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End-of-Life and Hospice Issues in Korean Aging Society*

Yi-Jong Suh | SEOUL NATIONAL UNIVERSITY

This paper deals with legal and institutional aspects of end-of-life and hospice issues in Korea. With the high speed of aging in Korean society we face end-of-life issues and policies at the terminal stage. Policies on life-sustaining treatment decisions to death in later life were developed from the 2000's and legislated into the Cancer Control Act in 2010. It was not until February 2016 that the Cancer Control Act was a legal provision of hospice and palliative care even for terminal cancer patients. The Cancer Control Act made an impact on the institutional and financial situations of hospice and palliative care. The first impact is a medical care-centered care flow and a transfer model for hospice and palliative care. Public policies focus on hospice services inside general hospitals, so that independent hospice centers or community services are underdeveloped. The second impact is a patient-initiated decision model into hospice and palliative care. Physicians had no legal obligation to explain to patients their terminal situation and prognosis and could inform them only when they choose Therefore, it was not until July 2015 that hospice and palliative care was covered by the public health insurance system.

Keywords: *hospice and palliative care, end of life, aging society. hospice center, life-sustaining treatment decision*

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Introduction: Korean Aging Society with a High Speed of Aging

Korean society is quickly becoming a super-aged society due to a higher speed of aging. The population of older adults is rapidly growing. Population of 65+ yet remains 13% of entire population in 2015, but it will grow to 28% in 2035 and to even more than 38% in 2055. In a vortex of these rapid aging, not only the number of young elderly (65-79) but also of older elderly (80+) is growing fast among older adults. Older adults of 70+ are estimated to increase from 8% in 2015 to 20% in 2035, and even to 31% in 2055, while older elderly of more than 80 years old are estimated to increase from less than 3% in 2015 to 16% in 2055.

This growing number of older adults causes a radically changing national population structure with lowest fertility rate. In <Figure 1> we can see a flood of the largest age group moving from 40's and 50's in 2015 to 50's and 60's in 2025 and even to 60's and 70's in 2035.

It is emphasized that a high speed of aging in the national population structure requires a systematic need for end-of-life policies. Health statistics in 2014 shows us a rapidly growing mortality at an older age and more chronic diseases such as malignant neoplasm and circulatory organ system diseases especially at older age,[1] which amount to as much as 47% among causes of death. We can, however, see a greater variety of chronic diseases as causes of death at older ages of 80+.

In a rush to becoming an aged and super-aged society, Korean society is facing various end-of-life and related later-life issues, in which we can see a

TABLE 1
Changing Subgroups of Older Adults in 2015-2055

	2015	2025	2035	2045	2055
65+	13.08%	19.87%	28.42%	35.06%	38.40%
70+	8.89%	12.75%	20.55%	27.55%	31.48%
75+	5.49%	7.90%	12.99%	19.53%	23.64%
80+	2.78%	4.46%	6.76%	12.14%	16.15%

Source.—National Statistics of Population Change in the Future (2015)

[1] Growing mortality from cardiovascular diseases was considered as a characteristic of the Korean health situation among OECD countries (OECD 2015).

