



ORIGINAL ARTICLE

# Comparison of Consensus on Life-sustaining Treatment of the Elderly in Care Facilities and Family Member Dyad

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**Abstract**

**Objectives:** The purpose of this study is to compare the agreement in opinion between the elderly in care facilities and their family members regarding the life-sustaining treatment at the deathbed and to find out if the intentions of the elderly are being properly reflected in their deathbed treatment.

**Methods:** Data were collected from 85 elderly individuals at five care facilities in Chungcheongnam-do and 85 family members. The data were collected with a self-administered questionnaire from July 22, 2013 to August 15, 2014. A total of 170 cases were analyzed using SPSS version 21.

**Results:** First, the family members' preference for life-sustaining treatment was higher than the patients' preference. The preference between the elderly and their family members regarding life-sustaining treatment was statistically significant with regards to oral nutrition, pain control through oral and anal administration, pain control through intravenous administration, transfusion, and admission to an intensive care unit. Second, looking at the agreement between elderly and guardians regarding life-sustaining treatment, there was significant concordance about general testing, oral nutrition, intravenous hydration, intravenous nutrition, antibiotic treatment for severe infection with low resiliency, admission to an intensive care unit, blood pressure increase medication use, cardiopulmonary resuscitation, and tracheotomy.

**Conclusion:** It is essential for the medical staff to confirm agreement between the elderly and their family members regarding life-sustaining treatment, and if such a prior agreement is not feasible, the patient's intention should be considered more actionable than their family members.

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## 1. Introduction

In modern society, artificial prolongation of life has become possible with rapid development of medicine, and because of this, a decrease in mortality, increase in the average lifespan, and aging of the population is rapidly progressing. Even in Korea, the percentage of the population over 65 years reached 11% in 2011 and is expected to reach 14.3% in 2018 and 20.8% in 2026 [1].

The places of death of the elderly are shifting from homes to medical institutions and according to the statistical data, the death of 80% of the elderly in 2010 occurred in facilities or hospitals [1,2]. With the change in death environment, life-sustaining treatment such as respirators and cardiopulmonary resuscitation (CPR), which would have been denied if the death was met at home, are being used in the last moments of life.

Despite the fact that a decision on the discontinuation or continuation of life-sustaining treatment should be made by the individual, such decisions in Korea are often made by agreement between the family and the medical staff, excluding the patient [3,4]. In addition, unlike most Western nations where a decision on life-sustaining treatment is made in advance when the individuals are healthy, it was shown that in Korea, such decisions are mainly made when the death is imminent [5,6].

Due to such a medical reality, the elderly in Korea are excluded from making the decision on life-sustaining treatment and receive medical treatment that does not reflect their values. However, most elderly individuals want to make a decision on life-sustaining treatment after listening to detailed information on the pathological notification and prognosis from healthcare professionals [7,8]. If the individual is faced with a situation where the decision cannot be made on their own, it was shown that the decision was granted to the medical representatives, a spouse, or a child [4,8,9,10].

Thus, in Korea, although family members played a significant role in the decision making regarding life-sustaining treatment, a decision on life-sustaining treatment was made based on the judgment of family members, such as a spouse or a child, without sufficient prior discussion with the patient, because it is not common to discuss death in Korea [4]. However, studies that verify whether the family members reflect the values and decisions of the elderly on life-sustaining treatment are hard to find.

Therefore, this study was conducted with the purpose of identifying whether the decision of the elderly was properly reflected for the treatment during the period of death, by identifying the degree of consensus on the preference of life-sustaining treatment targeting the elderly residing in care facilities and their family members. Elderly individuals residing in care facilities are much more vulnerable due to high severity of disease compared to the elderly at home, therefore, they

were selected as targets because they can be seen to be in a relatively near-death situation. The results of this study are expected to provide important basic data for ensuring self-determination in the process of treatment during the period of death.

