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Measuring Social Values in End-of-Life Care



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Measuring Social Values in
End-of-Life Care

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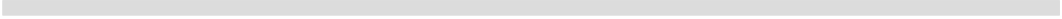
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1

Introduction

Section 1. Research Background and Objective

Section 2. Research Content and Method

Section 1. Research Background and Objective

As the Korean population continues to age, the number of deaths is expected to increase each year. With an increase in the number of seniors, while the current death toll is 260,000 (2010), the annual number of deaths is expected to rise sharply and to reach 450,000 and 580,000 by 2030 and 2040, respectively (National Statistical Office, 2012). Although the annual death rate in Korea during 2010 was 5.1 per thousand people, which was not high as compared to the rate of 10.5 in Germany, 9.5 in Japan, and 8.0 in the United States (US), the same is expected to rapidly increase to 9 by 2030 and 11 by 2040 (National Statistical Office, 2012) (National Statistical Office, 2012).

Moreover, the health care cost before death is expected to increase sharply. Even without prediction, it is a fact that the medical expenses before death have increased rapidly. In 2010, the average monthly medical expenses during the 36 months prior to death (health care expenses from the national health insurance) was 367,000 KRW, while that during the 2 months before death and 1 month before death increased by 6 times,

which was 2.608 million KRW and 2.846 million KRW, respectively (Lee et al., 2011). Additionally, with reference to cancer patients in Korea, approximately 1/3rd of the cancer-related medical expenses were incurred during the month before death (Health Policy Developments, 2010).

Surgery or treatment for terminal patients is generally not as cost-effective as other general treatments. In other words, health gains through such treatment are relatively low. Although significant medical expenses are used for surgeries or treatments for the extension of life expectancy, the quality of death index of many patients is not very high because of poor pain management (van den Beuken et al., 2007), receiving only the treatment that is possible rather than the best treatment (Lancet, 2012), and discrepancy between the preferred place of death and the actual one (Pritchard, 1998).

Today, the use of healthcare before death is very high; however, the basis for providing financial social support for acute hospitalizations within the health insurance framework has not yet been established. Although short-term life span extension may be achieved through surgery or treatment at the end of life, we need to examine whether the allocation of resources for such treatment is socially viable from a perspective of social value. In other words, we need to review whether prioritizing the development of a policy for treatments that extend the life span of patients receiving end-of-life care is a result that re-

flects the system preferred by the public needs to be reviewed.

Accordingly, this study examined whether the public prefers life prolonging treatment over palliative care such as end-of-life pain management; that is, whether such a result would reflect social values. Through this analysis, basic data for the prioritization of resource allocation will be provided.

- Examining the status of end-of-life care service,
- Conducting a survey analysis on the social values regarding end-of-life care, and
- Measuring the social values regarding end-of-life care using an experimental design.

Section 2. Research Content and Method

This study aimed to explore the use of health care and expenses at the end of life, and measure the social values regarding end-of-life care through surveys on the perceptions related to end-of-life care, and through surveys that employ an experimental design.

Chapter 2 presents the findings of the comparison of the quality of death index between Korea and the other OECD countries through a literature review, to explore the trends in death by age and disease by analyzing the National Statistical Office's DB on the cause of death. In addition, we present a policy and pilot

project for hospice and palliative care in Korea.

Chapter 3 examines the distribution of cancer patients' medical expenses before death, using the health insurance cohort data from the National Health Insurance Corporation. The analysis results on the status of medical expenses before death by income level have also been presented.

Chapter 4 analyzes findings from a survey of the awareness of end-of-life care. It examined the understanding of life prolonging treatment at the end of life, hospice, preferred place of death, and of the decision making for life extension.

Chapter 5 presents the analysis of the utilization of the experimental design method for measuring social values using the discrete choice model. A discrete choice experiment was conducted through a survey that comprised some "choice sets." Several alternative profiles were developed using attributes and their levels within the scope of the attributes. This method was used to draw the preferences of decision makers by comparing alternative profiles and asking them to select their preference. Through this, the chapter presents the results of respondents' preferred system for end-of-life care and its utility.

Chapter 6 presents the conclusion. Here we reexamine the end-of-life care based on the analysis results and present a multilateral discussion on the approach to end-of-life care.

Despite the enactment of a law on hospice-palliative care, establishment of the system for the same may be difficult unless

the social understanding is changed. Although uncertainties in the health care field (survival possibility and prolongation possibility), efforts of medical personnel, and institutionalization are important, they should be accompanied by a change in the social understanding regarding dying patients. Rather than focusing on the bio-ethical approach that focuses on the value of life and pointless legislation to ban life prolonging treatment, or the reimbursement rate model of palliative treatment, this study aimed to focus on the public's perspectives and social values regarding well-dying. Through this, we aimed to inform the public about the need for palliative care, and develop social understanding regarding values. We aimed to provide an opportunity to foster social understanding on the quality of life and happiness for terminally ill patients.

2

Current Status of End-of-Life Care

Section 1. Comparison of Quality of Death Index of
the OECD countries

Section 2. End-of-Life Patients' Preferred Place
of Death

Section 3. Subject and Benefits of Hospice
Palliative Care

Section 1. Comparison of Quality of Death Index of the OECD countries

1. Items of the quality of death index

The Economist Intelligence Unit (2010) research team developed and measured the quality of death index by comparing country-specific end-of-life services. Using data from 30 OECD countries and 10 additional countries with available data, index scores were calculated in 4 areas, for a total of 40 countries. The 4 areas were classified into basic end-of-life healthcare environment, availability of end-of-life care, cost of end-of-life care, and quality of end-of-life care.

The sub-items constituting end-of-life healthcare service environment include political stability, per capita Gross Domestic Product (GDP), elderly population ratio, life expectancy, health care expenditure as a percentage of GDP, number of hospital beds per thousand non-accidental deaths, number of doctors, number of nurses, health care security, and national pension coverage.

The category of availability of end-of-life care consists of availability of hospice palliative care service for those older than 65 years old, availability of volunteers, ratio of death through

end-of-life care, and national strategy for palliative care.

Cost of end-of-life care includes public expenditure of end-of-life care and the patient's out-of-pocket payments. Finally, the quality of end-of-life care category consists of the public's awareness, availability of pain relievers, accreditation of suppliers, transparency between doctors and patients, government attitude, and life prolonging treatment policy.

〈Table 2-1〉 Items of the quality of death index

Index	Item
Environment	<ul style="list-style-type: none"> - Political stability - Per capita Gross Domestic Product (GDP) - Elderly population ratio - Life expectancy - Health care expenditure as % of GDP - Number of hospital beds per thousand non-accidental deaths - Number of doctors per thousand non-accidental deaths - Number of nurses per thousand non-accidental deaths - Expenditure on health care security - National pension coverage
Availability	<ul style="list-style-type: none"> - Availability of hospice palliative care service for those aged 65 and older - Availability of volunteers for end-of-life care - Ratio of death through end-of-life care - Status of national strategy for palliative care
Cost	<ul style="list-style-type: none"> - Availability of public funding for end-of-life care - Patient's financial burden for end-of-life care - Patient's average weekly expense for end-of-life care
Quality	<ul style="list-style-type: none"> - Public's understanding of end-of-life care - Educational training on end-of-life care at medical school - Availability of pain relievers - Accreditation for suppliers of end-of-life care - Transparency between doctors and patients - Government's attitude toward end-of-life care - Status of palliative care (cardiopulmonary resuscitation) policy

Source: Economist Intelligence Unit (2010).

2. Comparison of the quality of death index across the OECD countries

The UK ranked the highest among the 30 OECD countries in terms of the quality of death index, followed by Australia, New Zealand, Ireland, and Belgium. With Turkey and Mexico, Korea ranked 28th, which was the lowest among the 30 OECD countries.

In terms of the sub-categories, Switzerland ranked the highest in terms of the basic end-of-life health care environment, followed by Japan, Netherlands, France, Belgium, Germany, and Luxembourg. Korea was ranked 19th, implying that its basic end-of-life health care environment was relatively not very poor.

However, Korea was ranked 25th and 29th in terms of the availability of end-of-life care and cost of end-of-life care, reflecting very poor direct use of end-of-life care. Again, the UK was ranked the highest in terms of the availability of end-of-life care, followed by New Zealand, Australia, Switzerland, Belgium, and Austria. In terms of cost of end-of-life care, Australia, New Zealand, Netherlands, and Norway were all ranked in 1st, while Germany, France, Sweden, and Denmark were ranked 2nd.