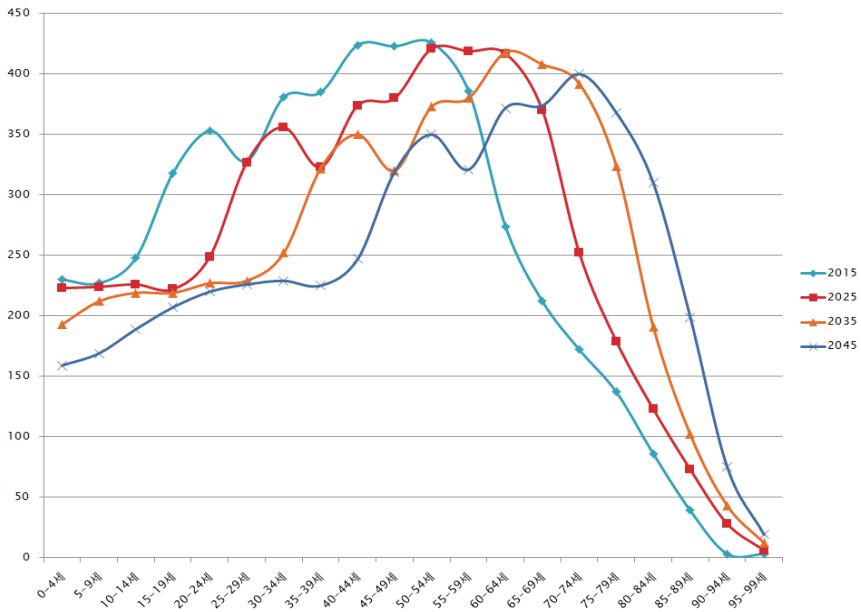

Fig. 1.—Population Change according to Age Group in 2015-2045

TABLE 2
Causes of Death among Older Adults in 2014(Unit: per 100 thousand persons)

	65-69	70-74	75-79	80+
Malignant Neoplasm	435.3	690.5	1.049.8	1,524.1
Circulatory Organ System Diseases	176.9	375.4	762.2	2,311.1
Respiratory System Diseases	58.1	138.9	332.2	1,188.7
Endocrine/Metabolic Disorder	45.7	93.7	171.0	371.3
Gastrointestinal Diseases	39.6	61.5	103.2	255.2
Other Causes except Diseases	96.2	136.1	201.8	388.5
Total	971.8	1,751.2	3,193.5	8,597.5

Source.—National Statistics of Causes of Death in 2015

basic limit of cure-oriented health policies. Aging can be considered as the natural lifespan from various chronic diseases and disorders[2] to death.

[2] Chronic diseases are defined as diseases which are incurable within 3 months by the US National Committee on Chronic Illness. They are called "Non-Communicable Diseases" by the WHO, and "Lifestyle Diseases" in Japan.

Modern medicine has no almighty power in preventing and curing a growing number of various chronic diseases approaching death itself in later life. Ethically following natural process from chronic diseases to death in later life is a core of end-of-life issues (President's Council on Bioethics 2005; Center for Bioethics/UM 2005). In public policies for facilitating care flow institutionally from comprehensive care of chronic diseases at old age to well-dying, a hot issue is now the underdevelopment of hospice and palliative care, especially for elderly Koreans, in comparison not only with American and European countries, but also with East Asian countries such as Japan and Taiwan.

Palliative care means a person-centered care approach to withhold unnecessary aggressive medical treatment and to alleviate the pain and suffering with social, psychological and spiritual care. Hospice means more than palliative care; it's an integrative service approach to promote a patient's and his family's quality of life, not only with palliative medical care but also with social, psychological and spiritual care. Palliative care is, naturally, a person-centered approach to be implemented not only near the end of life, but also in the entire medical process with active cures.[3] This practice of palliative care is not only a care for the patient's quality of life; it is a paradigm shift that a goal of medical practices is not in curing a patient's diseases, but in promoting patient's quality of life (Callahan 2000). Most medical physicians consider it as the most pivotal goal of their practices to cure diseases and to help to prolong the lifespan of patients in the hospital setting. The problem related to a paradigm shift into hospice and palliative care comes to the fore at the point when a physician's practices offer no more positive effects against a patient's diseases (Council on Ethical and Judicial Affairs 1999). Most medical experts think that all possible tools and practices should be used even for naturally dying old men. From that viewpoint, more than 73% of Korean people meet their death at hospital, although only 16% want to do so.[4]

If life-sustaining tools such as a resuscitator or a ventilator would offer a patient no more meaningful life and only prolonging lifespan of pain, we could cast doubt on the legitimacy of these practices. At any point of curing diseases, we have a mind that death is a natural process of patients. The

[3] The World Health Assembly proposed a sentence of strengthening of palliative care as a component of integrated treatment within the continuum of care on 23 January 2014.

