received in revised form 19 December 2017

Accepted 19 December 2017

Available online

Keywords:

Life-sustaining treatment

Preference

Older inpatient

Family caregiver

ABSTRACT

This descriptive cross-sectional survey aimed to investigate the preferences of older inpatients and their family caregivers for life-sustaining treatments (LSTs) and their influential factors. Inpatients aged 60 and older and their family caregivers in three acute hospitals in Seoul, South Korea, were invited to participate in the study. A total of 180 surveys were returned from 90 pairs of patients and family caregivers with a response rate of 95%. Older inpatients expressed a significantly high desire for “not wanting to have cardiopulmonary resuscitation” ($\chi^2 = 10.07, p = 0.007$) and “mechanical ventilator” ($\chi^2 = 10.35, p = 0.006$) compared to their caregivers. Given that experiences of conversations about LSTs was a common factor in both groups and may prevent futile LSTs, it is important for nurses to initiate and support patients and family caregivers, helping them engage in formal and informal conversations about future health-care preferences.

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Introduction

Death is a universal and inevitable phenomenon that all human beings experience.¹ Global citizens have many varying cultural beliefs and values about death and dying. On one hand, death has been taboo; on the other hand, it is a sacred topic and dying well has been of interest to people in many cultures.² Among them, Korean ancestors traditionally called dying away from home *street death* and one was to avoid it at all costs. Patients expecting impending death were cared for at home and died in their own home with their family surrounding them. Death was considered part of life and it was natural to accept death.³ However, since the advent of the 20th century, as medical treatments have become available, the dying process has become medicalized and people's perceptions of death and dying have changed from natural acceptance to helpfulness and fear, arising from medical failures.⁴ The meaning of a good death in Korea includes dying comfortably with family members in one's own home or a place one has liked, but without physical pain, regrets, and obsessions.⁵ However, this perception is distinctively different from how people experience death these days in Korea, as death has become taboo and more people die at medical

institutions than in their homes.⁶ Thus, a discrepancy exists between preferred end-of-life care and actual end-of-life care received in South Korea.

Internationally, a variety of factors have contributed to great interest in preferred places of death, end-of-life care, and a good death. Among these are the ageing population, new life-sustaining technologies, healthcare costs, patient awareness, demands for autonomy, older people without relatives or friends who can make care decisions for them, and litigation associated with health care.^{7,8} In recent years in South Korea, increasing interest has arisen about patients' right to make medical decisions and the extent of doctors' legal duty to withhold or withdraw medical treatments. One example is the *Boramae Hospital case*, in which two doctors who discharged a patient based on the repeated requests of the patient's wife, due to financial burdens, were found guilty of accessory to murder in 2004. More recently, the Supreme Court allowed a doctor to remove the ventilator of Grandmother Kim in Severance Hospital in 2009, who was in a persistent vegetative state for 17 months. The *Grandmother Kim case* has formed a precedent, allowing withdrawal of life-sustaining treatments (LSTs) in South Korea.⁹ Those two cases became a catalyst to increase public interest about LSTs, the conflict between patients' “right to comfortable death” and healthcare professionals' “duty of care” as a political and social issue.¹⁰ A detailed description of the two cases is given in [Table 1](#).

In February 2016, in South Korea, the “ACT ON DECISIONS ON LIFE-SUSTAINING TREATMENT FOR PATIENTS IN HOSPICE AND PALLIATIVE CARE OR AT THE END OF LIFE (Life Sustaining Treatments

Conflicts of interest: None.

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Table 1
Major cases affecting the enactment of Korea's Life Sustaining Treatments Act.

Case	Summary
Boramae Hospital Case	In 1997, a patient underwent surgery to remove a hematoma due to a massive cerebral hemorrhage, and was attached to a ventilator due to difficulty in breathing caused by cerebral edema. The patient's wife asked the patient to be discharge because she could not continue treatment for economic reasons, and the medical staff discharged the patient after the patient's wife filled out the form called Discharge Against Medical Advice. The patient died shortly after arriving home, due to dyspnea. Two doctors involved in the treatment of the patient were sentenced for homicide.
Grandmother Kim Case	In 2008, a patient who underwent a lung biopsy experienced cardiac arrest due to excessive bleeding. The patient, suffering from hypoxic brain damage, fell into a persistent vegetative state and was treated in intensive care units with a ventilator. The patient's family requested removal of a ventilator because the patient refused to extend meaningless life and wanted to die. The Supreme Court ruled that physicians would be allowed to withdraw life-sustaining treatment if the patient was recognized as exercising self-determination based on dignity, value, and the pursuit of happiness at the unrecoverable stage of death.