In terms of the quality of end-of-life care, the UK was ranked the highest, followed by Australia, New Zealand, Hungary, Ireland, Canada, the US, and Belgium. Korea was ranked 24th in this regard

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(Table 2-2) The OECD countries' rankings in terms of the quality of death index and its sub-categories

	Environment	Availability	Cost	Quality	Total
UK	27	1	17	1	1
Australia	18	3	1	2	2
New Zealand	27	2	1	3	3
Ireland	15	7	9	5	4
Belgium	5	5	13	8	5
Austria	8	6	10	9	6
Netherlands	3	14	1	14	7
Germany	6	16	5	13	8
Canada	19	9	23	5	9
US	9	8	26	7	9
Hungary	14	24	10	4	11
France	4	19	5	14	12
Norway	12	17	1	12	13
Poland	24	10	14	10	14
Sweden	22	11	5	16	15
Luxembourg	7	12	10	20	16
Switzerland	1	4	14	25	17
Czech	10	28	18	10	18
Denmark	21	26	5	17	19
Japan	2	23	26	18	20
Italy	23	13	16	27	21
Iceland	11	15	21	26	22
Spain	24	21	24	21	23
Slavakia	16	29	22	19	24
Finland	17	27	25	22	25
Greece	13	22	19	27	26
Portugal	26	30	20	23	27
Korea	19	25	29	24	28
Turkey	30	18	26	30	29
Mexico	29	20	30	29	30

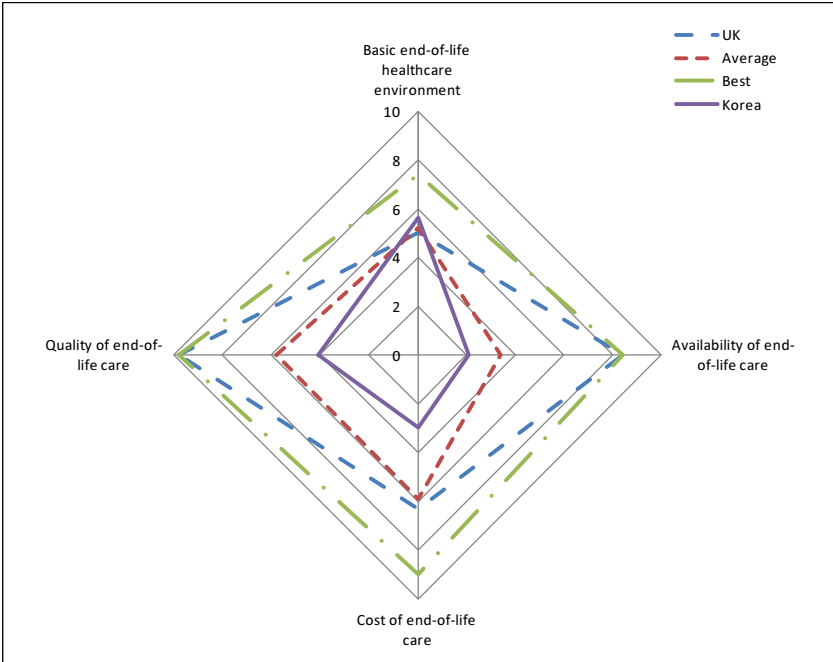
Notes: Targeted 30 OECD countries.

Source: Reconstructed data from the Economist Intelligence Unit (2010).

Figure 2-1 illustrates the findings regarding the quality of death index in the 40 countries of the OECD and others, including Singapore, Malaysia, India, and China. Note that, of the 40 countries, Korea was ranked in 32nd, while the UK was ranked the 1st,

followed by Australia, New Zealand, Ireland, Belgium, Austria, Netherlands, Germany, Canada, the US, Hungary, France, Norway, Taiwan, Poland, Sweden, Luxembourg, Singapore, Switzerland, Hong Kong, Czech Republic, Denmark, Japan, Italy, Iceland, Spain, Slovakia, Finland, Greece, South Africa, Portugal, Korea(32nd), Malaysia, Turkey, Russia, Mexico, China, Brazil, Uganda, and India(40th), respectively.

[Figure 2-1] Comparison of the quality of death in Korea and key countries



Notes: The UK ranked in 1st place, Australia in 2nd place, New Zealand in 3rd place, ... Korea in 32nd place, ... Mexico in 36th place, China in 37th place, Brazil in 38th place, Uganda in 39th place, and India in 40th place.

Source: Reconstructed from the Economist Intelligence Unit, The quality of death: Ranking end-of-life care across the world, 2010.

The rhombus (solid line) located in innermost area of the figure stands for Korea, while the rhombus marked by the second dotted line represents the average values of the 40 target countries (including Singapore, Malaysia, India and China, as well as the OECD countries). Korea's quality of death index was generally lower than the average of the target countries, thereby reflecting a lack of end-of-life services related to death as compared to most other countries.

3. Public understanding of hospice-palliative care

According to the results of the public's understanding on the end-of-life care, the understanding level of Belgium, Ireland and the UK were found to be high (Economist Intelligence Unit, 2010). Of the 5 groups, Korea fell under second category, thereby indicating a high understanding regarding hospice palliative care.

〈Table 2-3〉 Public's understanding of hospice-palliative care in Korea

High ranking (excellent)			Low ranking (poor)	
5	4	3	2	1
Belgium	Australia	Canada	Brazil	China
Ireland	Austria	Czech	Finland	
UK	France	Republic	Greece	
	Hungary	Denmark	India	
	Japan	Germany	Italy	
	Korea	Hong Kong	Luxembourg	
	Netherlands	Iceland	Mexico	
	New Zealand	Malaysia	Portugal	
	Sweden	Poland	Russia	
	Taiwan	Singapore	Switzerland	
	Uganda	Slovakia	Turkey	
		South		
		Africa		
		Spain		
		US		

Source: Economist Intelligence Unit, 2010.

According to a study by the National Cancer Center (2008), 84.5% of Koreans were found willing to use the hospice-palliative care and the response, "I will use hospice-palliative care if the disease cannot be treated with the present method. and aggravates" largely increased from 57.4% in 2004, to 84.5% in 2008¹⁾.

1) The National Cancer Center's survey on the public's understanding of well-dying, national research project for conquering cancer, 2008.

4. Pain management for end-of-life patients

As there is a high barrier for the use of morphine in Korea, Korea ranked low regarding the availability of pain relievers for pain management of patients before death.

〈Table 2-4〉 Ranking regarding the availability of pain relievers (Morphine and morphine substitutes) for end-of-life patients

High ranking (excellent)			Low ranking (poor)	
5	4	3	2	1
Australia	China	Austria	Czech Republic	India
Canada	Germany	Belgium	Greece Mexico	
Denmark	Hong Kong	Brazil Finland	Asia	
Luxembourg	Hungary	France	Turkey	
Netherlands	Ireland	Italy	Uganda	
New Zealand	Japan	Norway	Korea	
Portugal	Poland	Singapore		
Sweden	Spain	Switzerland		
	Taiwan			
	UK			
	US			

Source: Economist Intelligence Unit. The quality of death: Ranking end-of-life care across the world. 2010.

Section 2. End-of-Life Patients' Preferred Place of Death

1. Preferred and actual place of death

Although there is no recent data on Korean end-of-life patients' preferred place of death, a 2005 study reported that 54.8% patients preferred home as a place of death (Choi et al., 2005). However, in reality, most patients face death in acute care hospitals. In 2010, out of the 70,000 patients who died of cancer²⁾, only 6,564 terminally ill patients who received palliative care³⁾ in a specialized institution (9%) died of cancer (National Cancer Center, 2011).

The National Statistical Office information on the place of death categorized the same as home, medical institution, social welfare facilities (nursing home, orphanage, etc.), public facilities (school, playground, etc.), roads, commercial service facilities (shops, hotels, etc.), worksite, farm (fields, barns, farms, etc.), during transport to a hospital, and other. The places of death by age have been shown in <Table 2-5>.

2) Terminal cancer patient: Patient who is expected to die within a few months as there is no possibility of recovery despite aggressive treatment, and symptoms worsen gradually.

3) Palliative care: Medical treatment aimed to improve the quality of life of terminal cancer patients and their families through a comprehensive assessment and treatment for physical, psychosocial, and spiritual areas, including pain and symptom management.

Regarding the place of death for those aged over 65 years, with disease as the cause of death, excluding accidents and damage, 81.1% of the deaths occurred data medical institution, while 15.1% occurred at the patient's house. With reference to cancer, 85.1% of the deaths occurred at a medical institution. Further, regarding cardiovascular disease, 75.5% of the deaths occurred at a medical institution, and a relatively high proportion (4.4%) occurred during transport to a hospital (Table 2-6).

〈Table 2-5〉 Place of death in Korea: 2010

(Unit: %, person)

place of death	Under 19 years of age	20-44 years of age	45-64 years of age	65-79 years of age	Over 80 years of age	Total
* Medical institution (subtotal)	74.5	56.8	74.3	77.3	67.7	71.9
- Within a medical institution	68.1	49.5	69.7	73.7	63.3	67.5
- Death during transport to a hospital	6.4	7.3	4.6	3.6	4.5	4.4
* House	11.9	22.8	16.7	17.6	25.6	20.4
* Social welfare facilities	0.5	0.3	0.6	2.2	5.1	2.7
* Other	13.0	20.1	8.4	3.0	1.6	5.0
Total	100.0	100.0	100.0	100.0	100.0	100.0

Notes: Medical institution (subtotal)= Within a medical institution + during transport to a hospital. Other (public facilities, roads, commercial facilities, workplaces, farms, etc.), total number of deaths (N=257,066)

Source: Raw data from a survey on the cause of death, National Statistical Office.