## 2. Materials and methods

### 2.1. Study population

In this study, a survey was conducted targeting the elderly who were admitted to care facilities and their family members. Sampling of elderly persons residing in care facilities was made focusing on the institutions which have approved the study participation and the selection of individuals among care facilities located within the Chungnam region, and the individuals that satisfy the selection criteria of this study were introduced through superintendents or case workers. The selection criteria of this study were elderly residents over the age of 65 years without cognitive deterioration or major mental illnesses who could accurately give their own opinion; the questionnaires of 85 elderly individuals who consented to the purpose of this study were used for the actual analysis. Family members were limited to the spouse, children, brothers, and sisters who could participate in the decision of treatment for the elderly.

### 2.2. Data collection

This study was conducted after obtaining the approval of the Institutions Bioethics Committee. To collect data, five professional care facilities for the elderly were selected, which were located in the Chungnam region. They approved with the selection of individuals who consented to participate after explaining the purpose of the study to the superintendent of the long-term care facilities. Researchers visited the cooperating facilities and the survey was conducted after consent was granted. Those who consented to the survey listened to the explanation of the purpose of the study before the interviews were started.

A structured questionnaire was separately prepared for the elderly individuals and their family members and the survey on the elderly persons and their family members was conducted separately at different times and places. For the elderly persons, the survey was conducted through face-to-face interviews by the researcher alone, and when the study participant was able to read and write the questionnaire, the questionnaire was directly completed. However, for those individuals who wanted to respond to the survey but could not read or write due to physical discomfort, the researcher read the survey questions and wrote the answers instead. The family members were asked to complete the questionnaires on their own.

The data collection was made between July 22, 2013 and August 15, 2014, through direct distribution and collection. A total of 85 copies of questionnaires in the elderly group and a total of 85 copies of questionnaires among the family members were distributed and collected. Of these, a total of 85 copies of questionnaires were used in the analysis by determining that its efficacy was useful for comparing the consensus of elderly patients and family members dyad.

### 2.3. Measurement of variables

The life-sustaining treatment variables used in this study to examine the consensus between elderly persons and their family members refer to the general life-sustaining treatment and special life-sustaining treatment established by the Guidelines Enactment Special Committee [11] on the discontinuation of life-sustaining treatment and were composed based on the 'pre-medical letter of intent' used by Seoul National University Hospital.

Although general life-sustaining treatment is essential for sustaining life, it is a treatment which does not require professional medical knowledge, medical techniques, and special equipment, and is composed of six items; simple tests, oral feeding, intravenous hydration, intravenous feeding, oral pain control, and intravenous pain control. It was measured using a Likert 4-point scale (1 point: not necessary up to 4 points: very necessary); where the scores were higher, it was interpreted to mean that individuals preferred life-sustaining treatment.

Special life-sustaining treatment requires highly specialized medical knowledge, medical techniques, and special equipment, and is composed of seven items: administration of high units of antibiotics for severe infection, blood transfusions and blood derivatives injection, applying a respirator, intensive care unit (ICU) admission, use of blood pressure elevating medicine and CPR, and tracheotomy. It was measured using a Likert 4-point scale (1 point: not necessary up to 4 points: very necessary); where the scores were higher, it was interpreted to mean that individuals preferred life-sustaining treatment. The results of measuring the reliability in order to secure the internal consistency of the variables are shown in Table 1. The Cronbach alpha values of all

variables were higher than 0.9, which shows a high degree of internal reliability.

### 2.4. Statistical analysis

The findings were processed through computational statistics using the SPSS Ver. 21.0 program (SPSS Inc., Chicago, IL, USA). Frequency analysis was conducted to examine general characteristics and the awareness of prolongation treatment of individuals and an independent *t* test was conducted to compare the preferred mean values on prolongation treatment between the participants. In addition, a comparison of the index of coincidence for the prolongation treatment preference of the two groups used the intraclass correlation coefficient (ICC) to obtain the Kappa values.

## 3. Results

### 3.1. Sociodemographic characteristics

The general characteristics of the elderly individuals are shown in Table 2. The average age was 81.9 years with a distribution of 65 to 95 years. With regards to gender, females accounted for 62 of the participants (72.9%) and the level of education was low in average, but included 25 individuals (29.8%) who graduated from universities, showing a wide range of distribution. The monthly income for the 76 individuals (89.4%) was less than 1 million won. For activities of daily living (ADL), 51 participants (60.0%) were independent, with more people ( $n = 46$ , 54.1%) having long-term care insurance ratings. The mean duration of admission was 26 months and 59 individuals (69.4%) had no spouse.