[4] According to a Survey of Health Care by National Health Insurance Service Agency in August 2014, 57.2% of 1,600 survey respondents want to die at home, while only 16.3% want to die at a hospital.

WHO recommended that palliative care should be expanded from care near the end-of-life to all medical processes together with active treatment (WHO 2002). Hospice and palliative care regains new meaning in the medical setting especially because of changing medical attention from the patient's disease to the patient himself and even his quality of life. At his end of life there is a need to avoid more unnecessary treatment and a need for alternative cares such as relaxation and control of pain and symptoms, and socio-psychological and spiritual care. Therefore, "hospice" means a philosophically new, person-centered, so-called quality-of-life centered approach rather than disease-centered medical approach, and not only a medical but an integrative approach of medical and social care.

Hospice Services in History and Revision of Cancer Control Act

Hospice has been already internationally popular since its establishment by the Little Sisters of Mary (Piccola Compagnia di Maria) in England in 1867. In the US there are more than 5,500 hospice facilities, and 44.6% of total deaths were reported in these facilities.

Like this international context, the Little Sisters of Mary had a pivotal role in beginning hospice service for dying persons in Korea. The Korean Catholic church invited the Austrian Little Sisters and established Calvary Hospital as an independent hospice facility at 1965 in Gangwon province. Sisters offer hospice care services there, and additionally developed home-visit hospice care. It was, however, not until the late 1980's that Korean people knew of hospice services other than the small Calvary Hospital. Evangelical groups played a role in offering hospice services in Seoul. In 1987, the nursing department at Yonsei University began home-visit hospice care services with the help of American missionary Marian Kingsley and developed a network of hospice facilities and experts in 1991. This group focused on hospice education for expanding human resources and services. These educational activities were up-graded and internationally certified; for example, the educational center of the Catholic Nursing School was recognized and developed into the Collaborating Center of Hospice and Palliative Care by the WHO. A Buddhist group was the last major religious group that began hospice services in 1995.

Based on charitable religious activities and the recommendation of the WHO, the Korean government started to work on legislation for hospice

services only in 2002. The Ministry of Public Health and Welfare had a plan for promoting hospice services as a comprehensive policy plan against elderly diseases and for health promotion. Public health policy focused on cancer as an exceptionally common cause of death in Korea.[5] From 2003-5 it developed a pilot project of hospice services foremost for terminal cancer patients, and tried to legislate it in a revision of the Cancer Control Act. After the second pilot project from 2006-8, the Ministry developed a pilot project of financial support from National Health Insurance and finally made a revision to the Cancer Control Act in May 2010, in which hospice services could be used by the terminal cancer patients if they wanted it.

This revision of the Cancer Control Act is basically a legal and institutional breakthrough to open a nationwide "care flow" towards hospice and palliative care. But the Cancer Control Act is foremost a legal provision for cancer research, prevention and treatment, and, with its revision in 2010, of hospice the palliative care, particularly for terminal cancer patients. The revised Act, however, might demonstrate a tension between active cancer treatment and inserted palliative care from a perspective of legal orientation. In the hospital setting, most oncologists with more interest in cure basically have a conflict of interest with their patients who want hospice and palliative care for their quality of life. From this innate dilemma there is in the Act no concept of hospice, but only of palliative care in services and facilities for terminal cancer patients. Additionally, palliative care in the Act is only for terminal cancer patients particularly who want to use it (§20). This act specified no legal obligation of medical physicians to inform and to explain to patients their medically incurable situations with a prognosis of their diseases. It means no legal provision of informed consent for patients' choice of palliative care. This act is only a declaration of governmental responsibility for providing terminal cancer patients hospice and palliative care different from normal treatment if they themselves want to do it. According to the Act, hospice and palliative care facilities could be recognized institutionally and financially by the government, but underdeveloped under little institutional and financial support.