〈Table 2-6〉 Place of death for those aged over 65 years, by disease in Korea (excluding accidents and damage): 2010

(Unit: %, person)

place of death	Cancer	Cardiovascular	Respiratory system	Other	Total
* Medical institution (subtotal)	85.1	75.5	83.6	81.9	81.1
- Within a medical institution	83.6	71.1	80.5	78.0	78.0
- Death during transport to a hospital	1.5	4.4	3.1	4.0	3.2
* House	12.4	18.9	12.9	14.7	15.1
* Social welfare facilities	2.1	4.0	2.9	2.7	3.0
* Other	0.4	1.5	0.6	0.7	0.9
Total	100.0	100.0	100.0	100.0	100.0
Number of deaths	48,270	46,136	16,938	34,442	145,786

Notes: Medical institution (subtotal)= Within a medical institution + during transport to a hospital.

Other (public facilities, roads, commercial facilities, workplaces, farms, etc.), total number of death by diseases (N=145,786)

Source: Raw data from a survey on the cause of death, National Statistical Office.

According to the results of a survey by the Japanese Ministry of Health and Welfare, 63% of respondents chose home as a preferred place of death. However, only 12.3% of the deaths occurred at home, while 85.3% of them occurred at the hospital (Investigation into end-of-life care, 2007).

Higginson (2003) found that although 2/3rd of the people in the UK chose home as a preferred place of death, only 1/3rd of the respondents actually faced death at home. This issue highlighted the gap between the preferred and actual place of

death. In 2012, the UK’s Statistical Office conducted a survey on the preferred place of death, targeting individuals whose family members or friends had died within the last three months (Office for National Statistics: ONS, 2013)⁴. It was found that 80% of those who died preferred to face death at home, but only 49% of them actually died at home. Additionally, 52% of all death so occurred at the hospital.

〈Table 2-7〉 Place of death in the UK: 2012

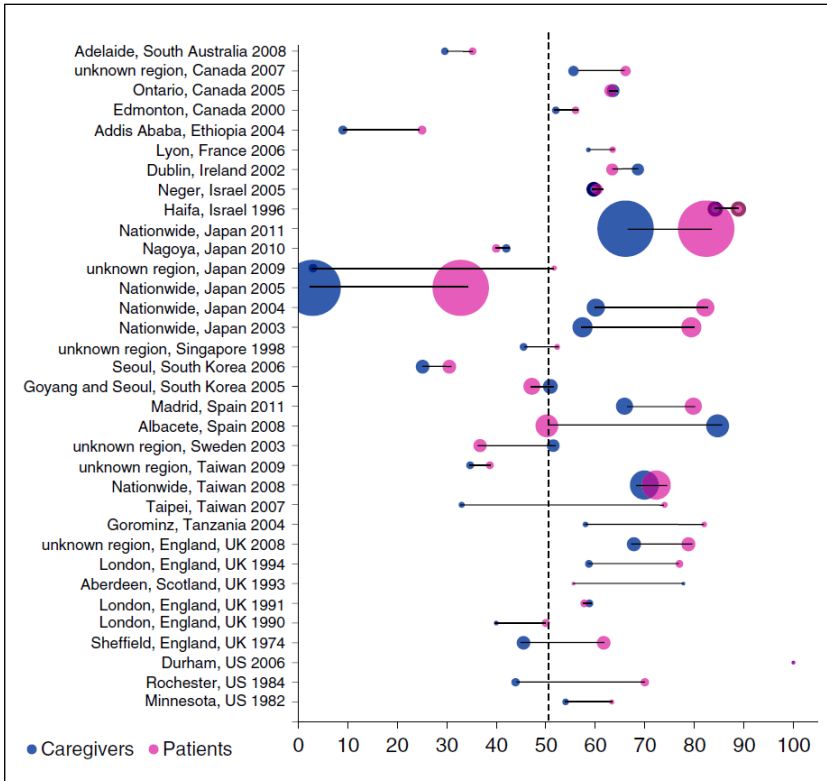
	(Unit: %)			
	House	Hospital	Care home	Hospice
Cardiovascular disease	25.6	56.3	17.6	0.5
Cancer	30.1	38.4	13.0	18.4
Other	12.4	55.1	31.7	0.9

Notes: Statistics Office, UK, 2013.

[Figure 2-2] presents the results of the studies that have been put together based on the preferences of the patients and their caregivers on death at home. The number of points or circles in the figure illustrate the number of studies included in the result and the size of the points or circles indicate the number of participants in each study (the largest circle indicates 4,175 participants).

4) National Bereavement Survey (VOICES).

[Figure 2-2] Results of a systematic literature review about patients' and caregivers' preferences for dying at home



Notes: Rate of preference for dying at home (%) (Left- patient's care provider; Right-patients).

The following Korean studies were included in this systematic review: (1) Choi KS et al. Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. *Support Care Cancer* 2005, 13(8):565-572. (2) Yun YH et al. Understanding disparities in aggressive care preferences between patients with terminal illness and their family members. *J Pain Symptom Manage* 2006, 31(6):513-521.

Source: Gomes B, Calanzani N, Gysels M. et al. Heterogeneity and changes in preferences for dying at home: a systematic review, *BMC Palliative Care* 2013, 12:7.

Section 3. Subject and Benefits of Hospice Palliative Care

The Ministry of Health and Welfare had planned to build a healthcare system for the activation of palliative care by conducting a comprehensive assessment of the adequacy of the reimbursement rate model through a pilot project (briefing paper by the Ministry of Health and Welfare, 2014). In addition, it is expected to have a legal base for diversifying the service system including setting up of home hospice and dispersal palliative care teams to activate palliative care. A home hospice will provide the service by having palliative care specialists visit a patient's house, and a dispersal palliative care team will not be restricted to the palliative care ward, but will provide services at wards in which a patient is hospitalized, by forming a team consisting of doctors, nurses, social workers, and priests.

By continuously conducting education and promotion campaigns for the general public, patients, and medical personnel, it is planned to increase the level of awareness regarding palliative care, to allow the people to receive adequate palliative care services from an early phase.

A. Eligibility for terminal cancer patient-centered benefits

Although Korea provides hospice-palliative care mainly for cancer patients, only 6,564 (9% of cancer death) out of the total

cancer deaths that occurred in 2010 received palliative care services at a palliative care specialized institution (National Cancer Center, 2011).

In the US, although the palliative care system was mainly for cancer patients at the initial phase, its use had recently increased to 40.1% for cancer, 13.1% for debility, 11.5% for heart disease, 11.2% for dementia, and 8.2% for lung disease (in 2009).

B. First pilot project on the medical insurance reimbursement rate for palliative care for terminal cancer patients

The first pilot project on the medical insurance reimbursement rate of palliative care for terminal cancer patients was conducted from December 2009 to August 2011. A fixed reimbursement rate per hospitalization day was set by the medical institution type (comprehensive specialized institution, general hospital, hospital, and clinic) with reference to the amount of resources committed to palliative care. Furthermore, to prevent unnecessary hospitalization, a system of diminishing hospital charge and increasing out of pocket payment was introduced. By referring to the average length of stay for palliative care, acute hospital beds, and reduction system in foreign countries, a decrease in hospital charge and increase in out of pocket payment was applied from the 16th day of hospitalization (see<Table2-8>).

With reference to the facility equipment standards for specialized medical institutions for terminal cancer patients set by the Cancer Control Act, there are regulations for hospital wards, bathrooms, counseling rooms, and treatment rooms, and standards for personnel.

〈Table 2-8〉 Reimbursement rate applied in the first pilot project on medical insurance reimbursement rate for palliative care (applied reimbursement rate per day)

(Unit: 1 KRW)

	Advanced general hospital	General hospital	Hospital	Clinic
* Basic reimbursement rate (A)	159,290	129,140	77,790	70,720
* Additional payment amount (B)				
Nurse more than 1.5- less than 1.0	5,340	5,210	4,610	3,770
Nurse less than 1.0	11,210	10,940	9,680	7,920
Social worker	3,240	3,110	2,990	2,860
Total amount (A)+(B)	173,740	143,190	90,460	81,500
〈Reduction of hospital bill〉	50% of reimbursement rate for hospice palliative care starting - on 16 th day of hospitalization			
〈Out of pocket〉	20% deductible starting on 16 th day of hospitalization Equivalent to the existing (10% deductible)			

Notes: Total amount = Basic reimbursement rate (average reimbursement cost) +maximum additional payment.
Source: Ministry of Health and Welfare, press release (August 24, 2009).

C. Second pilot project on the medical insurance reimbursement rate for palliative care for terminal cancer patients⁵⁾

The second pilot project to implement palliative care services for terminal cancer patients in the health insurance system was conducted from September 2011. The pilot institutions included 13 national palliative care specialized institutions including the Seoul St. Mary's Hospital.