The general characteristics of the family members involved in this study are shown in Table 3. The average age was 53.0 years with a distribution of 33 to 85 years. With regard to sex, there were 44 (51.8%) women and the level of education was relatively high. A monthly income of 2–4 million won was the most common. Most were the children of patients ( $n = 74$ , 87.1%). Those paying medical bills on their own accounted for 31.8% and the medical bills paid by the elderly, their spouses, and children accounted for 58 individuals (68.2%).

**Table 1.** Survey instrument and results of reliability coefficients.

Classification	Measurement factors	Question number	Number of questions	Reliability coefficient (Cronbach alpha)
Elderly	General life-sustaining treatment	1, 4~8	6	0.955
	Special life-sustaining treatment	2~3, 9~13	7	0.977
	Total		13	0.979
Family	General life-sustaining treatment	1, 4~8	6	0.929
	Special life-sustaining treatment	2~3, 9~13	7	0.944
	Total		13	0.962

**Table 2.** Characteristics of the elderly individuals.

Classification	Frequency (%)	Classification	Frequency (%)
Age (y)	≤70	Monthly income (won)	≤1 million
	70–79		≥1 million
	80–89		≤12
	≥90		≤13–36
	Mean (SD)		≤37–60
Gender	Female	≥60	10 (11.8)
	Male	Mean (SD)	26.12 ± 30.85
Religion	Have religion	ADL	Independent
	No religion		Dependent
Level of education	0	Long-term care rating	Have rating
	1–9		Excluded
	≥10		Have a spouse
	Mean (SD)		No spouse

ADL = activities of daily living; SD = standard deviation.

### 3.2. Comparison on the preference level of the life-sustaining treatment administered during the period of death of elderly individuals

The results showed that in general, the elderly had lower average preferences for life-sustaining treatments than their caregivers (Table 4).

As a result of comparing the preference level of elderly individuals and their family members with respect to the general life-sustaining treatment in detail, the preference level  $2.46 \pm 0.78$  of family members in general was shown to be higher than the preference level of the elderly ( $2.22 \pm 0.68$ ). For oral feeding, family members (2.40) had a higher average than the elderly (2.14), for oral and anal pain control, family members (2.51) had a higher average than the elderly (2.25), and for intravenous pain control, family members (2.56) had a higher average than the elderly (2.25); all of these showed statistically significant differences.

Although the preference level of family members was higher in the case of simple tests, intravenous hydration, and intravenous feeding, there were no statistically significant differences. In addition, as a result of

comparing the preference level of the elderly and their family members with respect to a special life-sustaining treatment, the preference level ( $2.02 \pm 0.67$ ) of family members in general was shown to be slightly higher than the preference level of the elderly ( $2.14 \pm 0.73$ ). For blood transfusions and blood derivatives, family members (2.27) had a higher average than the elderly (2.02) and for ICU admission, family members (2.25) had a higher average than the elderly (1.99), showing statistically significant differences. In contrast, the preference levels of family members for the administration of antibiotics for severe infection, use of respiratory track intubation and respirator, use of blood pressure elevating medicine, CPR, and tracheotomy were slightly higher, but there were no statistically significant differences.

### 3.3. Consensus between the elderly and family members on the life-sustaining treatment administered during the period of death of the elderly

Kappa values ( $\kappa$ ) were obtained in order to examine the consensus of items on the life-sustaining treatment administered during the period of death of the elderly

**Table 3.** Characteristics of family members.

Classification	Frequency (%)	Classification	Frequency (%)
Age (y)	≤40	Monthly income (won)	≤2 million
	40–49		2–4 million
	50–59		≥4 million
	≥60		Have religion
	Mean (SD)		No religion
Sex	Women	Relationship	Spouse
	Men		Children
Level of education	≤9	Medical bill payment	Brothers and sisters
	10–12		Self
	≥13		Others

**Table 4.** Analysis on the difference of preference level of the life-sustaining treatment of the elderly and family members.

