Striving for a Good Death:

End-of-Life Care in a South Korean Tertiary Hospital System

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For My Aunt Jeongsun, Grandfathers, and Grandmothers

For My Parents

And For My Universe, My Daughter, Bom

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While I was in the terminal-cancer ward, I thought about my aunt and grandparents who had passed away. If I had known what I learned in the ward when they were in their last weeks in this world, I could have helped them to experience a better death. I hope my aunt, grandmothers, and grandfathers are peaceful wherever they reside.

All the power to complete this dissertation came from my daughter, Bom, my unalloyed delight, my universe. We were, we are, and we will be happy together.

Abstract

This dissertation explores the practices of a palliative care team in a tertiary hospital in South Korea. A tertiary hospital is an institution where patients with life-threatening diseases come with an expectation of recovery. Due to its mission as an acute care institution and its profit-seeking nature, a tertiary hospital is regarded as an unsuitable place for death. In particular, after a legal case in 1997, Korean doctors were extremely reluctant to stop treatments and, consequently, patients were forced to receive aggressive life-saving measures until the end. The ethnographic research for this dissertation was conducted in a terminal-cancer ward of S Hospital in Seoul, between 2016 and 2018, during the time in which a new law that finally permitted the withdrawal of life-sustaining treatment was introduced into the clinical setting.

Drawing upon this timely fieldwork, I explore the ways in which the palliative care staff endeavors to ensure their patients experience a good death in a tertiary hospital where death is marginalized. First, the legalization of treatment cessation brought into being a new way of dying—in hospitals—that had not officially existed previously in Korea. In order to institutionalize this form of dying within the hospital system, the palliative care staff members take into consideration all the delicate and diverse moral, technological, temporal, and spatial conditions necessary for good dying, in all their unpredictable variety. Second, within a medical system, when the terminal stage of cancer is declared, a sick body is transformed into a dying body. In contrast to this disease-centered configuration of terminal stage cancer, the patients and their families understand this time within their own life histories. Between these two ways of understanding the terminal stage, the palliative care team members negotiate the contested meaning of natural death, struggle to move up the timing of the activation of terminal stage, and strive to make their patients' end of life meaningful. Third, because of the political-geographic inequity of the health care infrastructure, the marginalization of palliative and hospice care, and the profit-seeking nature of hospitals, terminal-stage patients are supposed to move to another place for dying, although they are not always able to do so. In part, the palliative care staff members carry out this displacement as hospital employees, but they struggle to arrange their patients' destinations along with their criteria for good dying—painlessness, family presence, and love. Finally, I define the nature of the care of the palliative care staff as relational-generative care. Through trivial and small actions, the nurses and volunteers not only aim to strengthen family relationships but also generate new relations by linking isolated patients and family members to the palliative care team, to the local community, and to others.

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Chapter One

Introduction

The Beginning of My Story

Doctor Jee Eunsuk, my old friend, and I were having tea. We shared news about our mutual friends and our own research interests. In the middle of the conversation, Doctor Jee, with a twinkle in her eye, said, “Here is an interesting story—and you will like this.” I expressed my interest.

“I heard this story when I attended a funeral. You know, people share stories about death while at funerals, and this story was told by one of my friends there. His father had a stroke and was carried to an intensive care unit (ICU). He was put on a ventilator. An attending doctor said to the family that there was very little hope that the patient would live. The man’s wife and younger son wanted to end the father’s suffering, claiming that he would not have wanted to prolong his life in the ICU. The eldest son, however, would not agree to withdraw the ventilator because he felt as if they were agreeing to make their father die. Can you guess how this argument, which seemed interminable, was finally settled? It was in such a Korean way. The eldest son saw his father in a dream, saying, ‘My son, I don’t want to live this way.’ Eventually, the son changed his mind.”

Dr. Jee burst into laughter when she said, “Korean way.” I also laughed. We both understood that very few Koreans would ignore such a dream.

“This is not the end of the story,” Dr. Jee continued. “Despite the dramatic family agreement, the father still could not rest in peace. Now the attending doctor refused to remove the ventilator.”

“Why?” I asked.

“Once a patient is put on a ventilator, most doctors will not remove the machine, even if the patient has no chance of survival, because doctors can make a profit considerably without needing to cure the patient and because doctors do not want to take responsibility for the patient’s death. So, back to the story of my friend, each member of the family one by one ‘grabbed the doctor’s collar’ every day, requesting the withdrawal of treatment. The doctor finally agreed under the condition that the family never sue him for this withdrawal of treatment. At last, the poor man was allowed to die. When everything was done, all that remained for the family was the large sum of money owed for the period of ICU admission. Anyone who has insight into or has experienced with the massive cost of futile life-prolonging treatments would wait five or ten minutes after her parents have collapsed before calling 119.[1] She would know it is better to let her parents die in peace at home than put them on a machine meaninglessly.”

This story, which led me to studies of death, condenses multifaceted features of death in South Korea. Life-saving technologies are commonly used as a default procedure; the patient rarely had a conversation with his family members regarding his end-of-life care; his family members were supposed to make decisions on behalf of the patient without knowledge of the

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[1] A direct-dial emergency number for fire brigade and ambulance service.

patient's true wishes, which caused family conflict; the doctor was extremely conservative in regard to withdrawing life-sustaining treatment. This story also reveals the prevailing distrust of medical professionals.

Simultaneously, there are some things untold in this story. This story does not suggest that it could be the doctor who was most reluctant to force futile treatment upon the patient. This story does not speak to structures and systems that propelled the actors into certain actions. This story does not show the long route the patient took before being forced to the ICU. Most of all, this story does not show how a specific, new time frame—an "end of life"—has come into being in hospitals or that a new group of specialists now manages the care for those in their end-of-life to avoid the kinds of conflicts that the people in this story experienced.

My story explores both the things told and those untold in the story that Doctor Jee delivered to me, by focusing on practices of palliative and hospice care specialists in a tertiary hospital in Seoul, Korea. Among diverse forms of medical institutions, a tertiary hospital is the pinnacle of the state-of-art medical knowledge and technologies where patients with life-threatening diseases come with an expectation of recovery. Also, a tertiary hospital is an institution in which internal rules that organize the workplace by governing time, space, and its workers' roles intersect with the outside forces that have built the state's healthcare delivery system The entanglement of medical technologies, the hospital system, and the national health care grid produces a segmented time period, "the end of life" and generate particular possible options of dying, all in the context of a tertiary hospital. Here, patients are classified into terminal-stage patients, and the remainder of their lives is called their "end of life," which requires special care and attention.

It is the palliative care staff who is responsible for the end-of-life care. Their ultimate goal is to ensure that a terminal-stage patient experiences a “good death” in the end. And the palliative care staff’s endeavor covers a variety of activities, ranging from mediating conflicts between patients’ relatives and doctors, as seen in Doctor Ji’s story, to moving dying patients to a good place to die, to making the end of life meaningful, and to helping the dying to die in the care of their family. In exploring what a palliative care team’s members do in S Hospital in Seoul, I ask: how does the hospital system produce a good or bad death, and what practices are entailed to make a death good and to turn a bad death to a good one? By the concept of end-of-life care, what does terminal-stage mean, and how is this terminality activated through what practices of care? Ultimately, why do we take care of dying patients and what does this care mean to us, humans?

The extremely conservative atmosphere in the Korean medical community regarding the termination of life-sustaining treatment was in part a reaction to some legal cases over the past two decades in Korea; and, with a law passed in 2016 that allows withdrawal of life-prolonging measures, this atmosphere in medical settings underwent a second transformation. My story is about this very period between 2016 and 2018, in which the new regulations and stipulations were just being introduced in S Hospital, where the research that this dissertation draws upon was conducted. This timely research provides a chance to observe the vivid ethnographic scenes in which the palliative care staff tries to establish a new way of dying as prescribed by the law. I explore the ways in which scientific knowledge and technology, bureaucratic systems, laws, and familial moral imperatives converge on the care practice of the doctors and nurses in a large, complex hospital.

Good Death and Bad Death

Death is the single most private event for humans, in that no one can truly accompany another in her dying process, and no one can die in another's stead. Simultaneously, death is a public affair, in that social relations that a person has established during her lifetime are convened both before and after their death. None of us can avoid this event. Stories of those who live forever are told in tales and folk stories, but these people still seem to live in the tales, not in our present world. So far, every human is born once and dies once. This dissertation is about this universal event, death.

This topic has contributed to the formation of anthropology within modern academia from the beginning of this discipline. To date, the *Annual Review of Anthropology* has published three pieces on the anthropology of death (Palgi and Abramovitch 1984; Engelke 2019, including Kaufman and Morgan's work (2005) that covers both life and death). These three reviews trace back to James Frazer's *The Golden Bough* (1990), which explored the ritual murder of the priestly King, and list Hertz's work (1960) on a secondary burial ritual, Van Gennep's analysis (2013[1960]) of death as a ritual passage, and Malinowski's work (1948) regarding mortuary rites to reintegrate the remaining into everyday life. Although death has not received much coverage in comparison with other topics (for example, its antipodal point, birth), it obviously has never stopped providing cross-cultural ethnographic materials and opportunities to construct theoretical frameworks.