〈Table 2-9〉 Institutions for the second pilot project on the health insurance reimbursement rate for palliative care

Medical care institution type	Institution name
Advanced general hospital(2)	Seoul St. Mary's Hospital (Seoul), Gachon University Gil Medical Center (Incheon)
General hospital (5)	St. Vincent's Hospital, the Catholic University (Gyeonggi), National Health Insurance Corporation Ilsan Hospital (Gyeonggi), Busan St. Mary's Hospital (Busan), Hongseong Medical Center (Chungcheong), Changwon Fatima Hospital (Gyeongnam)
Hospital (3)	Saemmul Hospice Hospital (Gyeonggi), Emmaosarang Hospital (Jeonbuk), Nampyeong Mirae Hospital (Jeollanam)
Clinic (3)	Calvary Clinic (Gangwon), Mohyeon Center (Gyeonggi), Jeonjinsang Clinic (Seoul)

Source: Ministry of Health and Welfare, press release (August 31, 2011).

Regarding the reimbursement rate applied in the second pilot project, the fixed amount for each hospitalization day was

5) Ministry of Health and Welfare's press release (August 31, 2011). Second application of pilot health insurance reimbursement rate of palliative care for terminal cancer patients.

categorized into 2 types (higher than general hospital level/lower than hospital level) considering the amount of resources being committed to palliative care. Additional payment was made according to the nurse and social worker staffing level. Meanwhile, with the health insurance reimbursement rate reduced to 50% (60,000–80,000 KRW per day) from the 16th day of hospitalization, since patients and medical personnel had a difficulty in using and providing adequate services due to worries and pressure on discharge time, the hospital bill was discounted at 10% (7,000–9,000 KRW per day) from the 16th day of hospitalization such that terminal cancer patients could receive palliative care at adequate periods.

〈Table 2-10〉 Reimbursement rate applied in the second pilot project on the health insurance reimbursement rate for palliative care (applied reimbursement rate per day)

(Unit: 1 KRW)

Category	Advanced general hospital/General hospital		Hospital/Clinic	
* Basic reimbursement rate (A)	175,980		113,580	
* Additional payment (B)				
– 1 st class nurse	11,450		8,890	
– 2 nd class nurse	5,450		4,240	
– Social worker	3,330		3,120	
Total amount(A)+(B)	190,760		125,590	
〈Reduction of hospital bill〉	Between 16-30 days	After 31 days	Between 16-30 days	After 31 days
* Basic reimbursement rate (A)	5,450	8,180	4,240	6,350
– 1 st class nurse	6,600	9,900	5,120	7,690
– 2 nd class nurse	6,000	9,000	4,660	6,990

Notes: Total amount =Basic reimburse rate (average reimbursement cost)+ maximum additional payment.

Source: Ministry of Health and Welfare, press release (August 31, 2011).

Moreover, based on the service provided by the palliative care specialized institution for cancer patients, nurses and social workers were required to provide spiritual and emotional care. Nursing workforce level and level of hospitalization were higher than those of the general medical institution.

Korea has insufficient care plans for the end-of-life patient referral system. Despite an increase in the number of palliative care institutions, mainly in the advanced general hospitals or general hospitals, the fundamental objective of palliative care is not being achieved. Regarding treatment of terminal patients, medical guidelines such as the care pathway should be provided. For example, the UK's referral system provides terminal patients with a comprehensive service to prepare for death through the National End-of-life Care Programme. Thus, treatment plans for patients as well as their family should be considered. Children's hospices in the UK focus not only on improving the quality of life of the child but also on the provision of physical and emotional support for the family in order to provide comprehensive care.

As such, a program that reduces pain and improves the quality of life of the patient and his/her family is needed. A referral system that allows patients to receive services at home or at palliative care institutions near their residence, rather than at (advanced) general hospitals, needs to be established.

3

Cost Analysis of End-of Life Care

Section 1. Method of Analysis

Section 2. Results of Analysis

3

Cost Analysis of End-of Life Care

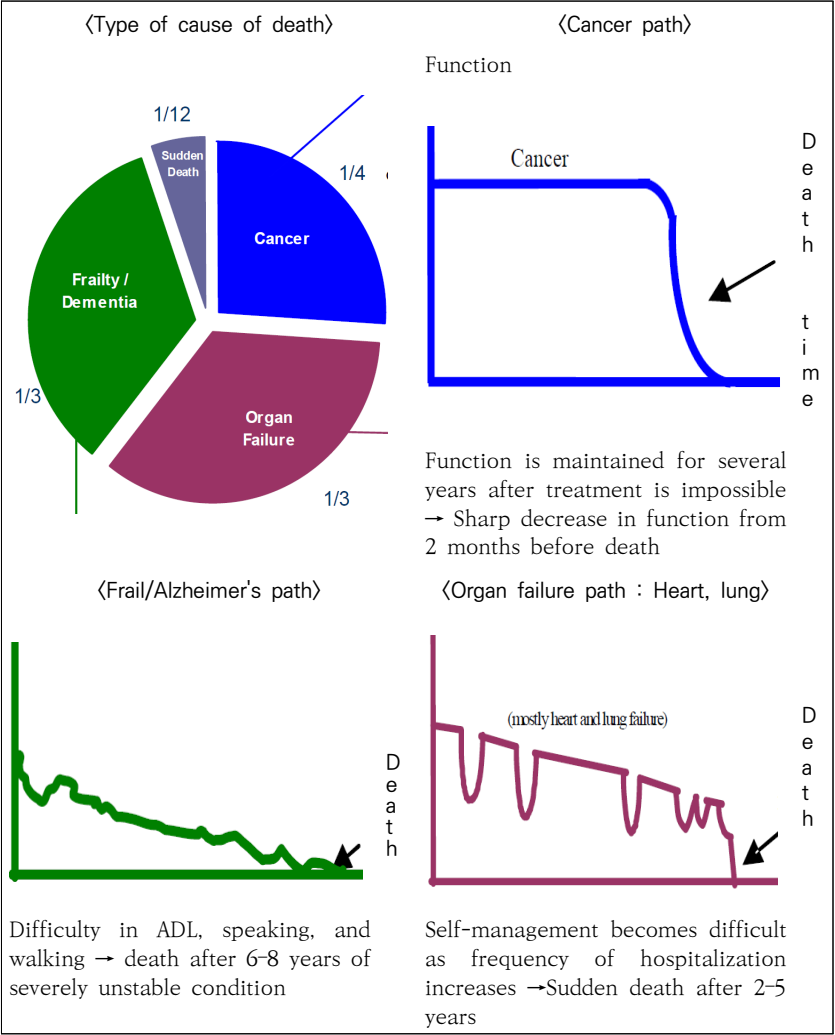
Section 1. Method of Analysis

This chapter provides policy implications to respond to the demographic changes due to aging and to the unmet needs for care services. Although end-of-life patients prefer to die at home, the number of deaths occurring in hospitals is increasing. Related studies presented that the number of inpatient facilities needs to be increased by 20% than the current level in accordance with the annual death in 2030 (Gomes et al, 2008).

Service for end-of-life care should be provided on the basis of various routes according to the disease condition. [Figure 3-1] presents findings of the work that had been carried out to provide services for hospice patients at the Kings College London, England. Cancer patients had the most predictable path, and access to palliative care service provided by a specialist was easier.

Patients who did not have cancer but had organ failure did not need palliative care service by a specialist. Patients' needs were met with support, services, facilities, and equipment of primary care providers: for example, general practitioners, nursing services, and other professional staff).

[Figure 3-1] Path of functional status change by disease at the time of death



Source: Royal college of general practitioners, Gold standard framework(GSF) Prognostic indicators, version February 25, 2006.

Frail patients have complex needs as they have the highest level of social reliance, and do not react to simple care

protocol. They usually have neuro-degenerative diseases, multi-organ failure, and multi-system diseases including diabetes and dementia. They have a high intensity of dependence and need high level of intervention (treatment) or continuous care. Thus, they fall under the patient group that should receive services through a partnership between primary medical practitioners and specialists, as a care plan suited for individual disease characteristics needs to be accompanied.

〈Table 3-1〉 Period-specific changes in end-of-life care needs

Category	Before end-of-life care	Unstable phase	Continuous care	Terminal care
Cancer	13 weeks	26 weeks	12.5 weeks	3-4 days
Organ failure	13 weeks	13 weeks	25.5 weeks	3-4 days
Debility	0	0	51 weeks	7 days
Other	0	26 weeks	25.5 weeks	3-4 days

Notes: Assumptions are based on a consensus view made by 27 clinicians during a series of workshops held by the NEoLCP (National End-of-Life Care Programmes).
Source: NHS, 2010.

In order to analyze the medical expenses of a cancer patient at the end-of-life, health insurance cohort data provided by the National Health Insurance Corporation was used. A regression analysis using a Generalized Linear Model (GLM) was applied, which is generally used for medical cost analysis. GLM is often used for analysis of medical costs with a distribution skewed to the right side and is a model that can correspond to a potential failure that can occur due to non-linear or log conversion.

Section 2. Results of Analysis

First, distribution of medical expenses before cancer death in 2010 is illustrated in <Table 3-2>. The insurer’s share during the month before death was 7.26 million KRW per patient and deductible excluding the non-coverage was 650,000 KRW. Meanwhile, an insurer’s total share during 24 months before death was 26.18 million KRW per patient, while average monthly share was found to be about 1.09 million KRW.