Classification	Measurement factors	Elderly	Family members	F/t
		Mean $\pm$ SD	Mean $\pm$ SD	
General prolongation treatments	Simple tests	2.30 $\pm$ 0.76	2.45 $\pm$ 0.93	5.867
	Oral feeding	2.14 $\pm$ 0.73	2.40 $\pm$ 0.89	11.240*
	Intravenous hydration	2.20 $\pm$ 0.74	2.42 $\pm$ 0.91	10.288
	Intravenous feeding	2.21 $\pm$ 0.74	2.34 $\pm$ 0.89	9.084
	Oral and anal pain control	2.25 $\pm$ 0.79	2.51 $\pm$ 0.96	10.568*
	Intravenous pain control	2.25 $\pm$ 0.79	2.56 $\pm$ 0.93	7.398**
Special prolongation treatments	Total	2.22 $\pm$ 0.68	2.46 $\pm$ 0.78	
	Administration of antibiotics for severe infection	2.12 $\pm$ 0.71	2.26 $\pm$ 0.89	14.231
	Blood transfusions and blood derivatives	2.02 $\pm$ 0.67	2.27 $\pm$ 0.87	20.266*
	Use of respiratory track intubation and respirator	2.00 $\pm$ 0.71	1.99 $\pm$ 0.84	4.074
	ICU admission	1.99 $\pm$ 0.72	2.25 $\pm$ 0.88	17.591*
	Use of blood pressure elevating medicine	2.08 $\pm$ 0.73	2.15 $\pm$ 0.81	2.897
	CPR	1.99 $\pm$ 0.73	2.09 $\pm$ 0.86	9.027
	Tracheotomy	1.96 $\pm$ 0.72	1.96 $\pm$ 0.75	2.062
Total	2.03 $\pm$ 0.67	2.14 $\pm$ 0.73		

\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ . CPR = cardiopulmonary resuscitation; ICU = intensive care unit; SD = standard deviation.

(Table 5). Kappa value ( $\kappa$ ) has a value between 0 and 1 and it can be interpreted as having a higher consensus as the value becomes higher. For reference, according to the standard of Cohen's  $\kappa$ ,  $\kappa \leq 0.2$  is poor, when  $0.2 < \kappa \leq 0.4$  is fair, when  $0.4 < \kappa \leq 0.6$  is moderate, when  $0.6 < \kappa \leq 0.8$  is substantial, and when  $0.8 < \kappa$  is good [12].

The degree of consensus of the elderly and family members was shown to be relatively lower. The item with the highest degree of consensus was intravenous feeding ( $\kappa = 0.52$ ,  $p = 0.02$ ) and the item with the lowest degree of consensus was intravenous pain control ( $\kappa = 0.18$ ,  $p = 0.221$ ).

For general life-sustaining treatment, the item with the lowest degree of consensus was pain control (oral, anal, and vein) which was not statistically significant. Items such as feeding, hydration, and simple tests had a moderate degree of consensus and showed statistically significant results. For special life-sustaining treatment, items such as the use of respiratory track intubation and respirator, blood transfusions and blood derivatives injection, and ICU admission had a low degree of consensus, whereas items such as tracheotomy, use of blood pressure elevating medicine, and administration of antibiotics for severe infection had a moderate degree of consensus and showed statistically significant results.

#### 4. Discussion

This study was conducted with the purpose of identifying whether the decisions of the elderly would be properly reflected in treatment.

It was also conducted to determine the degree of consensus between the elderly and their family members on the life-sustaining treatment provided during the process of death. To achieve that, the study targeted elderly individuals and their family members residing in long-term care facilities.

The results of this study are as follows. First, for life-sustaining treatment administered to the elderly, it was shown that both elderly individuals and family members in general had low scores. In the studies of Park and Song [13] targeting the elderly residing in care facilities and home care, it was shown that they did not prefer artificial extension of life using life-sustaining treatment and such results are interpreted as some levels of social consensus being formed on 'death with dignity' or 'discontinuing meaningless life-sustaining treatment' recently being discussed in Korea.