[5] In OECD statistics of death causes in 2009, Korea is an exceptional country in which cardiovascular diseases were not higher, but cancer was higher among OECD countries (OECD 2015, p. 173)

Hospice Services for Terminal Cancer Patients with Little Institutional Support

Hospice and palliative service is legally permitted only for terminal cancer patients under the Cancer Control Act. They can choose and receive hospice and palliative care if they want it. According to this Act the government has provided institutional support for it, with official permission for palliative care units in general hospitals. Hospice and palliative care facilities are, however, institutionally underdeveloped; there was a slight increase to1,009 beds in 60 facilities up until August 2015, but the increase almost stalled because of little financial support. Most hospice facilities are organized and operated by religious groups and public medical facilities in a charitable way: most all with donation and volunteers.

This result leads to a situation in which only 13.2% of total terminal cancer patients used hospice facilities in their end of life in 2014. This usage rate seems to be increasing in comparison with 9.1% in 2009, but yet it remains low.

This may be explained in the context of the special life culture of Koreans. Koreans have a long history of brutal experiences such as Japanese colonization and the civil war at the beginning of modern society. In those difficult situations Koreans kept up their relatively strong will for living. A survey result in <Table 4> clearly reveals a hidden self-deceptive desire of aged persons for life-sustaining treatment in response to their family's cases more than "their own" cases.

That strong will for living seems to be reinforced by familial culture of filial piety (Hyo) in the setting for life-sustaining treatment decision. Life-

TABLE 3
Palliative Care Units for Terminally Ill Cancer Patients

	No. of Facilities		No. of Beds		Average No. of Beds per facility	
	2014	2015	2014	2015	2014	2015
Higher General Hospital	13	14	182	209	14	15
General Hospital	28	31	441	504	16	16
Hospital	5	6	132	169	26	28
Clinic	8	9	128	127	16	14
Total	54	60	883	1,009	-	-

TABLE 4
Public Opinion about Withholding Life-Sustaining Treatment[6]

	If you were terminally ill	If your family were terminally ill
Aged Persons	73.53%	52.94%
Medical Experts	80.99%	91.73%
Care Workers	76.47%	82.35%

Source.—Suh et al. 2014: p. 76-8

sustaining treatment in Korea is decided by family members' common opinions, therefore often finally decided by one member with a mind of supporting his parents' life sustaining treatment at any situation, because even this voice of a family member in support of life-sustaining treatment has more moral power from filial piety culture. This characteristic is inclined to support life-sustaining treatment more often than not in average attitudes of family members. Despite public opinions favoring withholding of life-sustaining treatment, it is general that Koreans continue such treatment instead of hospice and palliative care, even at terminal stages.

We can find out other reasons for institutional underdevelopment of hospice and palliative care. There are various types of hospice services: hospice centers in general hospitals, independent hospice center separated from general hospitals and home-based hospice care services. In reality, most hospice centers in Korea are yet inside general hospitals, because of care flow for cancer patients and of governmental policies. Most cancer patients are at first diagnosed with their terminal situations at a community hospital. However, they visit higher-quality hospitals and try to get more authorized confirmation of their terminal situations there. A problem is that they try to remain at that hospital although they can expect no more benefits from medical practices. It is mostly due to their need of active life-sustaining treatments, but also due to their anxiety about reliable medical care in emergency situations nearing death at neighboring community hospitals. This is reinforced by relatively low medical cost at high-quality general hospitals under the public health insurance system. From an outside perspective, general hospitals have no choice but to have internal hospice and palliative care centers for terminal cancer patients in order to governmentally

[6] This survey of bioethics and politics of the elderly surveyed 200 persons among older adults, 121 persons among medical experts, 102 persons among care workers and 219 persons among other groups January 14-February 10, 2014.

certify their own cancer centers that lead to more profits. Therefore, in reality they try to reduce hospice beds because of low profits in a comparison with the ICU and hospice and palliative care center among cancer centers.