For this long period, which traces back to the ancestors of anthropology, what has received the most attention is the fact that death evokes crises affecting both the collective and the individual. A death banishes one’s presence in the world, changes the previous social relationship to necrosociality (Kim Jieun 2016) between the dead and the living, and agitates the members of the community to which the dead belonged by waking those remaining from a dream of immortality. Departing from this point, as Robben (2004) and Palgi and Abramovitch (1984) argue, scholarship on death has explored how this existential crisis is resolved through symbolic contrivances of funerary and mourning rituals (Bloch and Parry 1982; Huntington and Metcalf 1979), how emotional responses to death and the disposal of corpses are navigated in acceptable ways (Rosenblatt 2001; Wilson 1939), and how people construe death through folk beliefs and superstitions (Ca´tedra 1992[1988]; Martin 1988). Regardless of different theoretical tools and analytical approaches to death, in a broad sense, works in anthropology of death find their niches in one of these threads, and mine is no exception. This dissertation also examines people’s practices that “matter to making death good” (Engelke 2019: 31; Seale and van der Geest 2004: 883).

Death entails moral judgments that assess one’s death as “good” or “bad.” Although what constitutes the “good death” varies from culture to culture and across time (Walter 2003) because ideas of good and bad deaths reflect a society’s cosmogony and morality (Counts and Counts 2004), Bloch and Parry (1982), in their edited volume which covered Hindu, Chinese, Laymi, Merina, and !Kung's death rituals, conclude that whether one's death is associated with regeneration serves as core criteria for good and bad death (Bloch and Parry 1982: 15). In a similar vein, previous studies on "traditional" attitudes toward death in Korea (Song Hyeon-Dong 2006; Choi Kilsung 1986; Lee Dojung 2015) have produced two categories of death: normal death and abnormal death. In normal death, the deceased is eligible to become an ancestor and thus the descendants will remember the dead by performing ancestral rites, *jesa*. In contrast, an abnormal death refers to the death of one who cannot be an ancestor due to their lack of descendants (Song Hyeon-Dong 2005: 233)—i.e., a child and an unmarried (childless) adult (Lee Dojung 2015). Various ritual devices had been developed for the purpose of transforming these abnormal deaths into a normal death (Lee Dojung 2015).

In the Korean language, *hosang* indicates an ideal death, which corresponds with the Euro-American notion of dying in one's own bed (Ariès 2016[1974]), such as an elderly person dying in her own home, surrounded by her relatives (especially her children and grandchildren). In contrast, all deaths outside home were called *gaeksa*, which was considered one of the worst forms of death (Bae Doyong 2018). *Gaeksa* implies that one died in an unfamiliar place at an unexpected moment, without the care and concern that one deserved.

I used quotation marks around the word "traditional" above, to mark a point on a timeline dividing the past and present. When we use qualifiers such as "traditional" or "contemporary," as Brannigan (1999: 290) warned, "it often happens that our images of a specific culture remain historically glued to some obscure, undesignated past, generally constituted as 'traditional.'" By "tradition," I mean that ideas and practices were found only in the literature and analyses of rituals, as the main practitioners of these ideas have already passed. In addition, it is important to understand, as Kellehear states (2007: 159), that there are "many exceptions and much overlap between the different values and styles of dying conduct, even in the same period or culture, despite analytical attempts to extract the social characteristics and distinctions between the styles of dying." For example, *gaeksa*—which was even used as an insult (e.g., "You, who will *gaeksa*!")—rarely appears in everyday life now; neither would contemporary Koreans cry out at a funeral, "No! She is dead without a child to hold a memorial service for her!" At the same time, however, no one in the present would consider premature death normal and favorable, as no one in the past did; young people's deaths always evoke grief much more than those of the elderly. The popular understanding of premature death as bad death has remained, but the implications behind premature death have changed.

Studies on the attitudes toward death among contemporary Koreans show that some of those ideas and customs surrounding normal/abnormal death have been forgotten; some have remained but with different connotations from the past usages; and some have continued. According to survey data (Yun Young Ho et al. 2004), Koreans still consider factors of family with regard to a good death, but these factors are no longer about the existence of descendants or being remembered through ancestral rites (*jesa*); rather, Koreans consider not being a burden to family members and being with family members at the last moment as the most important conditions of good death. One's home still remains the most favorable place for death to occur (54.8%), but not overwhelmingly so, given that preference for home death at the global scale ranged from 59% to 81% (Higginson and Sen-Gupta 2000). Given the strong avoidance of *gaeksa* in the past, the increase of preferences for end of life to unfold in medical institutions (hospitals: 28.0%, hospices: 7.95%, nursing homes: 6.5%) is noteworthy. In addition, Koreans prefer homes not because of *gaeksa* avoidance (4.5%) but in order to be with their loved ones (68.4%).

A literature review (Min Deulle and Cho Eunhee 2017) extracts the core attributions of good death in Korean society as follows:

> (1) The preparation stage for death: living sincerely, preparing for dying (e.g., writing a will)
>
> (2) The final stage of death: avoiding meaningless life extension, being respected as a person with dignity, comfort, interacting with healthcare providers
>
> (3) The post death stage: the family members' positive feelings about the death

Whether or not the remaining family members remember and miss the dead with positive feelings is counted as an important factor of good death, but the memorial services conducted by descendants are not directly addressed. The authors also point out that, in the past, preparation for death was equated with preparation for funeral rituals (e.g., preparing a piece of clothing for the dead body, *su-ui*, in advance), whereas the scope of preparation for death has now expanded to living a respectful life. In this study, it is noteworthy that medical technologies and health providers are listed in the final stage of death. It mirrors the reality that medical practice is already deeply entrenched in the story of death as elsewhere (Rubinstein 1995; Seale and van der Geest 2004: 884), and people are not likely to regard using life-sustaining treatment at the end of life as a good death.

Drawing upon this body of literature, I explore the ways in which good and bad deaths are *realized* in hospitals. If the palliative and hospice care specialists seek to ensure that their patients experience a good death, what material conditions and moral values contribute to their assessment of the quality of death? Particularly, I pay attention to a concept of bad, even worst, death that medical technologies and health care system coproduce in hospitals. Given that that good death can only be constructed in antithesis to an image of "bad" death (Bloch and Parry 1982: 18), how does the concept of good death emerge from the context where technology, laws, inside regulations of the hospital, and values collaborate to shape a specific way of dying, which is judged as a bad death? How do the practices to prevent bad and worst deaths become parts of the care the specialists carry out? These questions will shed light on how the choreography of the conceptual ideas about good or bad death, the changing material infrastructure of the conditions of death, and the actions that can be taken to realize the concepts of a good death within the hospital structure have come together to reshape the experience of the end of life and death in Korea today.

Contemporary Hospital Dying

While classic anthropological works examined death from cross-cultural perspectives in synchronic ways, some Euro-American scholars in adjunct disciplines read death in diachronic ways while steering the lens into one's own society, i.e., Euro-American culture. Death is not simply a physical event, for its nature and pattern are shaped by socio-cultural conditions such as the configuration of industry, economic wealth, and general standards of living as well as family structures and lay beliefs (Field 1996: 255; Shepherd 2011). Consequentially, as a society goes through transformations, the accepted way of dealing with death in the given society also changes. From this historical perspective, some scholars have explored the history of death in Euro-American societies. For example, Kellehear (2007) argued that urbanization and the emergence of the middle and upper class in cities changed the practices and ideas of good death; Blauner (1966) analyzed the ways in which demographic changes in the age of death and the extension of life cycles in industrial societies contributed to the isolation of death from ordinary life.

One of the most important achievements of a body of work in this literature is that it extracts some features of modern death that are distinctive from those of previous times. There are some differences in terms of period divisions and labeling within the process of death, but a general consensus can be found. In European cultures, death was an integral part of everyday lives until the nineteenth century. In contrast, death now is less firmly integrated into the daily life of communities, and it has been expelled from domestic places to institutions so as to become nearly invisible in daily life. In the past, the dying presided over the period of their own death, but nowadays the dying have lost the ability to exert control over their own death. The management of death has become the province of medical, religious, and legal experts, including palliative and hospice care specialists (Armstrong 1987; Ariès 2004[1985]; 2016[1974]; Field 1996; Kellehear 2007). In addition, as a component of biopolitics, death is managed by state powers through the production of statistics relating to causes of death, ages and gender of the dead, and places of death, as well as through administrative processes and legal regulations concerning death certificates and permissible forms of burial (Ariès 2004[1985]; Foucault 2007).

Meanwhile, there is another shift in the studies of death, along with the shift from non-Euro-American cultures to Euro-American societies: from death to dying. A large proportion of the earlier literature on death tends to deal with the post-death rituals and thus scrutinizes mortuary rituals, collective responses to bereavement, and memorial rituals and devices. To put it another way, these analyses position death as an event that has already occurred and instead focus on how the living respond to such an event. In this regard, death is likely to appear as a static and momentary event in the past. Consequently, this field has been "sub-disciplined into the anthropology of religion, ritual, and symbolism" (Goodwin-Hawkins and Dawson 2018: 269).

In contrast, the concept of dying has relatively recently emerged as an object of exploration. As indicated in its verb form, dying highlights the process of becoming dead as the threshold of life and death. Once our question alters from how people deal with death after the event has occurred to how people deal with it while the event is occurring, and once we begin asking not about "the dead" but about "the dying," we are able to see that death very often does not occur at one moment but happens gradually, for weeks, months, or years, in diverse forms. Of the considerable duration between a moment of recognition of one's finite existence and a moment of realization of the finite, the ways of social interactions between the dying and surrounding people and the social status of the dying change (Glaser and Strauss 1965; 2007[1968]; Kübler-Ross 1969); the time and place of dying become structured (or are believed to be structured) in a certain way.