Second, after comparing the preference level of the elderly and their family members on general life-sustaining treatment and special life-sustaining treatment which will be administered to the elderly, it was shown that the preference levels of family members were higher than the preference levels of elderly individuals. When looking at the comparative studies of Hong and Moon [7] on the preference level of life-sustaining treatment by family members, the preference level was significantly lower for the elderly individual concerned, but three times higher for a spouse, parents, or children. It has been described as a "duty" by guardians of elderly patients. In studies targeting cancer patients and their family members, it was shown that family members were the ones who opposed the

**Table 5.** Consensus between the elderly and family members on the life-sustaining treatment.

Classification	Measurement factors	Elderly	Family members	Kappa-value	<i>p</i>
		Mean ± SD	Mean ± SD		
General prolongation treatments	Simple tests	2.30 ± 0.76	2.45 ± 0.93	0.42	0.016*
	Oral feeding	2.14 ± 0.73	2.40 ± 0.89	0.41	0.019*
	Intravenous hydration	2.20 ± 0.74	2.42 ± 0.91	0.50	0.003**
	Intravenous feeding	2.21 ± 0.74	2.34 ± 0.89	0.52	0.002**
	Oral and anal pain control	2.25 ± 0.79	2.51 ± 0.96	0.29	0.089
Special prolongation treatments	Intravenous pain control	2.25 ± 0.79	2.56 ± 0.93	0.18	0.221
	Administration of antibiotics for severe infection	2.12 ± 0.71	2.26 ± 0.89	0.46	0.010**
	Blood transfusions and blood derivatives	2.02 ± 0.67	2.27 ± 0.87	0.34	0.058
	Use of respiratory track intubation and respirator	2.00 ± 0.71	2.03 ± 0.84	0.28	0.106
	ICU admission	1.99 ± 0.72	2.25 ± 0.88	0.36	0.047*
	Use of blood pressure elevating medicine	2.08 ± 0.73	2.15 ± 0.81	0.46	0.009**
	CPR	1.99 ± 0.73	2.06 ± 0.88	0.43	0.012*
Tracheotomy	1.96 ± 0.72	1.93 ± 0.77	0.46	0.007**	

\**p* < 0.05; \*\**p* < 0.01; \*\*\**p* < 0.001. CPR = cardiopulmonary resuscitation; ICU = intensive care unit; SD = standard deviation.

discontinuation of life-sustaining treatment, not the patients themselves [14,15].

Furthermore, it has been reported that the preference level of family members for pain control was higher than the patient's preference [16].

Third, the degree of consensus of the elderly and family dyad was shown to be relatively lower. Especially, when seeing that the degree of consensus on the use of pain control, respiratory track intubation, and respirator was lower, when determining the prolongation treatment at the end of life, a situation of not being able to properly reflect the opinions of the patients can be expected. Therefore, a variety of life-sustaining treatment at the end of life requires an effective communication with medical staff as well as patients and family members [17], and it can be said that the role of a mediator based on the preference level of life-sustaining treatment is important for improving the degree of consensus between the patients and their family members [18]. The law on life-sustaining treatment already exists in the developed countries where in recent years, the United States, Austria, France, Japan, and Taiwan, etc., focused on promoting the autonomy of the patients and have enacted the law on advanced medical intent, role, and rights of the patients and rights of representatives [19–21].

When looking at the results of this study, the decision of the family on the administration and discontinuation of life-sustaining treatment in Korea does not properly reflect the opinions of the patients. Based on this, a way that can reflect the opinions of themselves in the administration and discontinuation of life-sustaining treatment is proposed. First, a composition of social

and cultural conditions that can naturally accept the discussion on death and life-sustaining treatment is required. For this purpose, education on the death experience should be provided for all stakeholders. Government policy to facilitate this education is appropriate to bring about meaningful change in this area. Second, in order to improve the degree of consensus between the elderly and their family members, advanced directives and durable power of attorney for healthcare systems that can inform the thoughts and hopes of the patient in advance should be introduced, to be used as the basis for making decisions required at the end of life.

The limitation of this study lies in having difficult problems of obtaining the representativeness of samples by surveying only the elderly and their family members admitted to the elderly care facilities in some regions. In addition, a study is required not just on general and special life-sustaining treatment, but on additional life-sustaining treatment items according to the disease status of the elderly. In future studies, a review of the life-sustaining treatment should be made sufficiently through a variety of analyses of the disease status, type of care facilities, and medical personnel.

## Conflicts of interest

The authors declare no conflicts of interest.

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