A legal provision of hospice services only to terminal cancer patients partly supports an integrated model of ICU and hospice and palliative care because of a need of systematic transfer from ICU work to reliable palliative care, particularly for terminal cancer patients (Nelsen et al 2010). But this integrated model yet tends to be dominated by critical care clinicians and minimizes palliative care. It is, moreover, difficult to move into next stage: a hospice and palliative care unit, because of underdevelopment of palliative care teams in the ICU. In some cases of a transfer to an independent hospice center, it is not until 23 days on average that terminal cancer patients die there (Yun 2014). The unreasonable fact that among dying persons 76.7% died at hospitals reveals that most terminal cancer patients stay still until their death without hospice services.

For terminal cancer patients there is a need for a convenient transfer system from the ICU to a regional hospice center or an independent hospice center and even to home-based services. Independent hospice centers separated from general hospitals play a critical role for improving hospice

TABLE 5
Cases of Independent Type of Hospice Centers in Korea

	Mohyun Hospice Center	JajaeCare Hospital
Operating Subjects	Catholic religious group	Buddhist religious group
Type of hospital	Recognized hospice center for terminal cancer patients	Unrecognized hospice center for all terminal ill patients
Year of Establishment	1990 (recognized as special hospice center in 2008)	2008
Number of Beds	16	107 (hospice patients 18)
Medical Doctors (others)	1 (22)	2 (35)
Social Care Programs	15	10
Volunteers	25	20

services[7] because of their outstanding environment and services at regional and community level, Most independent hospice centers such as Calvary Hospital, Mohyun Hospice Center, Jajae Care Hospital, or Saemmul Hospice Center, etc. were established and operated by Catholic, Evangelical and Buddhist religious groups in a charitable way. Many social and spiritual services and programs are covered there and are being developed now.

Hospice Services for Terminal Cancer Patients with Little Financial Support

All Koreans are protected universally under the public health insurance system, and therefore they can easily visit hospitals, especially higher-quality hospitals, more often than other advanced countries (OECD 2015, p. 121). The aging trend seems to offer a challenge to the sustainability of the universal health insurance system because older adults have serious and chronic diseases more often (Hyun et al. 2012). In 2011, older adults 65+ accounted for 10% of the entire population but accounted for 33% of medical expenses, while in 2014 they were 12% of the population but accounted for 36.3% of medical expenses. It is estimated that their medical expenses will reach 45.6% in 2020 (Park et al. 2011). This trend has been accelerated according to the higher speed of aging. Even with a different medical expense structure, 87.0% of total medical costs for the Top 8 diseases were covered by public health insurance (Seo et al 2013, p. 91). Musculoskeletal diseases, cardiovascular diseases, malignant neoplasm including cancer, and neural psychiatric diseases, which are common at old age,[8] have higher costs. Aging itself has basically negative influence on sustainable universal health insurance. Medical expenses of older adults were annually increasing at the rate 17.2% higher than that of the general populations which was increasing 9.99% during 2001-2011 (Hyun et al. 2012).

It should be remembered that higher medical expenses are inclined to be paid before death.[9] In Korea, a similar trend was found out according to the

[7] An independent hospice center has the highest preference among Koreans (Choi et al 2014, p. 310)

[8] In older adults aged 65+ the ratio of getting hypertension reached 53.0% against 13.1% of the general populations, while that of getting degenerative arthritis reached 34.0% against 7.0% according to health statistics in 2011 (Yun 2015).