It is no surprise that an overwhelming majority of studies on dying have been conducted in medical institutions. With a transformation of disease incidence patterns from acute and infectious to chronic diseases, and the introductions of visual diagnostic technologies, the dying very likely spend their last period of life in hospitals. Hospitals and other medical institutions in charge of professionalization of death have become a primary "field" that provides an opportunity to observe how the dying process is shaped. It is in this field that this dissertation finds its locus.

Recent statistics support the current worldwide status of hospitals as places for dying. In the U.K., a country that is ranked highest in quality of deaths, 49.9% of people died in hospitals, 23.5% at home, 21.8% in care homes, and 5.7% in hospices in 2016. In Australia, about 50% of all deaths occurred in hospitals in 2014. In East Asian countries, nearly 90% of total deaths in Hong Kong, 80% in Japan (Long 2013: 52), 62.5% in Singapore in 2018[2], and 42% in Taiwan in 2008 occur in hospitals. In some countries, including the U.S., a steady and slow decline in percentages of hospital deaths has been observed,[3] but it is still true that in many countries a hospital remains a major institution where deaths occur (Broad et al. 2013).

However, the numerical superiority of hospitals as a popular place for dying is not the only reason to address the practices of such institutions. A hospital is a unique apparatus where knowledge production, bureaucratic grids, power relationships and professional authority, legislation, economic and health infrastructure, and the moral values of life intersect. It is in such institutions that particular cultural-technological forms of dying are produced.

Anthropologists and sociologists have paid attention to the uniqueness of hospital

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[2] https://www.ica.gov.sg/docs/default-source/ica/stats/annual-bd-statistics/stats_2018_annual_rbd_report.pdf

[3] https://edition.cnn.com/2019/12/11/health/dying-at-home-hospital-study-wellness/index.html

systems (e.g., Chambliss 1996; Chapple 2010; Glaser and Strauss 2007[1968]; Kaufman 2005; Rhodes 1991). As with any sort of system, the hospital system shapes the ways in which all people under the power of the system act, speak, and think, and, eventually, how people die within the hospital in specific ways. For instance, Kaufman (2005) analyzed the U.S. hospital system, and she observed two common pathways: a pathway of heroic intervention and one characterized as a revolving door. The former involves aggressive, high-technology measures, while the latter exhausts everyone involved as a patient repeats hospitalizations and discharges for a long time. Once a patient is placed on either pathway, the patient will be moved along its powerful logic, and the operation of this scheme is beyond individual doctors, nurses, and patients' control. In building a hospital system, a variety of forces are in play—ranging from the bureaucratic properties of the hospital to maintain its punctuality and order (Chambliss 1996), to the socialization of medical professionals (Mizrahi 1985), to the macro-infrastructure of insurance policies and medical industrial complex (Chapple 2010; Kaufman 2015), to specific ideologies such as rescue imperatives (Chapple 2010).

Drawing upon this body of literature, I explore how the dying are taken care of or neglected within the hospital system. I consider a hospital as a place where its inherent logic to govern and maintain the organization converges with outside forces and connections. The inherent logic of a hospital includes the way of organizing time (e.g., the rotation intervals of house staff and the regulations of patient stay length); the politics of space (e.g., what department is placed in a corner of the hospital and what dictates the flow of patients through these spaces); the philosophy and concepts of biomedicine; and implicit manners and rules that nowhere are written but the members of the hospital understand.

By the outside forces, I mean that a hospital does not exist as an island but rather as “a paradoxical place, both bounded and permeable” (Street and Coleman 2012). A hospital, as a part of the ordered system of the state, is subordinated to related organizations, such as the Ministry of Health and Welfare and Korean National Institute for Bioethics Policy in Korea, and is responsible for observing laws related to medical care. Also, as a part of the health care delivery system, a hospital must work with other medical institutions.

The landscape of hospital dying in Korea went through a profound shift after 1997, as the result of a lawsuit, the Boramae Hospital Case, and, during my time in the field, a second transformation, which was caused by another lawsuit, the Grandmother Kim Case and subsequent legislation in 2016 regarding the withdrawal of life-sustaining treatment. A new way of dying, which had not (officially) existed before, was about to be institutionalized, and it required a series of changes within the established hospital system, including reimbursement policies, the procedures for dealing with death, and the habitual practices of end-of-life care. Against this background, I ask: how is the end-of-life time framed in the hospital system and cancer treatment regimen? What happens to the patients who are diagnosed as in the terminal stage, in terms of their spatial displacement and the intersubjective understanding of the time period? How do the palliative care team members work to align the relatives of their patients with the end-of-life care as it is now produced within a hospital setting?

Death, Patient Autonomy, and End-of-Life Care Documents

Critiques of contemporary hospital dying focus on life-sustaining treatment. A set of life-saving technologies and techniques, including CPR, the mechanical ventilator, dialysis, and the vasopressor—which cover both low technology and high-technology approaches—are called life-sustaining treatments if they are used to maintain a person's vital body functions in a circumstance where the full-recovery of the person is hardly expected. This set of technologies produce a grey zone betwixt and between life and death (Lock 2002), and a new kind of life that can be characterized as not-dead-but-not-alive (Kaufman 2005). In a number of legal disputes between patients' family members who wanted to stop using life-sustaining technologies for their loved one and doctors who refused the request (or vice versa), there emerged some dramatic images of contemporary bizarre existences who become stuck in this grey area, and stories of family members who suffer from the enormous treatment cost and of patients who are not allowed to rest.

The core of lawsuits surrounding life-sustaining treatment generally does not lie in the technologies per se but rather in the fact that these measures are applied to any patient in hospitals as a default procedure. For the initial period of use for each technology and technique developed, the technology remained extraordinary medicine, rarely employed. Yet, as time goes by, the boundary between ordinary and extraordinary medicine becomes blurred (Kaufman 2015). In addition, the underlying philosophy of mainstream medicine, which Chapple (2010) calls "culture of rescue," compels many parts of life-sustaining treatment to be done in hospital settings as a default procedure, "regardless of the patient's underlying illness and/or ability to survive the procedure” (Marsh and Staver 1991).

As a social argument against this “unnatural, technologized” way of dying has gained power, public discussions of what makes a good death has addressed a right to refuse life-sustaining treatment, which is linked to an emergence of patient autonomy (Beauchamp and Childress 2001). In line with a philosophical transition in a doctor-patient relationship from a paternalistic model to a provider-client model, and a series of social movements—from national self-determination movements, the second wave of feminism, and consumerism in the 1960s (Hattori and Ito 2016[2015])—a patient’s right to decide whether or not to receive a treatment, even if the decision will be against the patient’s benefit, has gained public acknowledgment. As a result, we live in the “time of the triumph of autonomy in bioethics” in which “the law and ethics of medicine are dominated by one paradigm—the autonomy of the patient” (Stirrat and Gill 2005: 127).

This new tide, which underscores choice and self-determination, culminates in the appearance of the legal concept of “informed consent.” The historical background of informed consent originated from the Nazi’s human subject research and reflections on its cruel results, which led to the Nuremberg Code in 1947 (Manson and O’Neill 2007) and was followed by the Helsinki Declaration. It also derived from a series of lawsuits, including Schloendorff v. Society of New York Hospital in 1914 and Salgo v. Leland Stanford University Hospital in 1957, in the U.S. (Hattori and Ito 2016[2015]). The concept of informed consent is rooted in Enlightenment notions of social contracts, and a political philosophy that stresses consent and civil obligation (Manson and O’Neill 2007). The scope of and criteria for informed consent have been extended and strengthened, and regulations in the practice of informed consent have been reinforced (Manson and O'Neill 2007). The underlying idea is that a doctor provides relevant information to a patient, the patient makes a decision on the basis of the information given (even if the decision is against her best interest or her own life), and both parties establish their contract in the form of a signed document.

In the terrain of end-of-life care, a Do-Not-Resuscitate Order (DNR), an advance directive (AD), and Physician Orders for Life-Sustaining Treatment (POLST)—which I call end-of-life care documents—have developed as informed consent forms to provide a chance (or chances) for a patient to decide how she does and does not want to die and for medical staff to respect the patient's wishes. A DNR, which traces back to 1976, is a document to indicate that one does not want to receive cardiopulmonary resuscitation (CPR) if one's heart stops beating. Today, the DNR order has become "a part of contemporary ritual for dying, and DNR is one of the most widely recognized medical abbreviations" (Burns and Truog 2016).

Although the Advance Directive (AD) is known by many names in the U.S.—an advance healthcare directive, living will, personal directive, medical directive, or advance decision—and it differs between countries and within a nation in the scope of its legal force, and whether or not a power of attorney is legally recognized, in general, it is a document in which a person specifies what actions should be taken at the end of life if they are no longer able to make decisions for themselves because of disease or incapacity. The purpose and function of POLST are identical to those of AD. Yet, while an AD is written by the person ideally when the person is healthy, a POLST is written by an attending doctor when the patient contracts a serious illness or is frail towards the end of life. Also, a POLST has its legal force.

The crux of these end-of-life care documents is the idea that one can exercise choice over when and how one would die. It would be a false impression to imply that there was no room for choice and control before the present day, or that people could not help but just powerlessly watch the dying process. As Bloch and Parry wrote (1982: 15), human cultures have created various ritual devices “to determine the time and place of death, and to disassociate social death from the termination of bodily function,” and these represent “an attempt to control the unpredictable nature of biological death and hence dramatize the victory of order over biology.” Nevertheless, life-sustaining treatments, as the organ transplant techniques do, create new ways of “enacting death” (Hadders 2009), by addressing the questions, “Is the cessation of breathing or brain death a criterion of death?” and “When can we stop and let a patient die?” The technologies offer a possibility to make a choice over death, and the end-of-life care documents realize the choice by the sanction of legal authority.