<Table 3-2> Distribution of cancer patients’ medical expenses before death
(Unit: Number of people, 1000 KRW)

	Before death-1 month	Before death-2 months	Before death-6 months	Before death-12 months	Before death-24 months
Number of subjects	747	843	894	940	959
Inpatient					
- Covered by insurance	6,912	12,176	20,185	22,293	22,391
- Out of pocket	588	1,092	1,927	2,173	2,228
Outpatient					
- Covered by insurance	346	834	2,501	3,502	3,787
- Out of pocket	57	119	350	503	576
Total					
- Covered by insurance	7,258	13,010	22,687	25,795	26,178
- Out of pocket	645	1,211	2,277	2,676	2,804

Notes: Non coverage was excluded from deductibles. Those over 65 years of age, who died in 2010, were targeted.
Source: Health insurance cohort data.

Income level-specific distribution of medical expenses per cancer patient has been shown in <Table 3-3>. Income in the health insurance cohort data is largely divided into 10 percentiles on the basis of health insurance paid by the caregiver. When this is categorized into 5 percentiles, the insurer's share for the 1st quintile income (low income) was 6.64 million KRW for the month before death, while it was substantially higher for the 5th quintile income, at 8.1million KRW.

<Table 3-3> Distribution of cancer patients' medical expenses before death:
By income level

(Unit: number of people, 1000 KRW)

	Before death-1 month	Before death-2 months	Before death-6 months	Before death-12 months	Before death-24 months
<Number of patients>					
Medical benefits	2	3	25	62	76
1 st quintile Income (low income)	132	149	152	154	155
2 nd quintile income	98	111	117	117	117
3 rd quintile income	108	130	141	142	143
4 th quintile income	135	147	148	150	151
5 th quintile income (high-income)	272	303	311	315	317
Health care coverage					
- Covered by insurance	4,174	4,267	1,290	1,549	1,839
- Out of pocket	693	920	139	169	226
1 st quintile income (low income)					
- Covered by insurance	6,641	11,790	21,022	26,263	26,786
- Out of pocket	671	1,209	2,080	2,506	2,634

38 Measuring Social Values in End-of-Life Care

	Before death-1 month	Before death-2 months	Before death-6 months	Before death-12 months	Before death-24 months
2 nd quintile income					
– Covered by insurance	7,442	13,268	23,426	27,820	28,961
– Out of pocket	674	1,246	2,415	3,034	3,214
3 rd quintile income					
– Covered by insurance	6,902	11,963	21,527	24,331	24,950
– Out of pocket	607	1,100	2,039	2,377	2,520
4 th quintile income					
– Covered by insurance	6,369	12,271	24,003	30,089	30,996
– Out of pocket	544	1,054	2,307	3,014	3,206
Income 5 (high-income)					
– Covered by insurance	8,096	14,410	24,841	28,202	28,946
– Out of pocket	688	1,325	2,588	3,094	3,290

Notes: Non coverage was excluded from deductibles. It is a combination of inpatient and outpatient costs. Income of health insured was classified into 5 percentiles. Targeted deaths of those over 65 years of age, in 2010.

Source: Heath Insurance Cohort Data.

Period before death was categorized into before death-2 months, before death-6 months, and before death-12 months, and each category was set as a dependent variable for the regression analysis. Findings revealed that, in the model that had before death-2 months as a dependent variable, for those over 65 years of age, medical costs at the 5th quintile income level was significantly higher than those at the 1st quintile income level.

(Table 3-4) Results of the regression analysis (1): Inequality of medical expenses by income level of end-of-life cancer patients

	Before death-2 months		Before death-6 months		Before death-12 months	
	Coefficient	SE	Coefficient	SE	Coefficient	SE
Constant	14.569	0.110	14.472	0.117	14.551	0.114
1 st quintile income (ref.)	0.000	0.000	0.000	0.000	0.000	0.000
	0.179	0.109	0.146	0.115	0.176	0.113
	-0.060	0.103	-0.038	0.109	-0.068	0.106
	0.177*	0.102	0.107	0.108	0.171	0.106
5 th quintile income	0.223**	0.087	0.226**	0.093	0.215**	0.090
Male	0.106*	0.064	0.077	0.068	0.116*	0.066
Female (ref.)	0.000	0.000	0.000	0.000	0.000	0.000
65-69 years of age	0.273**	0.108	0.146	0.116	0.235**	0.113
70-74 years of age	0.150	0.106	-0.015	0.114	0.080	0.110
75-79 years of age	0.116	0.103	-0.049	0.111	0.070	0.108
80-84 years of age	0.163	0.114	0.069	0.122	0.134	0.118
Over 85 years of age (ref.)	0.000	0.000	0.000	0.000	0.000	0.000
Scale	1.286	0.055	1.162	0.050	1.204	0.051

Notes: The GLM model was applied. The health insured aged over 65 years were targeted.

* $p < 0.1$, ** $p < 0.05$, *** $p < 0.01$.

By dividing the period before death into before death-2 months, before death-6 months, and before death-12 months, and establishing each as a dependent variable, a regression analysis was conducted. The results showed that, in the model that established the period of before death-2 months as a dependent variable, for the targeted health insured aged over 65

years, the medical costs at the 5th quintile income level was significantly higher than those at the 1st quintile income level.

〈Table 3-5〉 Results of the regression analysis (2): Inequality of medical expenses by income level of end-of-life cancer patients

	Before death-2 months		Before death-6 months		Before death-12 months	
	Coefficient	SE	Coefficient	SE	Coefficient	SE
Constant	14.137	0.703	12.079***	0.219	12.088***	0.165
Medical benefits (ref.)	0.000	0.000	0.000	0.000	0.000	0.000
1st quintile income(ref.)	-0.179	0.715	2.546***	0.245	2.530***	0.169
	-0.141	0.717	2.704***	0.251	2.717***	0.177
	-0.271	0.716	2.518***	0.248	2.465***	0.171
	-0.300	0.716	2.666***	0.248	2.707***	0.171
5th quintile income	-0.079	0.713	2.781***	0.240	2.756***	0.160
Male	0.093	0.074	0.050	0.071	0.140	0.072
Female(ref.)	0.000	0.000	0.000	0.000	0.000	0.000
65-69 years of age	0.053	0.127	-0.003	0.126	0.211	0.124
70-74 years of age	-0.081	0.124	-0.170	0.123	-0.054	0.123
75-79 years of age	-0.012	0.121	-0.213	0.121	-0.049	0.119
80-84 years of age	-0.042	0.133	-0.109	0.130	0.011	0.129
Over 85 years of age (ref.)	0.000	0.000	0.000	0.000	0.000	0.000
Scale	1.011	0.044	1.054	0.044	0.954	0.039

Notes: The GLM model was applied. The health insured aged over 65 years were targeted.

* $p < 0.1$, ** $p < 0.05$, *** $p < 0.01$.

4

Survey on the Awareness of End-of-Life Care Understanding

Section 1. Overview of the Survey

Section 2. Results of the Survey

4

Survey on the Awareness of End-of-Life care Understanding

Section 1. Overview of the Survey

In order to examine the general public's awareness on end-of-life care, an interview survey was conducted with 1,013 adults aged over 30 years. To obtain national representativeness, the sample was extracted by population allocation proportionate to age, sex, and region. The survey was conducted from October 13, 2014 to November 5, 2014.

〈Table 4-1〉 Socioeconomic characteristics of respondents

Category		Number of respondents	%
Sex	Male	500	49.36
	Female	513	50.64
Age	30-44 years of age	352	34.75
	45-64 years of age	467	46.10
	Over 65 years of age	194	19.15
Marital status	Unmarried	84	8.29
	Have a partner currently	823	81.24
	Although married, I currently do not have a partner	106	10.46
Educational level	Elementary school or less	95	9.38
	Middle school	133	13.13
	High school	436	43.04
	University or higher	344	33.96
	Don't know/no response	5	0.49
Number of members in the household	Single person household	73	7.21
	More than two persons	940	92.79
	Mean	3.27	-
Total		1,013	100.00

Section 2. Results of the Survey

A. Discussion about death and end-of-life plan with others

To explore whether subjects talked about death and end-of-life plan comfortably with their family and friends, the following question was asked: “Do you talk comfortably about your own death and end-of-life plan with other people?”

It was found that 58.8% and 62.0% of the male and female respondents, respectively, said they talked comfortably. For those between the ages 30 and 44 years, 53.4% responded that they talked comfortably, while 63.4% of those aged between 45 and 64 years, and 66.0% for those aged over 65 years reported the same. As the age increased, the proportion of those who reported that they talked comfortably increased.

〈Table 4-2〉 Discussion on death and end-of-life plan with others

(Unit: %)

		Talks comfortably	Does not talk comfortably	Total
Sex	Male	58.8	41.2	100.0
	Female	62.0	38.0	100.0
Age	30-44 years of age	53.4	46.6	100.0
	45-64 years of age	63.4	36.6	100.0
	Over 65 years of age	66.0	34.0	100.0
	Total	60.4	39.6	100.0

Notes: The following question was asked: “Do you talk comfortably about your own death and end-of-life plan with other people?”

To subjects who responded that they do not talk comfortably about the own death and end-of-life plan, the following question was posed: “Which of the following reasons explains why you don’t comfortably talk about such issues with others?” For those aged over 65 years, “I just do not want to talk about it” was the commonest response, with 53.0% choosing this reason, while 19.7% picked the reason “I am still far away from death.”