[9] In the US 60% of the total medical cost was paid within 90 days before death, and 36% was paid within 30 days (Bruntin et al. 2004). In another paper, with Medicare, 30% was paid one year before

TABLE 6
Trend of Medical Expense Structure Before Death (Unit: Thousand Won)

	Total Cases		Hospitalized Cases	
	Male	Female	Male	Female
1 Month	3,064	2,568	4,042	3,386
4 Months	1,490	1,399	3,673	3,252
7 Months	1,030	981	3,016	2,689
10 Months	856	850	2,826	2,571
13 Months	712	711	2,627	2,353
16 Months	621	637	2,499	2,297
19 Months	555	571	2,436	2,181
22 Months	509	530	2,339	2,115
25 Months	463	493	2,305	2,134

Source.—Lee et al, 211: 146.

statistics of medical costs of deaths in 2011: medical cost increased from one year before death and rapidly increased 6 months before death.

Medical costs paid before death were the highest for terminal patients. If we focus on medical cost paid 3 months before death, malignant neoplasm, including cancer, has the highest cost, at 9,122 thousand Korean Won, with cerebrovascular diseases at 6,343 thousand Won. Cardiovascular diseases cost 3,718 thousand Won, and others cost 4,904 thousand Won (Lee et al. 2011). These results reveal an economic reason for implementing hospice service foremost for terminal cancer patients (Suh et al. 2015, p. 97).

For comprehensive management of cancer patients, the government began a pilot project for financial coverage of hospice and palliative care in public health insurance with a trial for legal implementation of hospice and palliative care. From 2009-2011, 7 hospitals participated in the first project, and from 2011-2014, 20 hospitals participated in the second pilot project in order to develop the insurance unit cost of hospice and palliative care. After the pilot projects, hospice and palliative care are covered by public health insurance with more realistic payments from July 2015.As is shown in <Table 7>, it is covered by a basic payment of 161-186 thousand Korean Won (US$ 130-155) per day and a caregiver cost of 80 thousand Won (US $66), etc.

However, this public coverage has problems: first, hospice services are

death (Shugarman et al. 2009).

TABLE 7
Public Health Insurance Coverage of Medical Cost for Example of Hospice Patient Using a 5-person room during 17 days of Hospitalization

	Pilot Project	Real Coverage from July 15, 2015
Daily Pay	Basic Pay 133,280 Won/Day	Basic Pay 161,539 Won/Day
	Additional 12,220 Won/Day (To Hospital with Nursing Specialist) 3,360 Won/Day (To Hospital with Social Worker)	Additional 17,210 Won/Day (To Hospital with Nursing Specialist) 7,919 Won/Day (To Hospital with Social Worker)
		Caregiver 80,000 Won/Day
Other Coverage	Meal Pay 9,037 Won/Day	Meal Pay 9,037 Won/Day
		Narcotics 12,372 Won/Day

Source.—Suyoung Chu, Coverage Trend of Hospice & Palliative Care in Public Health Insurance. Feb. 25th 2015.

covered inside a fixed total payment per day. Hospice centers cannot try to develop and provide many new services financially, except volunteer activities. Poor dying persons have no choice but minimal services because of private payment of all over-costs. The core problem is an unrealistically low level of fixed total coverage. The second problem is the medical care-centered coverage system. Not only medical, but also social and spiritual care is needed for a terminal patient; all psychosocial and spiritual care is not covered except at an unrealistically fixed total cost. The latter can be covered under long-term care insurance. Public health insurance and long-term care insurance are operated in totally separate ways because the government wants to protect its financial soundness by preventing elderly patients from receiving dual benefits. But this separated operation has barriers to offering an integrative service, especially in hospice facilities.

Challenges from an Enactment of a New Hospice and Palliative Care Act

Hospice service can be used institutionally only by terminally ill cancer patients under the Cancer Control Act. Since Korean government's trials of

hospice for terminal cancer patients, there was a long history of trials for expanding hospice service for all terminally ill patients from 2008, but they ended in failure. The new Hospice and Palliative Care Act is now in legislation as a basic act for offering hospice service to all terminally ill patients with financial support. After many legislation failures, this Act was supported once more by more than 10 thousand persons including opinion leaders with their signature and proposed to Parliament in April 2015. It was not until February 2016 that this Act was passed and promulgated at the front of the high speed of aging.