However, this underlying ideology of choice has been critically examined. Scholars have pointed out that, at least in the matter of life-or-death, the thought that life-sustaining treatments let us make a choice can be merely an illusion (Mol 2008; Strathern 1992; Slomka 1992). They have argued that the technology *forces* us to make a choice. “The politics of moving things along and the rhetoric of dignity, suffering, and quality of life shape knowledge of what the patient wants and characterize the patient’s condition, including his or her aliveness” (Kaufman 2005: 321). Many presuppositions of patient autonomy, in fact, are unrealistic in this setting. For example, it would be very hard for patients to receive all the information necessary to make a decision because the patient also does not have an idea of what would follow their choice (Manson and O'Neill 2007). It cannot be said that, whatever a patient decides, it is a "pure" voluntary choice because, in reality, patients often feel that there was no other choice to be made (Hardwig 1990; Mol, Moser, and Pols 2010: 9). However, these end-of-life documents claim that we do have choices to make, and forces this decision-making on us all (Kaufman 2005).

Drawing upon this body of literature, I pay attention to the circumstances in which patient autonomy has recently emerged as a key to improve the quality of death in Korea. Along with the discourse of self-determination, the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life focuses on the end-of-life care documents as tools to guarantee death with dignity, by introducing an AD and a POLST to the clinical setting. While exploring the ways in which these end-of-life care documents are transplanted and utilized during the initial phase of the enactment of the Act, I ask what meanings these documents acquire in a hospital system. Do an AD and a POLST create fissures in the rigidly woven medical and hospital system to let the patients die a good death? Or, do these forms only serve to reinforce the bureaucratic nature of hospital dying?

Meanwhile, with regard to the decision-making process near death, some studies have noted that different countries and ethnic groups show different patterns and preferences (Kwak Jung and Haley 2005). For example, in the U.S., significantly fewer Korean Americans and Mexican Americans believe that bad news (e.g., metastatic cancer, terminal prognosis) should be delivered to the patient and that the patient's family members should make decisions regarding life-sustaining treatment (Blackhall et al. 1995). In the U.K., elderly Caucasians prefer hospices as an ideal place of death, whereas elderly people of Chinese origin prefer hospitals (Seymour et al. 2007). These disparities among ethnically diverse groups are often interpreted as a result of ideological orientations such as individualism, familism, and Confucianism. For example, Brannigan (1999), in his analysis of the dispute over brain death and transplantation, argues that “the Japanese have historically and philosophically understood individual identity in terms of the relational web within which that individual exists”; this contrasts with the American emphasis on the individual as a separate entity.

Although familism and Confucianism tend to be attributed to the pattern of a high rate of decision-making by the family in Korea, a study demonstrated that, even in “Confucianism cultures,” decision-making regarding end-of-life care and preferences regarding life-sustaining treatment are not identical (Kwon Ivo et al. 2015; Phua et al. 2015). It is very hard to prove whether an ideology actually impacts people’s specific behaviors and ideas. Rather, it is more important to understand how stakeholders come to be involved in situations in which communication occurs because diverse meta-communicative factors are entailed in decision-making processes, truth-telling, and interacting with medical professionals (Blackhall et al. 2001). Therefore, I suggest closely looking into the on-site circumstances in which people are called to make decisions regarding life-sustaining treatment rather than assuming that a certain philosophy is the root cause of the phenomenon. I ask: in which situations are a patient’s family members deeply involved in the decision-making process, and how do other actors respond to familial decision-making?

Palliative and Hospice Care in a Tertiary Hospital

The palliative care and hospice approaches have emerged as “a rejection of the funeral industry” and “push back against the normative protocols of biomedicine” in line with various efforts, including natural burials and home funerals (Engelke 2019: 32). This approach opposes the medicalization of death in hospitals and the biomedical philosophy that regards saving a life as the most—if not only—important value. Rather, under the catch-phrase, “live fully until [one] dies as himself” (Saunders 1967), the palliative and hospice movement advocates that death is not a failure of medicine, but rather a chance to complete one’s life (Clark 2007). Consequently, the proponents of palliative and hospice philosophy emphasize care over cure and the quality rather than the quantity of one’s life. No one is subjected either to aggressive life-sustaining strategies or to excessive technological interventions during their final weeks or days of life (Lawton 2002). Freed from being subject to the medical professional’s control, they assert that we must take control over our own way of living in order to end our days with dignity. Thus, to some extent, the emergence of the palliative and hospice movement has appeared at the intersection of the advocates for choice and patient autonomy and the medicalization of death, while this movement contributes to creating new experts of death by introducing “death doulas” (Olson 2018).

It can be said that hospital dying and the palliative and hospice care movement lie at the antipodes of one another. Previous studies on the end-of-life care have tended to explore either the (bad) quality of hospital dying or the ways in which independent hospice institutions provide an alternative place for dying. My dissertation takes this very point as a departure: what if proponents of palliative and hospice philosophy work in an environment that is intrinsically antithetical to the conditions for the "good death" that this movement aims to achieve? What the palliative care staff in S Hospital do is end-of-life *care*, but as stated, a bureaucratic hospital and scientific biomedicine serve only to *cure* not to care (Kleinman and van der Geest 2009). Thus, the story of the palliative care team members who work in a hospital equipped with the state-of-art technologies necessary both to "save a life" and to create a profit provides us with a lens through which multiple concepts of good or bad deaths are contested; the end-of-life care is institutionally marginalized; and those who come to this renowned hospital with a hope of recovery are transformed from the sick into the dying. In searching for answers to these questions, I explore the double bind of the palliative care staff who suffers from the shortage of resources in a resourceful environment.

In addition, the story of the palliative care team provides a new perspective on the power structure of medical authority. In terms of power relationships in medical settings, medical professionals have been supposed to take a position of power (Lazarus 1988). Yet, the palliative care team's story reveals a multi-layered medical authority that is stratified within the biomedical system and makes evident that the professionals dealing with death in hospitals are perhaps the most marginalized to the extent that the palliative care nurses do not exercise power over their patients and their relatives as other doctors and nurses do. By exploring how doctors and nurses work *with* their patients and family members, I present a complex picture with "no one role or single style of relationship characterizing the whole course of a patient's end-of-life and dying experience" (Kellehear 2007: 158).

I read what the doctors, nurses, social workers, and volunteers of the palliative care team do in S Hospital as care practice. As Kleinman and van der Geest (2009) argued, while medical professionals became too absorbed in curing patients' bodies, hospitals have lost their purpose and function of care, and the bureaucratic character of hospitals also hampers care to be realized in a hospital. Since a hospital is fundamentally not designed to "care" for "the dying," it generates crucial differences between working in a hospice and working in a hospital as a palliative and hospice care specialist. Thus, we need to ask not only what the palliative care staff does, but also under what circumstances they do it and how the palliative care staff relates to the architecture of the hospital system (Barnes 2012).

Caring for the dying cannot be standardized. It depends on many variables ranging from the individual patient's personality, family dynamics, the values that each patient cherishes, and their wishes regarding the end-of-life. Besides, death in particular belongs to a terrain of uncertainty, and unexpected things always happen. Thus, the palliative care team members, on the one hand, struggle to satisfy the institutional demands (both from the hospital system and the new law) to standardize a way of dying and a way of caring for the dying. Yet, on the other hand, they tinker (Mol 2008) and improvise (Livingston 2012) in their work in order to "attune their work to the idiosyncratic and heterogeneous experiences and wishes of their patients. The palliative care staff members "meticulously explore, test, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) has been reached (Winance 2010: 111).

Meanwhile, care practices produce specific personhoods of care-receiver (Zigon 2011), subject of the politics of care (Ticktin 2011), and recipient agency (Scherz 2017) in the contexts where multiple ideologies and political-economic regimes interact. If care practices entail fashioning of subjects, the end-of-life care that the palliative care staff members carry out as well envisions a new being, the dying. In particular, I pay attention to that a big proportion of their practices center on ensuring their patients receive good family care, through interventions in family dynamics. By looking at family education, family consultation, and the assistance of family caregivers, I ask, how are the kind of the dying patients and the role of family caregivers configured?

Last, all the caring work of the palliative care team seems very trivial, and it is absolutely not true that all care-receivers welcome their care services. From this angle, one might ask if we can call it care if the action is too trivial to improve the care-receiver's condition or if it is not what the care-receiver wants. However, I argue that, in front of this ultimate Other, i.e., the dying (Lingis 1994), these trivial care practices are both the minimum and maximum actions that a humble human can do for another vulnerable human. On the one hand, the palliative care staff's work concentrates on strengthening the family relationship. On the other hand, however, through touching, hugging, and being together, the palliative care staff generates new social relations among the dying patients, their family members, the nurses, the volunteers, and the community. All the practices that the palliative care team members carry out show "how care, love, and commitment exceed the functional calculus" (Engelke 2019: 35).

Therefore, drawing upon several threads of literature, my story explores the ways in which a biological event, family relationship, institutional system, laws, moral values and ethical principles, care, and temporal-spatial materiality converge on making a death good.