〈Table 4-3〉 Reason why one cannot discuss about death and end-of-life plan (N=612)

(Unit: %)

	30~44 yrs	45~64 yrs	65 yrs+	total
I am still far away from death	49.4	35.1	19.7	38.4
I am still young for talking about death	16.5	3.5	0.0	8.2
I have no one with whom I can talk about death	2.4	1.8	4.6	2.5
Others do not want to talk about my death	6.7	11.1	12.1	9.5
I just do not like to talk about it	17.1	32.8	53.0	29.7
I like to postpone thinking about death	4.9	13.5	4.6	8.5
My family knows what I want	0.6	2.3	3.0	1.8
Other	2.4	0.0	3.0	1.5
Total	100.0	100.0	100.0	100.0

Notes: The following question was asked: “Which of these reasons explains why you do not talk about such issues with others?”

B. Thoughts about awareness of death by disease

In response to the question on whether the patients wanted to be aware that he/she was on the verge of death from a dis-

ease, 65.8% and 75.2% of the male and female respondents, respectively, answered “yes.” With reference to age, 75.3% of those aged between 30 and 44 years, and 59.8% of those aged over 65 years said that they wanted to be aware of the same.

〈Table 4-4〉 Thoughts about awareness of death by disease

		Want to know	It is better not to know	Total
Sex	Male	65.8	34.2	100.0
	Female	75.2	24.8	100.0
Age	30~44 yrs	75.3	24.7	100.0
	44~64 yrs	71.5	28.5	100.0
	65 yrs+	59.8	40.2	100.0
	Total	70.6	29.4	100.0

Notes: The following question was asked: “When your life has not much left due to the disease, do you want to be aware or do you think it is better not to know?”

C. Needs at the end-of-life

Regarding what one needs at the end-of-life, the following question was asked: “When you found out that you cannot live long due to a disease like cancer, which one of the following was the most important need, such that you spoke to others about it?” The response, “pain relief” was selected by 26.0% of the respondents, while “excellent hospital treatment (medical needs)” was selected by 24.7%, and “psychological and religious stability” was selected by 19.9% of the respondents.

〈Table 4-5〉 End-of-life needs

	30~44 yrs	45~64 yrs	65 yrs+	total
Excellent hospital treatment (medical needs)	24.4	23.6	27.8	24.7
Psychological and religious stability	16.8	21.8	21.1	19.9
Disease pain relief	24.4	25.9	28.9	26.0
The last place you want to finish your life (place of death)	17.9	17.8	15.0	17.3
Respect for privacy and peace	15.6	10.5	7.2	11.7
Other	0.9	0.4	0.0	0.5
Total	100.0	100.0	100.0	100.0

Notes: The following question was asked: "When you found out that you cannot live long due to a disease like cancer, which one of the following was the most important need, such that you spoke to others about it?"

Regarding the question on the preferred place of death, 39.5% and 27.2% of the respondents chose home and hospital, respectively. Further, 39.2% of the respondents aged over 65 years preferred to die at home, while 38.7% preferred to die at the hospital.

〈Table 4-6〉 Preferred place of death

	30~44 yrs	45~64 yrs	65 yrs+	total
Home	40.1	39.2	39.2	39.5
Hospital	22.7	25.7	38.7	27.2
Hospice institution	8.8	11.6	4.1	9.2
Facility	1.4	3.0	4.1	2.7
Other	5.4	3.4	2.6	4.0
Have not thought about it	21.6	17.1	11.3	17.6
Total	100.0	100.0	100.0	100.0

Notes: The following question was asked: "When you know that you cannot live long due to the disease, what is your preferred place of death?"

Regarding important matters regarding end-of-life care, “dying without pain” was the commonest response, at 33.3%, followed by “I do not wish to burden others,” at 20.5%. In other words, 53.8% of the respondents did not wish themselves and their family to experience pain and burden(see <Table 4-7>).

Regarding the decision on life extension, majority of the respondents responded “I make the best decision for myself”(37.3%), followed by “I want to decide together with a doctor”(33.5%) (see <Table 4-8>).

<Table 4-7> Important matters in end-of-life care

	30-44 yrs	45-64 yrs	65 yrs+	total
No pain	31.0	33.0	38.1	33.3
Maintaining my dignity	12.2	10.3	8.8	10.7
Being with family or friends	20.7	16.3	12.4	17.1
Peace and quiet	16.2	16.7	13.9	16.0
I do not wish to burden others	17.9	21.4	23.2	20.5
Others paying attention to my desire	2.0	2.1	3.6	2.4
Other	0.0	0.2	0.0	0.1
Total	100.0	100.0	100.0	100.0

Notes: The following question was asked: “When you are near death, what is the most important matter regarding end-of-life care?”

<Table 4-8> Preferred decision maker for life extension

	30-44yr	45-64yr	65yr+	total
I want a doctor to make the best decision for me	16.2	15.9	20.1	16.8
I want to decide together with a doctor	34.9	33.8	29.9	33.5
I make the best decision for myself	36.7	38.5	35.6	37.3
I will follow my family’s opinion, which is the most important	12.2	11.8	14.4	12.4
Total	100.0	100.0	100.0	100.0

Notes: The following question was asked: “When making a decision about your own life extension, which one of the following is your most preferred method?”

Regarding decision making for life extension at the end of life, the response, “I want to continuously receive hospital treatment despite low possibility of survival at the end of life (6 months before death)” was chosen by majority of the participants (43.44%) and 43.24% selected the response, “I want to receive CPR when the heart suddenly stops at the end of life (6 months before death).”

Meanwhile, 58.14% of the respondents chose “dignity,” which is higher than the rate of wishing to extend one’s life.

〈Table 4-9〉 Decision making for life extension at the end of life

	30~44 yrs	45~64 yrs	65 yrs+	total
- I'd like to continuously receive medical treatment despite a low possibility of survival at the end of life (6 months before death).	41.5	44.1	45.4	43.44
- I want to receive CPR when the heart suddenly stops at the end of life (6 months before death).	45.7	43.5	38.1	43.24
- I want to choose dignity if I am on the verge of irrecoverable death at the end of life (6 months before death).	56.5	60.8	54.6	58.14

Notes: Percentage of “yes” responses.

5

Analysis of the Social Value of End-of-Life Care

Section 1. Method for Measuring Social Values

Section 2. Design for Measurement of Social Values
of End-of-life Care

Section 3. Results of the Measurement of the
Social Value regarding End-of-life care

5

Analysis of the Social Value of End-of-Life Care

Section 1. Method for Measuring Social Values

The Discrete Choice Model is a concept that states that a decision maker selects the most useful alternative among various available alternatives. A Discrete Choice Experiment (DCE) draws people's preferences based on the stated preferences by applying a virtual decision (Louviere et al., 2000). In other words, it is a method of drawing preferences by asking a decision maker to choose in a hypothetical but similar situation, although the result of the decision is not produced in reality.

DCEs are conducted through surveys consisting of some "choice sets." By using attributes and levels applicable to a range of attributes, profiles of several alternatives are developed, and respondents are asked to choose from the alternative profiles. The contribution to utility is estimated based on the participants' selection (Lancsar and Louviere, 2008).

In DCEs, response data can be concretized into the random utility model developed by McFadden (1974). In the random utility model, utility (U_{nj}) represents utility in a case in which a respondent n selects the given j th alternative. The utility function U_{nj} can be divided into two, as shown below.

$$U_{nj} = V_{nj} + \epsilon_{nj}$$

V_{nj} indicates the explainable element like characteristics of the decision maker and alternatives, and ϵ_{nj} represents inexplicable errors. If ϵ_{nj} is regarded to be unobservable and random, V_{nj} becomes the indirect utility function. A probability P_{ni} of a respondent selecting alternative (i) from among alternative (i) and (j) is as follows:

$$\begin{aligned} P_{ni} &= \Pr(V_{ni} + \epsilon_{ni} > V_{nj} + \epsilon_{nj}) \quad \forall j \neq i \\ &= \Pr(\epsilon_{ni} - \epsilon_{nj} < V_{ni} - V_{nj}) \quad \forall j \neq i \end{aligned}$$

Suppose the error term is IID(independently and identically distributed), a conditional logit model can be applied to draw a probability value from the choice set (Louviere et al. 2000). The expected probability that alternative (i) will be selected is as follows:

$$P_{ni} = \frac{e^{V_{ni}}}{\sum_{j=1}^J e^{V_{nj}}} \quad j=1, \dots, J$$

In other words, it is a value of the probability that X_{nj} will be selected among the set of all alternatives ($j=1, \dots, J$).

In case is a characteristic of the alternative in the above equation, a conditional logit model is $V_{ni} = \beta X_{ni}$, and thus,

$$P_{ni} = \frac{\exp(\beta X_{ni})}{\sum_{j=1}^J \exp(\beta X_{nj})}$$

Section 2. Design for Measurement of Social Values of End-of-life Care

A. Scenario design method

1) Attributes and level of attributes

By dividing life expectancy into one without treatment and one with treatment, the present study included its attributes. Additionally, regarding attribute levels for such life expectancy, 24 months was set as life expectancy without treatment by referring to the attribute level presented by Shah et al.(2012). Based on 24 months of life expectancy, the phases that are shorter than 24 months, including 3 months and 12 months, were included, and the phases that are longer than 24 months, including 36 months and 60 months, were included.