Act hereafter)" was enacted and will be implemented in February 2018. Under this Act, LSTs are defined as means medical treatment by cardiopulmonary resuscitation, hemodialysis, administering anticancer drugs, and mechanical ventilation to a patient at the end of life, which merely extend the duration of the end-of-life process without curative effect.¹¹

While the Life Sustaining Treatments Act is expected to provide some guidance, given the controversial nature of the issue, lack of understanding about the tenets of the Act by all stakeholders and its impact on actual decision-making processes are of concern. As a first step, one must understand the preferences of people for LSTs. Preferences for LST, desiring or not desiring LSTs in situations where treatments are no longer effective, will affect intention to act and will influence decisions made on LSTs.

Previous research conducted in South Korea was mainly descriptive, focusing on the provision of LSTs from legal,^{12,13} ethical^{14,15} and religious^{16,17} perspectives. In addition, although patients and their autonomy should be at the center when making decisions on LSTs, the focus of research was the preferences of medical practitioners,¹⁸ guardians,¹⁹ and the general public.²⁰ Although international literature has given considerable attention to patients and families,^{21–23} domestic research studies seldom investigated patients' views. Considering that 80% of deaths in 2016 were of people over the age of 60, and that the three main causes of death for this population group are cancer, cardiac, and cerebrovascular diseases,⁶ healthcare services and decisions on LSTs for this group of older patients has reached the forefront of the discussion.^{24–26}

In Korean society, any illness of any family member is generally the concern of the entire family, rather than an individual issue, due to a strong family-centered orientation.^{27,28} Despite the rapid changes in Korean society, such as the increase in nuclear families, decreasing birth rates, and individuals' willingness to participate in decision making for their own health issues,²⁹ patients still tend to follow decisions made by family members rather than making their own decisions on treatment and care.³⁰ A discrepancy has been noted between what patients want and what family members decide as guardians, during the actual LST decision-making process, and has resulted in undesirable consequences.³¹ Thus, the aims of this study were to investigate the preferences of older inpatients and their family caregivers on LSTs and their

influential factors, and to discuss the implications for the nursing profession.

Methods

Research design

A cross-sectional survey was conducted with inpatients aged 60 and older and their family caregivers in three acute hospitals in Seoul, the capital city of South Korea. The research team developed a set of questionnaires for this study by the following process. First, the team developed a preliminary questionnaire of 24 items based on a review of the literature that included major issues of LSTs. Second, the team verified the content validity of preliminary questionnaire items. A group of experts, including nursing and law faculty members, a hospice specialist, and an oncology nurse unit manager took part in the process of verification, and the team revised the questionnaire accordingly. Questionnaires for older inpatients and their family caregivers were prepared separately. The team deleted the seven items that the expert panel considered of low relevance. The team selected a total of 17 items with content validity of .8 or higher as the final version of the preliminary questionnaire for older inpatients and family caregivers. Finally, a pretest of the final version of the preliminary questionnaire targeted two patients and two caregivers of each patient to confirm the complete version of the questionnaire. The complete questionnaire included sociodemographic and disease-related characteristics: 31 items for older inpatients and 27 items for family caregivers.

The questionnaire had four sections: 1) sociodemographic characteristics, 2) disease-related characteristics, 3) experiences with and attitudes toward LSTs, and 4) preferences for LSTs. LSTs included cardiopulmonary resuscitation, hemodialysis, chemotherapy, and mechanical ventilation, as defined by the Life Sustaining Treatment Act. Also, this section included closed-ended questions of Wanted, Unwanted, or Do Not Know to assess participants' intentions about LSTs. Because participants were asked to indicate their preferences for LSTs assuming a terminal situation that could not be cured, "Wanted" and "Unwanted" meant those who wanted to initiate LSTs and those who did not.

Sample

The team invited inpatients aged 60 and older, and their family caregivers who could verbally communicate, to participate in the study. Inclusion criteria for patients were (i) 60 years old or older; (ii) primarily diagnosed with cancer and diseases of cardiovascular, respiratory, digestive, urinary, or nervous system; and (iii) hospitalized for more than 3 days. Inclusion criteria for caregivers were (i) over 19 years of age, and (ii) participates in the decision-making process for patient treatment. A sample size of 167 participants was calculated through G*Power 3.1 software by applying cross analysis with a significance level (α) of 0.05, power ($1-\beta$) of 0.8, effect size of 0.3, and 8 degrees of freedom.

Procedure

The team sought consent for voluntary participation in the study from three hospitals, once ethics approval was obtained. Convenience sampling was used to recruit paired samples of patient-family caregiver in three general hospitals in Seoul. Participating patients were asked to respond from their own perspective; caregivers were asked to respond from the patient's perspective. Each paired patient-family caregiver participant completed the survey separately in separate spaces to avoid sharing opinions.

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