Field Site and Its People

My research project for this dissertation took place between September 2016 and August 2018 in S Hospital in South Korea. During the period, I worked with the palliative care team as a volunteer and participated in two research projects as a researcher that the doctors and nurses of the team led. For my doctoral research, I have obtained IRB approvals from both University of Virginia and S Hospital, respectively.

S Hospital

South Korea is one of the countries in the world where visual diagnostic test examination techniques and technology are overused, and where economic logic, neo-liberalism, and commercialism coexist with a powerful intervention of the government in health care infrastructure, discourses and practices, and S Hospital, as a tertiary referral hospital in the capital, with its own school of medicine, stand at the climax of the health care delivery system of this country.[4] As one of the most renowned hospitals in this country, S Hospital sees 2.8 million people with various illnesses every year, and has a total staff of over six-thousand people, with

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[4] S Hospital is one of the five most well-known tertiary hospitals in South Korea. Accidently, all of their names start with an "S": the Seoul Asan Hospital, Severance Hospital, Seoul National University Hospital, Seoul Sungmo Hospital, and Samsung Seoul Hospital. It is for this reason that I named my field site "S Hospital " in this dissertation.

approximately 1800 beds. This S Hospital consists of inpatient wards and outpatient clinics: the doctors meet patients at their individual offices in the outpatient clinics; if a patient needs to be hospitalized, the patient will stay in one of the inpatient wards, and the doctors make rounds in the wards every day. When I use the word, “outpatient clinics,” this refers to the outpatient clinics that belong to S Hospital, not independent local clinics.

In general, whether a hospital is a public or private one determines how a health care institution establishes relations with the outside world, e.g., the public, other health care institutions, the state, and commercial sectors. Legally and institutionally, S Hospital is a public hospital in that its mother university is a public university and a law defines this hospital’s obligation to serve as a public health care institution. Yet, if “public hospitals” refer to hospitals that provide medical care free of charge to patients, covering expenses and wages by government reimbursement, S Hospital does not fit the image of public hospitals. Treatment costs of this hospital are no cheaper than those of “private hospitals” in Korea. Rather, due to the cultural connotation of the mother university of S Hospital, this hospital is considered as providing the best quality of care by the most competent staff.

Cancer is one of S Hospital’s specialties to the extent that an independent Cancer Hospital is located on its campus. Cancer has long been the leading cause of death in South Korea, and one third of the total deaths in South Korea is attributed to cancer. This disease is one of the most common and most terrifying in this country. On the one hand, people are afraid to contract this disease, yet they are also aware that it is not easy to avoid. According to survey data in 2013, 59.9% of the total population had private cancer insurance.[5] Not only the large number of cases commonness of this disease but also the profitability has propelled hospitals to concentrate on cancer treatment. Because cancer treatment includes diverse diagnostic tests and targeted therapies that are not covered by the National Health Insurance, hospitals seek profit from cancer treatment.[6] They spend considerable money in hiring medical professionals, in buying equipment, and in constructing complex cancer centers. Thus, the cancer "business" has become a cash cow in the Korean medical system.[7] The existence of the Cancer Hospital of S Hospital results from this local context.

The Cancer Hospital consists of 28 specialized centers, such as cancer specialty centers, multidisciplinary cancer treatment centers, and clinical trial centers. A half million cancer patients come to the hospital every year. The six-story building contains about 200 beds, which is not enough to accommodate all inpatients, so most inpatients are hospitalized in the main building of S Hospital. In general, the patients are admitted to the wards that are associated with their tumor classification (for example, a patient with cervical cancer would stay in the OB/GYN ward), but the patients in their terminal stage are hospitalized in the terminal-cancer ward.

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[5] "The Ratio of Cancer Insurance Subscription," *Maeil Business News Korea*. 2013. 8. 13. https://www.mk.co.kr/news/special-edition/view/2013/08/712440/

[6] With regard to the uniqueness of the National Health Insurance system in Korea, see Kwon Soonman (2003, 2009); Lee Sang-Yi et al. (2008).

[7] "Growing Cancer Hospitals, an infinite competition for whom?" *The Kyunghyang Shinmun*, 2014. 3. 19. http://news.naver.com/main/read.nhn?mode=LSD&mid=sec&sid1=001&oid=032&aid=0002454691

The Terminal-Cancer Ward

S Hospital is not equipped with a palliative care ward or a hospice ward, and I will explain the reason for this absence and its meaning later. It is this terminal-cancer ward that substitutes for a palliative care ward or a hospice ward, in that this ward mainly accommodates the patients who are diagnosed as in the terminal stage. The palliative care team takes care of these patients in the terminal-cancer ward. There are 12 rooms in the ward on the right side of the corridor, with a total of 21 beds. Each room is gender-specific, with three for women and four for men. Two rooms are quintuple rooms while five rooms are double rooms. Also, there is a consultation room. Here, the nurses often meet their patients and their relatives, but also the volunteers use this room as their base, and the staff meetings are held in this room. On the left side of the corridor, there is a station where the ward staff members (three nurses, a head nurse of the ward, and two residents) maintain a presence, and a tea-making room, where the patients and their caregivers can use a sink, a microwave, and a water purifier. Last, in the terminal-cancer ward, there is a room that is reserved for the dying, which is called *imjongbang*.[8] If a patient is dying during their hospital stay, and if she is lucky that the *imjongbang* is not occupied by other dying patients during the period, the patient is moved to this room so that the patient and her relatives can protect their private time.

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[8] A combination of passing away (*imjong*) and room (*bang*).

The Palliative Care Team

The palliative care team[9] consists of nurses (Nurse Kim Yunmi, Nurse Roh Hyojeong, Nurse Yang Hui-eun, Nurse Lee Juwon (male), Nurse Choi Eun-A, and Nurse Heo Sujin), social workers (Mr. Shin Euiseok and Ms. Woo Miyeon), and approximately fifty volunteers. The nurses, whose office is located in the Cancer Hospital next to the main building where the terminal-cancer ward is housed, run the palliative care team, meet patients and their families upon doctors' requests, and supervise the volunteers. Nurse Kim is the one who manages the palliative care team operation. The team also has three doctors in affiliation: an oncologist, Doctor Nam Jinhun (male), another oncologist, Doctor Park Myeongkyun (male), a psychiatrist, Doctor Jin Suyeon, and a doctor at the department of family medicine, Doctor Yim Hyeonki (male).[10] Doctor Nam has been leading a group of people who are interested in palliative and hospice care in S Hospital over three decades, and he also has spoken to public audiences regarding end-of-life care issues. Doctor Park is a director of the terminal-cancer ward, and Doctor Jin and Doctor Yim are palliative care specialists in this hospital. These doctors do not belong to this team but meet their patients in their own outpatient clinics and round the wards while working with the palliative care nurses. Finally, Ms. Yun Yeongran is an administrative staff member in charge of the referral of the terminal-cancer ward's patients. In some sense, the palliative care team is a group with loose boundaries because its membership is not strictly

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[9] This group consists of nurses, doctors, social workers, and administrative staff, and each actor plays an important role in the end-of-life care. This is why I adhere to call them "the palliative care team" or "the palliative care staff" instead of "the palliative care nurses and doctors."

[10] The number of nurses, doctors, and volunteers fluctuated during my fieldwork. In particular, after two governmental demonstration projects began in 2018, three nurses (Nurse Lee Juwon, Nurse Choi, and Nurse Heo), one affiliated doctor (Doctor Yim), and one social worker (Social Worker Woo) joined the team.

closed. The members I introduced above are the core staff of the team, but there are other doctors and nurses who also work closely with the palliative care team.

It is also noteworthy that the terminal-cancer ward staff does not entirely overlap the palliative care team members although the residents and the head nurse of the ward participate in the staff meetings and although the ward nurses are deeply involved in the end-of-life care. The ward nurses' job is to carry out the orders of the oncologists (outside the palliative care team as well as Doctor Park and Nam). Also, Doctor Park is the director of this terminal-cancer ward, but his office is not located there. Instead, he works in his outpatient clinic in the Cancer Hospital building. Some of the patients in the terminal-cancer ward are Doctor Park's patients, but not all of them: the residents are in charge of all of the patients during their one-month rotation in the ward.

The palliative care team's work depends largely on volunteers. Several programs of the palliative care team are carried out by the volunteers, including bodily care, the prayer meetings of three religions, art therapies, an autobiography therapy, and meetings with bereaved family members. Among these programs, bodily care provided by volunteers is the most important in that these services meet the biggest needs of patients and their families. The volunteers mostly consist of women in their 60s and 70s, and many volunteers have been committed to this job for over a decade. The volunteers must take hospice courses over 20 hours prior to applying for volunteering and then go through a probation period of 3 months. I took and completed these courses in the first three months of my research project (between September 2016 and November 2016).

Research Methods and Approach

The research methods that I adopted were participant observation, informal interviews, and semi-structured interviews. Four days a week, I spent all day staying with the palliative care team members. Basically, I worked with the volunteers from 9 AM to 2 PM and, after the volunteering (at times between 9 AM and 2 PM), I shadowed the nurses and doctors, attended the diverse events which were held by the palliative care team in the hospital (the staff meetings, the conferences, etc.), and helped some work that I could contribute to, such as decorating the office with Christmas ornaments. Besides, I attended all events of the palliative care team outside of their regular schedule, including year-end parties and seminars. Through this intensive engagement in their affairs, I was able to be accepted as a member of the team for two years.