By setting 3 months as a standard point at which life expectancy increases when treatment is received, based on 3 months, those shorter than 3 months, including 1 month and 2 months, were included, and those longer than 3 months, including 6 months and 12 months, were included. Further, 0 months was also included considering cases in which life is not extended despite treatment.

〈Table 5-1〉 Attributes and levels

Attributes	Unit	Levels
Life expectancy in case one does not receive treatment	Month	3, 12, 24, 36, 60
Health status when one does not receive treatment	%	50, 100
Increase in life expectancy in case one receives treatment	Month	+0, +1, +2, +3, +6, +12
Improvement of health status in case one receives treatment	%	+0, +25, +50

To help respondents to easily respond to health status when a treatment is not received, health status was presented as 50% health status and 100% health status, where 100% health status indicated a completely healthy state and 0% indicated death. A concept of health status of 50% was considered equivalent to maintaining a health status of 50% for 2 years and having a health status of 100% for 1 year. Improvement of health status when treatment was received was set at 25% and 50% increments, and at 0% when the health status did not improve.

2) Experimental Design

Thus, 180 profiles were possible with the aforementioned attributes and levels. In other words, when a full factorial design was conducted regarding the 4 attributes and each level, a set of $5 \times 2 \times 6 \times 3 = 180$ profiles was drawn.

However, some of the profiles were realistically impossible. For example, it is impossible for the health status to increase to

125% with a 25% improvement after receiving treatment, despite the fact that health status was at a maximum of 100%. Such cases in which health status becomes over 100% after receiving treatment were excluded from profile set. Furthermore, profiles in which the health status decreased after receiving treatment were also excluded. After deleting the excluded cases from the overall set of profiles, 110 profiles were developed. When these were used, two pair-wise comparison choice sets of 5,995 were used.

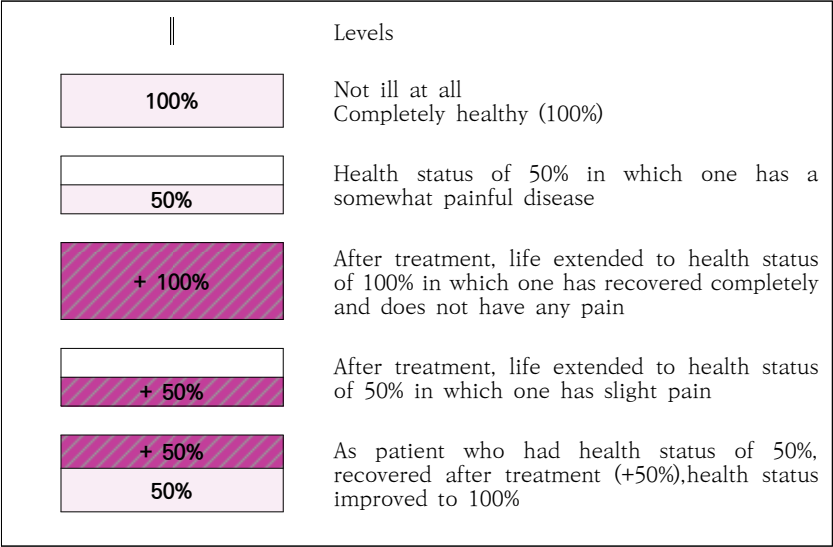
As it was not feasible to use all choice sets, 48 profiles were selected through a D-optimality algorithm for the 110 profiles. By dividing the questionnaire into 4 versions, 12 profiles were included for each questionnaire.

B. Method of designing the research tool

For design of the Discrete Choice Experiment, the type of decision for hypothetical scenarios was established in the following manner:

- Patient A: 3 years of survival without treatment, health status 50%vs. 1 year of survival with treatment, health status 75%.
- Patient B: 2 years of survival without treatment, health status 50%vs. 1 year of survival with treatment, health status 100%.
- Which of Patient A and Patient B should receive treatment?

[Figure 5-1] Health status and life extension notation method



Notes: Light color: Current health status of the patient.
Dark color: Improvement of health status of the patient after receiving treatment.
Shaded: Life extension.

[Figure 5-2] Questionnaire example

[Questionnaire example]

※ As shown in the figure below, two virtual patients were presented.

- “Patient A” can live 12 months longer if he does not receive treatment and currently has a health status of 50% in which he has slight pain.
- “Patient B” can live 12 months longer if he does not receive treatment and currently has a health status of 50% in which he has slight pain.

※ When “Patient A” receives treatment, he lives at a healthy level of 100% with no pain, although life is not get extended.

When “Patient B” receives treatment, his health status does not change and thus, he lives at a health status of 50% in which he has slight pain, although his life is extended by 12 months.

※ Among the patients, please select the patient who should receive treatment first.

Period
(Months)

0312243660

Patient A

+50%

50%

Patient B

50%

50%

	Patient A	Patient B
Age	Two patients of the same age (adult)	
Remaining life when treatment is not received	12 months	12 months
Health status when treatment is not received	50%	50%
Life extension when treatment is received	No life extension	Life extended by 12 months
Improvement of health status when treatment is received	100% health status (+50% health status)	No improvement in the health status (+0%)
Choice	① <input type="checkbox"/>	② <input type="checkbox"/>

Section 3. Results of the Measurement of the Social Value regarding End-of-life care

The results of the analysis using the conditional logit model through the questionnaire method of DCEs have been shown in <Table 5-2>. Compared to the baseline, all coefficients were statistically significant and positive. The fact that coefficients for life expectancy (LE_no) and health status (QoL_no) were positive implies that respondents were likely to select treatment for patients who had high life expectancy if they did not receive treatment or patients who had a high quality of life. That is, with a cumulative increase in the attribute level, there was an increase in the expected effectiveness level.

<Table 5-2> Results of the Conditional Logit Model

Attribute	Level	Coefficient	SE	p-value
Remaining life(LE_no)				
	3 months (baseline)	-	-	
	12 months	0.451	0.042	0.000
	24 months	0.665	0.045	0.000
	36 months	0.729	0.044	0.000
	60 months	1.202	0.049	0.000
Health status (QoL_no)				
	50%(baseline)	-	-	
	100%	0.633	0.044	0.000
Life extension when treatment is received (LE_gain)				
	0 month (baseline)	-	-	
	1 month	0.253	0.062	0.000

Attribute	Level	Coefficient	SE	p-value
Improvement of health status when treatment is received (QoL_gain)	2 months	0.428	0.063	0.000
	3 months	0.742	0.056	0.000
	6 months	0.940	0.056	0.000
	12 months	1.097	0.058	0.000
	0%(baseline)	-	-	
	25%	1.080	0.047	0.000
	50%	1.343	0.054	0.000

Moreover, expected effectiveness level increased as life was extended if one received treatment (LE_gain) or the level of health status (QoL_gain) increased.

The results which were applied to the 110 profiles that were selected in the full factorial design based on the results of the conditional logit model analysis have been presented in (Table 5-3). The expected probability of selection and utility score were calculated for all the possible types of profiles. The selection probability of each profile was standardized and then summed to generate a value of 1.00.

Regarding the baseline profile for comparison of individual profiles, life expectancy was set at 24 months when treatment is not received, and health status was set at 100%. A case in which life expectancy increased by 3 months when treatment was received was used as the baseline profile⁶⁾.

⁶⁾ This baseline profile is a baseline of treatment in NICE in the UK and the present study referred to it.

The findings showed that the baseline profile was in 57th place among 110 profiles. Among 56 profiles with a higher utility score than the baseline profile, 43 profiles were related to slight improvement in the health status (QoL_gain) (76.8%).

In contrast, among the 53 profiles that were ranked lower than the baseline profile, 17 profiles were related to a slight improvement in health status (QoL_gain).

Top ranked profiles showed substantial life extension or improved health status. Those ranked 1 to 25 were those in which life was extended. The profiles in which health status improved ranked from 1 to 34, except for the 12th, 16th, and 25th place.

Cases in which the health status did not improve despite life extension by 1-3 months fell in the bottom 10 profiles. Thus, respondents were very unlikely to select a treatment when there was no improvement in the health status.