Although this new Act takes over hospice items in the Cancer Control Act, it is characterized as follows: first it will lay a legal basis for expanding hospice service to all terminally ill patients. In the US, hospice service was used foremost for terminal cancer patients and expanded to other terminally ill patients; cancer patients used 40.1% of entire hospice services, while debility-unspecific patients used 13.1%, heart patients used 11.5%, dementia patients used 11.2%, lung cancer patients used 8.2%, etc. in 2009. The WHO recommended hospice service not only to cancer patients, but also to sufferers of Alzheimer's diseases, dementia, cardiovascular diseases, diabetes, renal failure, chronic respiratory failure, Parkinson's neurosis, Parkinson's disease, rheumatic joint disorders, drug-resistant tuberculosis, etc. The new Act includes AIDS, chronic respiratory failure and chronic liver cirrhosis, and makes a decision of gradual expansion, finally, into 9 non-cancer diseases recommended by the WHO. The government should provide a master plan for it because what diseases will be legally and institutionally included will be a socially hot issue. There is a need for standard guidelines of procedures and services according to different patterns of death in each disease.

Second, it offers a legal basis to support an establishment of hospice facilities and their financial expansion at the community level. But the new Act has an assumption of medical care-centered care flow from ICU to hospice facilities. In the new Act, most terminal patients are assumed to stay in hospitals.[10] But hospice service is better used in home- and community-based ways. Most Koreans want to meet their death in a familiar and relaxed environment like home. Therefore, more critical is an incentive or push measure for hospice patients to move from hospice centers near an ICU to regional hospice centers. It can include public support for transfer costs to regional hospice centers or independent hospice centers. In the care flow

[10] In a presentation at hearings of the enactment of the Hospice and Palliative Care Act, even hospice patients were assumed to stay at middle- and higher-level general hospitals (Yun 2015).

there is in reality a problem of oversupply of commercial care hospitals, which try to recognize a hospice facility officially. Therefore, the government should evaluate and certify service levels and facility criteria of hospice facilities strictly, for higher quality. Patients in long-term care facilities should be able to receive medical palliative care from palliative care teams in regional hospice center or public medical center nearby, and social-psychological cares supported by long-term care insurance. Home-visit care service, including hospice service, is yet underdeveloped. Home-visit social and medical care service seems to be difficult to be evaluated and paid by both long-term care insurance and public health insurance plans. But home-visit care services, including hospice services at a community level, are most able to enhance quality of life for older adults before death because of the intimate service environment and the cost saving, from the financial perspective of social insurance plans. Residential long-term care facilities, including "care hospitals," cannot hold additional hospice service, but in reality 40% of older adults using nursing homes die there before moving to a hospital. This reality shows us a situation in which many of the elderly on their deathbeds yet remain in nursing homes without hospice service.

Third, the new Act does not legally obligate physicians to explain terminal situations and prognoses to their patients. Hospice and palliative care services can be received by terminal patients who want it. Physicians can legally inform patients of their terminal situation and prognosis only when their patients want it. Activating hospice and palliative care is dependent only on consciousness and the values of terminal patients and their family members. Even in this legal context, only the government has a legal obligation for publicizing hospice and palliative care to the general population. To implement the new Act in successful way, we need a role not only for the government but also for civil movements for understanding hospice and palliative care well and for participating in it.

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YI-JONG SUH is now professor of Sociology and adjunct professor of STS, Seoul National University. He received his Ph.D. in Sociology from Free University of Berlin. His research interest is in social phenomena related to IT and BT, and he is currently organizing a research group named SSK of Bio-politics of the Elderly (since

2013). *Address*: #16-541 College of Social Sciences, Seoul National University, 1 Gwanak-ro, Gwanak-gu, Seoul, Republic of Korea, 08826. [*E-mail*: yjsuh@snu.ac.kr]