Participant observation forms a key part of anthropological identity and methodology. Despite some limitations and disadvantages of this methodology (e.g., qualitative studies take an overwhelmingly long time as compared to quantitative research), anthropologists still adhere to participant observation and in-depth interviews. I do not want to "mystify" the strength of participant observation. Yet, at least for studying death and dying, to adopt this research method is imperative. Participant observation is not simply the practice of observing. If only observation matters, we might just sit in the next room and observe how our "subjects" act through a hole in the wall. The reason we refer to this method as *participant* observation is that the observation is done in intersubjective ways. Because the people in my field site observed my earnest engagement both as a volunteer and as a researcher, they allowed me to participate in their most private moments.

An in-depth interview is another key methodology in anthropology. When conducting research projects previously, I often felt that we anthropologists appropriate our interviewees' stories. Our interviewees agree to be interviewed because they want to relate some stories. However, their priorities and our research purposes do not always match; in this situation, their stories are tailored for our research purposes. During interviews, we listen to our interviewees with our full attention; however, doing so actually has another purpose, namely, our research, and we are not free of the charge of instrumentalizing people's story.

However, in conducting this doctoral research, I realized the power of narrative. Briggs and Mantini-Briggs (2016) assert that a narrative is not merely a representation of the experience of an illness; the act of narrating also has the power to reconfigure a care relationship and a communicative relationship. The right to narrate is a right of health and a right of communication. Yet, as Frank (2013) wrote, patients and their family caregivers are nowadays not given a chance to talk in the doctors' room. In many interviews, especially with patients and their family members, my interviewee and I both cried together. At the end of the interviews, my interviewees thanked me for giving them a chance to talk about what they had been through as a patient or a patient's caregiver. My interview gave them the opportunity of "converting disease to a story so as to have a meta-control" (Frank 2013: 88). I still remember a day when I got a phone call from an elderly Korean man in his seventies or eighties. He said that he had seen the recruitment poster I had posted on the hospital's bulletin board and called me. He talked to me about his wife's recent death and his grief for thirty minutes. After the phone call, I thought of his earnest need to talk about his sadness. I could not fathom the depth of his grief where, when he saw a simple poster, he was willing to make a call and talk to a young female stranger on the phone. Although this man did not participate in the research interviews, it seemed like talking about his grief for thirty minutes on the phone consoled him. The in-depth interviews definitely gave my patients and their family members as well as medical professionals time to heal.

The occasions and situations I attended to collect material for this dissertation are: the morning briefings where Nurse Kim or Nurse Heo explained the details of each patient to the volunteers; the volunteer activities in the terminal-cancer ward; the staff meetings of the terminal-cancer ward where Doctor Park, residents, Nurse Cho (the head nurse of the ward), Nurse Kim, Nurse Roh, Nurse Yang, Nurse Lee, Nurse Heo, Referral Staff member Yun, Social Worker Shin gathered to share the details of each patient; the bereaved family gatherings; the staff meetings for preparation for governmental demonstration projects; the ethics grand rounds (EGR); the monthly education seminars, the biannual appraisals, and the workshops for the volunteers; and the conferences and public hearings for palliative and hospice care both inside and outside S Hospital; the residents' rounds, the nurses' consultations with the patients and their family members; and Doctor Park's outpatient practice. While participating in these situations, I jotted down what happened and who said what on my smartphone or my notepad and, right after they concluded, recorded more details, based on the jottings. Returning home, I transcribed the voice recording into a written account.

A large proportion of the materials for this dissertation came from informal interactions, such as personal conversations. Yet, formal in-depth interviews were also conducted with the palliative care team staff, the head nurse of the terminal-cancer ward, the patients, and their families in the terminal-cancer ward, particularly during the final period of research. In addition to the patients and their families who were staying in the terminal-cancer ward, I recruited patients and family caregivers through advertisements on the hospital's bulletin boards. All interviews were recorded with the interviewees' prior consent and then were transcribed.

Subsidiarily, I consulted an on-line community where patients with cancer and their family members exchange information regarding hospitals for the treatment of cancer, try to figure out the best practices, and support one another. I had joined this community when one of my relatives had been diagnosed with cancer. I referred to this on-line forum to comprehend the patients and their family caregivers' practices and opinions. The data I gathered from this on-line community are limitedly presented in Chapter Five without any identifying information.

The collected data (i.e., field notes, memos, diaries, logs, and transcripts of interviews) were stored in qualitative data analysis software (MaxQda). Via this program, I repeatedly read the materials and produced codes. Each code was incorporated into subthemes and themes.

To safeguard the privacy of the people in this dissertation, the names of the medical staff, patients and their relatives in this dissertation have been replaced with pseudonyms. In addition, I made slight changes to personal information of them (i.e., their ages and hometowns). Typically, photographs taken at the field site are exhibited in ethnographic writings as a silent message to confirm the fieldworker's presence at the field site and rapport between the field worker and the "informants," as well as to depict the field site. However, in this study, I judged that the benefits of including photographs of my fieldwork did not outweigh the potential risk of breaching the privacy of the medical staff, patients, and their family members.

On Hospital Ethnography: Being a Positioned Subject and Reading Practices

Doing “fieldwork” in a hospital can be challenging to anthropologists, especially in the case that the anthropologist does not belong to the medical community as a health practitioner (e.g., a doctor or a nurse) or is not a patient or a patient’s relative. In a hospital, where one must belong to categories of “hospital workers” or “patient,” there is no suitable position for an ethnographer.

I mobilized my two positions as volunteer and researcher, which were represented by a pink gown and a white gown. I mainly interacted with people—the volunteers, patients, and their family members—as a volunteer with a pink gown. The volunteer identity greatly helped me to interact with the people in my field, particularly in the initial phase of my research. As a volunteer, I could learn the ways of care and the structures of the hospital and medical institutions. Because I was wearing a volunteer uniform, the patients and their family members accepted my presence, and often spoke openly to me. Yet, when I shadowed the doctors and nurses, I put on a white coat that made me look like a member of the medical community, and this coat naturalized my presence in the place where the doctors and nurses met their patients, as Charis Thompson (2005) did in her ethnographic research in a fertility clinic. When with the medical staff, the researcher position worked well. I often discussed my research direction and the newly-introduced law with the medical staff, and also participated as a research member in research conducted by the medical staff.

Regarding hospital ethnography, gaining entry to medical institutions would be the hardest barrier faced by an ethnographic study in hospitals unless the researcher’s background was rooted in the medical community. Once I decided to research end-of-life care in Korea, I emailed Doctor Nam, who had publicly voiced his opinions regarding the life-sustaining treatment issue for a long time. He willingly agreed to meet with me, and in the meeting, he readily granted me permission to conduct fieldwork in the palliative care team of the hospital. It turned out that another anthropologist had conducted participant observation there, and Doctor Nam thus had a sense of what anthropologists did. Doctor Nam connected me to Nurse Kim, and Nurse Kim introduced me to other nurses and volunteers.

Behind this smooth acceptance, there were the doctors and nurses' expectations. Alice Street (2014: 31), who conducted fieldwork in a hospital in Papua New Guinea, wrote that people in the hospital allowed and welcomed her because they hoped her work would help make their clinical work more visible to people in the Papua New Guinean government and other countries, forcing them to recognize and respond to their predicament. Likewise, the "subjects" of my research also hoped my research would contribute to the development and proliferation of palliative and hospice care, which were not yet firmly rooted in the Korean medical system.

When I was a university student majoring in anthropology, we were taught the privileged strength of anthropology due to its holistic perspective and its "on-siteness": if an economist focused only on statistical indexes, an economic anthropologist could see how people actually live in such an economy in a broader sense. Can I say that I had a bird's eye view to understand how people were dying in the hospital beyond the view of the doctors, nurses, and patients themselves? I cannot claim so. First, I could access only what my informants allowed me to do. For instance, I have no idea what the attendants discussed in a meeting where the "higher ranks" of the hospital gathered. I also have no idea how severe the pain was that my informants felt. Second, my two-year-long research could never exceed the doctors' and nurses' long devotion to this field, or the family caregivers' experiences. I could only combine and assemble parts of each side. However, neither could my informants truly obtain a holistic view or understanding. In this highly fragmented institution, along with status and position, no one can entirely fathom all the corners of the hospital system where the law and the state's control operate.

What does it mean to look into what doctors and nurses do in a hospital? I have always believed that the ultimate goal of anthropology is not to examine if theories/rules/laws are applied well "in reality" but rather to observe what people really do "in reality" and to understand why they do what they do in a certain way. In order to understand what is going on in an oncology ward, I approach this subject with an empirical attitude, rather than adopting discourse analysis of a biomedical textbook, which is a common approach used in the critique of biomedicine. My position in this hospital is like that of an anthropologist who enters an unfamiliar culture in order to attempt to understand how the inhabitants of said culture view the world around them. An anthropologist would gather clues from the informants' words, gestures, conversations, images, and literature, and then synthesize all the data to configure the local people's outlook on their world. In the same manner, I did not draw my analysis from the biomedical theory of cancer presented in textbooks, but upon what I observed in the doctors' and nurses' discourses that emerged when explaining a patient's illness and health status to other practitioners and the patient/family members as I conducted my fieldwork. I am interested more in how *my interlocutors* understand the trajectory of cancer and how they apply their understanding of how to address the terminal stage of cancer in practice, rather than in how biomedicine—an abstract concept—explains cancer as a clinical object.