〈Table 5-3〉 choice probabilities and utility scores regarding profile

Rank	LE_no	QoL_no	LE_gain	QoL_gain	Utility	Probability	Cumulative probability
1	60	50	12	50	4.5817	0.0356	0.0356
2	60	50	6	50	4.4845	0.0323	0.0680
3	60	50	12	25	4.3193	0.0274	0.0954
4	60	50	3	50	4.2268	0.0250	0.1203
5	60	50	6	25	4.2222	0.0249	0.1452
6	24	50	12	50	4.0439	0.0208	0.1660
7	36	50	12	50	4.0439	0.0208	0.1868
8	60	50	3	25	3.9645	0.0192	0.2060
9	24	50	6	50	3.9468	0.0189	0.2249
10	36	50	6	50	3.9468	0.0189	0.2438

Rank	LE_no	QoL_no	LE_gain	QoL_gain	Utility	Probability	Cumulative probability
11	60	50	2	50	3.9124	0.0182	0.2620
12	60	100	12	0	3.8718	0.0175	0.2796
13	12	50	12	50	3.8303	0.0168	0.2964
14	36	50	12	25	3.7816	0.0160	0.3124
15	24	50	12	25	3.7816	0.0160	0.3284
16	60	100	6	0	3.7747	0.0159	0.3443
17	60	50	1	50	3.7379	0.0153	0.3596
18	12	50	6	50	3.7332	0.0152	0.3749
19	24	50	3	50	3.6891	0.0146	0.3894
20	36	50	3	50	3.6891	0.0146	0.4040
21	36	50	6	25	3.6844	0.0145	0.4186
22	24	50	6	25	3.6844	0.0145	0.4331
23	60	50	2	25	3.6501	0.0140	0.4471
24	12	50	12	25	3.5679	0.0129	0.4600
25	60	100	3	0	3.5170	0.0123	0.4723
26	60	50	0	50	3.4845	0.0119	0.4842
27	60	50	1	25	3.4756	0.0118	0.4960
28	12	50	3	50	3.4755	0.0118	0.5078
29	12	50	6	25	3.4708	0.0117	0.5195
30	36	50	3	25	3.4268	0.0112	0.5308
31	24	50	3	25	3.4268	0.0112	0.5420
32	3	50	12	50	3.3793	0.0107	0.5527
33	24	50	2	50	3.3747	0.0107	0.5633
34	36	50	2	50	3.3747	0.0107	0.5740
35	24	100	12	0	3.3341	0.0102	0.5842
36	36	100	12	0	3.3341	0.0102	0.5945
37	3	50	6	50	3.2821	0.0097	0.6042
38	60	50	12	0	3.2391	0.0093	0.6135
39	36	100	6	0	3.2370	0.0093	0.6228
40	24	100	6	0	3.2370	0.0093	0.6320
41	60	50	0	25	3.2222	0.0091	0.6412
42	12	50	3	25	3.2131	0.0091	0.6503
43	60	100	2	0	3.2026	0.0090	0.6592
44	24	50	1	50	3.2002	0.0089	0.6682

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Rank	LE_no	QoL_no	LE_gain	QoL_gain	Utility	Probability	Cumulative probability
45	36	50	1	50	3.2002	0.0089	0.6771
46	12	50	2	50	3.1611	0.0086	0.6857
47	60	50	6	0	3.1419	0.0084	0.6942
48	12	100	12	0	3.1205	0.0083	0.7024
49	3	50	12	25	3.1169	0.0082	0.7107
50	24	50	2	25	3.1124	0.0082	0.7189
51	36	50	2	25	3.1124	0.0082	0.7271
52	60	100	1	0	3.0281	0.0075	0.7346
53	3	50	3	50	3.0245	0.0075	0.7421
54	12	100	6	0	3.0233	0.0075	0.7496
55	3	50	6	25	3.0198	0.0075	0.7571
56	12	50	1	50	2.9866	0.0072	0.7643
57	24	100	3	0	2.9793	0.0072	0.7715
58	36	100	3	0	2.9793	0.0072	0.7787
59	36	50	0	50	2.9468	0.0069	0.7856
60	24	50	0	50	2.9468	0.0069	0.7925
61	36	50	1	25	2.9379	0.0069	0.7994
62	24	50	1	25	2.9379	0.0069	0.8063
63	12	50	2	25	2.8987	0.0066	0.8129
64	60	50	3	0	2.8843	0.0065	0.8195
65	12	100	3	0	2.7656	0.0058	0.8253
66	3	50	3	25	2.7621	0.0058	0.8310
67	12	50	0	50	2.7332	0.0056	0.8366
68	12	50	1	25	2.7242	0.0056	0.8422
69	3	50	2	50	2.7101	0.0055	0.8477
70	36	50	12	0	2.7013	0.0054	0.8531
71	24	50	12	0	2.7013	0.0054	0.8586
72	36	50	0	25	2.6844	0.0053	0.8639
73	24	50	0	25	2.6844	0.0053	0.8692
74	3	100	12	0	2.6695	0.0053	0.8745
75	36	100	2	0	2.6649	0.0052	0.8797
76	24	100	2	0	2.6649	0.0052	0.8850
77	36	50	6	0	2.6042	0.0049	0.8899
78	24	50	6	0	2.6042	0.0049	0.8948

Rank	LE_no	QoL_no	LE_gain	QoL_gain	Utility	Probability	Cumulative probability
79	3	100	6	0	2.5723	0.0048	0.8996
80	60	50	2	0	2.5699	0.0048	0.9044
81	3	50	1	50	2.5355	0.0046	0.9090
82	36	100	1	0	2.4904	0.0044	0.9134
83	24	100	1	0	2.4904	0.0044	0.9178
84	12	50	12	0	2.4877	0.0044	0.9222
85	12	50	0	25	2.4708	0.0043	0.9265
86	12	100	2	0	2.4512	0.0042	0.9307
87	3	50	2	25	2.4477	0.0042	0.9349
88	60	50	1	0	2.3953	0.0040	0.9389
89	12	50	6	0	2.3906	0.0040	0.9429
90	24	50	3	0	2.3465	0.0038	0.9467
91	36	50	3	0	2.3465	0.0038	0.9505
92	3	100	3	0	2.3146	0.0037	0.9542
93	3	50	0	50	2.2821	0.0036	0.9578
94	12	100	1	0	2.2767	0.0036	0.9614
95	3	50	1	25	2.2732	0.0035	0.9649
96	12	50	3	0	2.1329	0.0031	0.9680
97	3	50	12	0	2.0367	0.0028	0.9708
98	36	50	2	0	2.0321	0.0028	0.9736
99	24	50	2	0	2.0321	0.0028	0.9763
100	3	50	0	25	2.0198	0.0027	0.9791
101	3	100	2	0	2.0002	0.0027	0.9818
102	3	50	6	0	1.9395	0.0025	0.9843
103	36	50	1	0	1.8576	0.0023	0.9867
104	24	50	1	0	1.8576	0.0023	0.9890
105	3	100	1	0	1.8257	0.0023	0.9913
106	12	50	2	0	1.8185	0.0022	0.9935
107	3	50	3	0	1.6819	0.0020	0.9955
108	12	50	1	0	1.6440	0.0019	0.9974
109	3	50	2	0	1.3675	0.0014	0.9988
110	3	50	1	0	1.1930	0.0012	1.0000

6

Conclusion

This study explored the health care expenses at the end-of-life, presented the results of a survey on perceptions regarding end-of-life care, and measured social values regarding end-of-life care through a survey that employed an experimental design.

Regarding death and end-of-life plan, only 60.4% of the respondents said that they talked comfortably with their family and friends, and 70.6% of the respondents said they wanted to know when they were on the verge of death from the disease. Respondents said that disease pain relief (26.0%) and excellent hospital treatment (24.7%) were the most important at the end-of-life. Respondents said that they considered having no pain during end-of-life care (33.3%) as the most important. Furthermore, regarding decision making for life extension, most respondents wanted to make the decision themselves (37.3%), followed by doing the same along with the doctor (33.5%). The response, “I want to continuously receive hospital treatment even though the possibility of survival at the end of life (6 months before death) is low,” accounted for 43.44% (45.4% for those aged over 65 years), while the response “I’d like to choose dignity” accounted for 58.14% of the responses.

Regarding health care priorities, social preference about priority for treatment for an end-of-life patient was mainly examined. The results of the analysis on the selections made by adults aged over 30 years implied that they prioritized patients whose health status improved through treatment. Furthermore, regarding the selected profiles that are ranked the highest, alternatives that can increase life expectancy by more than 12 months or health status by more than 50% were selected. On the other hand, the probability of selecting treatment for patients whose life expectancy could not be increased by 1 or 2 months or health status improvement (0%) could not be expected was low.

When facing allocation of resources for end-of-life patients, prioritization of health care is required. Particularly in case of patients whose health status is unlikely to improve and life is unlikely to be extended, many medical problems and policy issues are involved. Particularly, as the condition of patients who are on the verge of death could vary, it is difficult to clearly distinguish between aggressive chemotherapy and palliative care stages. However, health policies and related systems that could relieve patients' pain before death, and reduce the emotional, social, and economic burden on the family, and alleviate the socioeconomic burden arising due to the inadequate use of care, by improving the quality of life of terminal cancer patients and institutionalizing to prevent meaningless life pro-

longing treatment, are needed.

As confirmed by the results of this study, there is a need to prepare various conditions in which patients are managed more actively at medical sites, within a framework of hospice palliative care.

For this, first, a reimbursement rate system or hospice palliative support system should be established for terminal cancer patients, and the phases for functional conditions for the same need to be clarified. Additionally, such a system should be extended to other chronic diseases. Moreover, continuous discussion and social consensus on well-dying is required. Thus, it is essential to create a social environment and system that allows patients to meaningfully enjoy the remaining life rather than experiencing pain due to unnecessary treatment and meaningless life prolonging care.

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