This work has several implications. First, it contributes to revealing the multiplicity and heterogeneity of biomedicine. The assumption of universal biomedicine has become deeply entrenched in our daily lives and popular thinking, and this assumption is linked to ideas about the stability of medicine's objects—e.g., universal bodies, technologies, and things (Livingston 2012: 71). However, as presented in Chapter Four, oncology and palliative medicine have different perspectives on the timeline of cancer, regardless of their common relationship with biomedicine. Second, this work highlights the fact that any theory is eventually carried out by each *person* and that we need to pay attention to what these actors *do*—i.e., their practice. Since my earlier work on fertility clinics in South Korea, I have been primarily interested in how practitioners associate their own ideas with actual actions. Finally, this work is about one way of understanding cancer, as found in one ward of a specific hospital in Korea. I intentionally do not extend what I learned in the terminal-cancer ward of S Hospital to other places as if it represents all of the wards, clinics, and hospitals in South Korea. Many of the practices I observed in this ward probably are not even shared with other wards within the same hospital. Focusing on the micro-locality of practice leads us to note diverse backgrounds and contexts produced within each local practice. I believe it is only when we understand each locality that our discussions can be expanded to assess the degree of and nature of the differences and commonalities.

Conducting Fieldwork in One’s Home Country and Writing in a Second Language

Writing is a political action. Those who write something position themselves in a certain context and reveal, either explicitly or implicitly, how they relate to the world, both through and in their writing. By writing this dissertation in English, with the presupposition that the hypothetical readers are English speakers, I am placing myself within the academia of North America. Although I believe that writing ethnography is always inevitably a work of translation, the fact that I conducted the fieldwork in my home country and wrote this dissertation in a second language, presented me with more intricate translation challenges, which are ultimately challenges of positioning myself.

Not all anthropologists, but many of them, conduct their fieldwork in the societies of others and write the results of their fieldwork in their own language. That is, anthropologists are strangers while visiting their field sites, and, later, they revert to becoming natives once more when writing up the research in their own countries. This means that the scope of the understandable world at the field site is narrower than that of the effable world while writing, and this means that anthropologists show Other’s story to those who belong to their own community. Conversely, in my case, while writing this dissertation, I had to repeatedly draw a line under what I could and could not translate. For example, as a native Korean, I was familiar with the extremely subtle language practices of the doctors and nurses (i.e., the use of *ssi* or *nim* as titles when addressing patients) and knew that these could indicate their attitudes toward their patients, but it was beyond my ability to address these micro-level language practices that were not directly related to the main purpose of this dissertation. I knew that it was noteworthy that the doctors and nurses used insider vocabulary to refer to a patient who remained for too long in the ward, but I could not find the most appropriate English expression that an American doctor would use in the same situation.

To translate the Koreanized English jargon used by my informants was another challenge. The medical professionals in S Hospital used English medical and nursing terminology, such as “extubation” and “bedridden.” Some words corresponded with American English usage, but others did not. For example, the doctors and nurses would use “O2-full” to refer to the provision of oxygen, whereas my friend Sara, who worked as a physician in a hospital in the U.S., told me that American health practitioners would use “FiO2.” The nurses working at the S Hospital would say “The patient has an insight” in reference to the patient having knowledge of her prognosis, but this expression would sound awkward to my American readers. In order to respect the language of the people in S Hospital as far as possible, I used quotation marks to indicate Koreanized English words.

In addition, I did not follow some of the writing rules that circulate within American academia. Firstly, the Korean names in this dissertation are a combination of the surname and first name because this is the way of presenting names in Korea. Secondly, I included both the surname and first name of the Korean authors because including the surname only does not serve the primary purpose of name, i.e., to identify a person. The top five most common surnames account for approximately 50% of all names in the entire population in Korea, and it is not easy to identify the author of an article based solely on her surname (i.e., see “Kim” in my bibliography). Thirdly, all Korean words in this dissertation were written according to the

Romanization of Korean rules published by the National Institute of Korean Language. Lastly, in my bibliography, I did not present the pronunciation of the Korean sources, but provided translated titles instead because I could not find a good reason to present how the Korean title of a book should sound and who would be the target audience.

Doing Fieldwork in an Emotional Field

I have had opportunities to present portions of this research in workshops and conferences. Each time, I encountered one or two audience members who left midway through the presentation, and some of them told me later that their personal experiences—such as recent bereavement of family members—made it difficult for them to remain. It was interesting to see what strong sentimental reactions my research had provoked. Among the diverse topics of death, it is this subject of dying in a hospital that elicits such strong emotions. In addition, many people who learned about my research topic and research site were astonished that I could handle my own emotions, especially when they learned that I conducted this research during pregnancy.

In fact, prior to this research, I had never experienced "dying." As typical Korean parents in those days, my parents had hidden my aunt's death when I was six and did not allow me (as a ten-year-old) and my younger brother to attend my paternal grandfather's funeral. I also was not able to be present at my maternal grandfather and two grandmothers' bedsides when they were passing away. Thus, it was during the fieldwork period that I first truly encountered someone who was really dying.

It was not easy to be in a setting where every day was opened with a prayer for the deceased who passed in the past two weeks. I liked my patients, and then I would encounter them again in the list of the deceased. To anyone, encountering death would be emotional, but I am an especially weepy kind of person. I could not help but shed my tears when I did my fieldwork, when I wrote my field notes, and when I reviewed my data for writing this dissertation.

In the initial period of fieldwork, I found myself going to a shooting range and fired guns every day that my patients passed away. It was strange because I had never been to such a place before this fieldwork. I interpreted my unfathomable behavior as a coping strategy that I unconsciously adopted to digest all my overwhelming feelings. The shooting range gave a coupon—you can exchange a bundle of the coupons for a doll—to those who got high scores, and because it turned out that I was quite good at shooting I earned the coupons on every visit. When I had collected dozens of the coupons, I found myself no longer visiting the shooting range. It is likely that it was at this point that I could embrace the fact that everyone would eventually die.

I include here my sentimental reactions and a mysterious coping strategy, with a hope that this note would help someone who is interested in this field. It is indeed an emotional field. However, time will teach us how to deal with psychological shock, sorrow, sadness, futility, and powerlessness. Above all, I would like to note here that I was very happy and fulfilled in my fieldwork. It sounds ironic that I was happy in such a sad field. Yet, sadness and happiness are not necessarily mutually exclusive. I was sad because I very much liked those whom I met there, because I knew that they loved each other, and because I could learn that eternal farewell was a part of life. I always told my baby in my womb, “We all fairly have one beginning and one ending, and no one knows when the ending is. That is why we must live our lives sincerely.” I was very happy to teach my daughter this lesson.

Outline of this Dissertation

My story consists of seven chapters, including this Introduction. In Chapter Two, I outline the historical background in which a legal act came to be introduced to South Korea in order to enable the withholding and withdrawal of life-sustaining treatment in certain circumstances. This chapter will help explain why so-called “futile” life-sustaining treatment was so prevalent in Korea, particularly in the hospital context where the palliative care team members work. In Chapter Three, I investigate the institutionalization of a new form of dying. In order to embody the Act in the hospital and national health care system, the nurses and doctors standardize the withdrawal of treatment and the matters that follow. In so doing, they orchestrate material, moral, and technological conditions, which at times conflict with one another, in order to make for a “good” death. In Chapter Four, I scrutinize the ways in which the terminal stage is defined and end-of-life care is activated in a framework of cancer trajectory and care plan. In Chapter Five, I trace some paths of dying that the terminal patients would follow, which emerge from the fragmented medical system. On the route to a good place for dying, popular thinking regarding hospice, bureaucratic processes, technological restrictions, and health care delivery systems converge on the care practice of the palliative care team members and often hamper the realization of good dying. By focusing on the ways in which the palliative care team staff members send their patients to other places, I ask if referrals of patients can be a form of care. Chapter Six deals with relationtionality in the end-of-life care. I examine the ways in which family members are involved in care work. As a production of moral duty, the health care system, and gendered kinship practice, the family members of the patients become "*bohoja*s" of patients and take responsibility for intensive care labor, which I call capillary care labor, communication with the medical staff, and decision-making regarding the end-of-life care. Then, by exploring the small and trivial care practices of the palliative care team, I argue that the ultimate goal of the end-of-life care is to generate new relationships. In the final chapter, I gather up the threads of the previous chapters. I seek answers to two final questions: "How can we improve the quality of dying?" and "Ultimately, what does good dying mean?" In answering to these questions, I propose several practical suggestions regarding the future direction of the new law and explore a more fundamental nature of care, relationality, and death.

Finally, as an anthropologist, I believe that a disease should not be reduced to a biological entity that labels people. I do not believe that we want to be recorded in a doctoral dissertation merely as a patient with cancer. It is for this reason that I endeavored to include patient's lives beyond cancer and dying in their stories. Nevertheless, I inevitably highlighted the diseases and their bodily deterioration overall because I was writing about hospital life and cancer. I hope that all I met in my field can thus excuse my rude labeling. I am sincerely grateful for all the lessons of life, love, courage, and happiness I learned from the patients and their relatives, not to mention the nurses, doctors, social workers, administrative staff member, and volunteers of the palliative care team. I hope that both the living and the dead in my story find peace wherever they are. I hope my readers will remember that all characters in my story were people who had sincerely lived their lives just as we live our own.

Chapter Two

Two Legal Cases and the Act

Introduction: Law Rules Life and Death

Since the moment at which life-saving technologies and transplant techniques were able to blur the boundary between life and death by creating new categories of person through brain death and permanent vegetative state (Kaufman 2005; Lock 2002), laws have intervened in the ambiguous situations to define through legislation who is living, who is dead, and who is allowed to die. Life became an event that could be decided through political deliberation (Agamben 1998; Kaufman and Morgan 2005). Just as the Quinlan Case in 1978, the Cruzan Case in 1990, and the Schiavo Case in 1998 were historic milestones in the U.S. that shaped medical practice involving end-of-life situations, two legal cases have significantly influenced the current landscape of hospital dying in Korea: the Boramae Hospital Case in 1997 and Grandmother Kim Case in 2008.

The Boramae Hospital Case was the first legal case in which courts began to intervene in hospital deaths in Korea. The verdict problematized medical practices that had prevailed in response to the widespread desire to avoid *gaeksa* and contributed to doctors' refusals to withdraw life-sustaining treatment. Ten years after the Boramae Hospital Case, the Grandmother Kim Case, finally legalized stopping life-sustaining treatment in situations where a patient was not expected to recover and led to the passage of the first law—called The Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life (hereinafter referred to as “the Act”)—regarding life-prolonging measures. In this chapter, I first provide the details of the two legal cases and the effects of the cases in the landscape of end-of-life care in hospitals. In the second half of this chapter, I analyze the contents of the Act and explore the underlying ideas that are embedded in it.

The Boramae Hospital Case in 1998[11]

Under the influence of alcohol, a 58-year-old man had a bad fall at his house on December 24, 1997. His landlord found the man, and he was admitted to the ER at Boramae Hospital. Since the patient’s family members were absent, a doctor asked the landlord to sign the surgery consent form, but the landlord refused. Inevitably, the surgeon decided to perform an emergency surgery anyway. The patient, on December 26, underwent a 9-hour-long operation to remove the hematoma caused by an epidural hemorrhage. During the operation, the man’s wife showed up. The doctors explained the patient’s history and current status, and the wife understood. The operation seemed to be successful as the patient was reactive to a pupillary light reflex test, responsive to external stimulation, and tried to open his eyes in response to hearing his name. Although the cerebral edema from the brain surgery caused difficulties in breathing, requiring the patient to be attached to a respirator in the ICU, and although the patient received a total of 100 pints of blood (Jung Hyo-sung 2008: 463), his surgeons believed that he had a high

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[11] I consulted the rulings (98GOHAB9(98고합9), 98NO1310(98노1310), 2002DO995(2002도995), “The Last 10 Years of Koreans, ” *The Chosun Ilbo* 2014. 9. 4. http://news.chosun.com/site/data/html_dir/2014/09/04/2014090400346.html, and “Dying with Dignity and Debate over Murder,” *Newsis* 2007. 6. 5. https://news.naver.com/main/read.nhn?mode=LSD&mid=sec&sid1=102&oid=003&aid=0000441641

probability of recovery.[12]

The patient's wife seemed unwilling to let her husband receive costly post-operative care and treatment. She testified at the trial that the patient had been an alcoholic and violent husband and father who had lived an idle life for 17 years after he had failed in his business. The family was socioeconomically encumbered while the wife alone shouldered the responsibility of securing income. The medical expenses accrued prior to the patient's removal from the ICU were already a large financial burden at approximately $2,600, not to mention the prospective medical expenditures that the wife would incur should he remain in the ICU. Although the medical staff told the patient's wife that the hematoma was successfully removed and that the patient's condition would improve, she strongly requested her husband be discharged due to the financial burdens. A resident overseeing the patient tried to dissuade the wife, explaining that he would likely recover with further treatment and that removing him from the hospital and the ventilator would make breathing difficult and cause his eventual death. The resident even secretly suggested to the wife that, if the financial burden was too heavy, she could let her husband receive the treatment and then run away with him after his condition stabilized; however, the wife was unbending in her request.

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[12] As to the patient's possibility of recovery, it is arguable. The doctors told the wife that the patient would recover after the surgery and subsequently testified to the police as such. However, they later changed their assertion during the prosecution investigation. The intern who accompanied the patient and the wife to their home was interviewed by *Chosun Ilbo* in 2014 and said that it was a hopeless discharge. The Korean Medical Association published "A Report of Medical Review on the Boramae Hospital Case" in 1998, which concluded that the male patient had a 90 percent expectation of morbidity due to complications (Heo Dae Seog 2004). It is beyond my ability and the purpose of this dissertation to examine whether the first favorable prognosis was wrong or the doctors changed their statement to win the trial. Yet, both positions require us to ask what "successful" surgery and the probability of "recovery" would really mean in the doctor's explanation provided to the wife and the prosecutor. Was it due to a lack of time to fully explain the details of the patient's condition, or was it due to the culture of rescue?

After numerous conversations, the resident referred the wife to his superior, saying that she needed to get approval from the attending doctor. The attending doctor reiterated that discharge would cause the patient's death, but the wife remained determined. The doctors gave up arguing with her, and the attending doctor ordered the patient's discharge. The resident took the wife through the discharge process and had an intern accompany the patient and his wife home. After arriving at the patient's home, the intern stopped ambu-bagging[13] and removed the tube from the patient's trachea. Less than five minutes after extubation, the patient began to have difficulty breathing and died.

Someone told the patient's wife that the police would provide monetary support for a funeral when a poor *byeonsaja* dies. The wife thus reported to the police that her husband had died. It is not known for certain whether the wife truly understood what the terminology meant because a *byeonsaja*, as legal terminology, refers to a person who has died unnaturally. Her report thus changed the categorization of the event entirely—from a medical event to a legal case.

In receiving the report, the police suspected that the patient's family had hurried to cremate the body. The police interrogated the doctors as to whether or not they had expected the patient would die after discharge. The doctors explained that it was customary practice to discharge a patient when requested to do so by the patient or family. The prosecution then filed charges against the wife, the attending doctor, and the resident as joint offenders in a homicide, and charged the intern with homicide. Afterwards, the then-spokesperson of the Korean Medical

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[13] A manual resuscitator; a hand-held device commonly used to provide positive pressure ventilation to patients who are not breathing or not breathing adequately. https://g.co/kgs/grRnCD

Association, Doctor Kwon Yongjin, said in an interview, “In retrospect, the medical community was ignorant of law and the legal community was ignorant of the reality of medical field.”[14]

The Seoul Western District Court declared the wife, the attending doctor, and the resident guilty of murder by omission; the court sentenced the wife to three years in prison with four years of probation, and sentenced the attending doctor and resident to two years and six months in prison with three years of probation. The court declared the intern innocent. The wife’s defense counsel argued before the court that discharging the patient due to lack of financial resources should be understood as a socially-accepted rule, but the court rejected this contention on the ground that the wife should have sought precise information as to the condition of the patient, the treatment procedure, the care plan, the prognosis, and the estimated medical fee. The court held that the burden of the medical costs should be objectively assessed as to whether or not the cost would actually exceed the scope of family resources. Even if the costs were to exceed the family’s financial ability, the court interposed, still the patient’s dignity of life should be prioritized.

The doctor and resident’s defense counsels argued that professional practice could be conducted only with permission from a patient capable of self-determination; if a patient is unconscious and a protector of the patient strongly requests discharge of the patient, the legal obligation of doctor to continue the treatment is subject to lapse. Although the court agreed that only the patient’s permission based on self-determination granted the legitimacy of medical

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[14] I interpret this comment as suggesting that the doctors and the medical community should have elaborated upon their report to the police so as to deflect any potential legal troubles.

practice, if termination of treatment directly led to a grave consequence—i.e., the death of the patient—doctors were obligated to protect the higher value: a life of the patient over a request for patient discharge. With respect to the self-determination issue in this case, the patient's explicit intention was absent, and the patient's wife requested termination of treatment. The doctors accepted her request, based on grounds of a release from the burden of medical expenses, without any consideration of the patient's intention. The court regarded that this case lacked both self-determination and consideration for the best interests of the patient.

The court rejected the doctors' contention that the possibility of recovery was low on the basis of both the initial testimonies and the postmortem report. Most of all, the court held that even if the doctors believed their conduct to be a customary action at the moment, they should have recognized that the conduct was in opposition to their conscience and ethics; the doctors should have carefully contemplated the situation and consulted with other professionals. The court found that they had been too rash in their termination of the treatment, based solely on their own judgments.

Both the prosecution and the accused appealed against the decision. The Appeals Court rejected the appeal of the wife and the prosecution. The Appeals Court held that the wife intended to let her husband die; whereas the attending doctor and resident did not intend for the patient to die. As the doctors had taken the best medical measures in caring for the patient and had repeatedly tried to dissuade the wife, the appeals court did not believe the doctors were willing to tolerate the patient's death. Yet, because the doctors had recognized the patient's likely death, the Appeals Court found discharging a patient with the imminent prospect of death as an aid of murder, not as murder by omission, which is how the District Court had ruled. The Appeals Court defined the cessation of treatment to a dying patient as passive euthanasia and stated that it could only be allowed for limited cases based on patient self-determination and a conscious decision by the doctor. In considering the circumstances allowing for mitigation of punishment, the court took into account the recent change in the doctor-patient relationship from a paternalistic to a contractual relationship, the prevailing decision-making by relatives of patients, the lack of institutional support for doctors, and the lack of available social support for patients and their families. As such, the initial length of the sentence for the attending doctor and resident was reduced to one year and six months in prison with two years of probation. The prosecution, the attending doctor, and the resident—everyone except the wife—appealed to the highest court against this decision.

The case, which was originally opened in 1997, dragged on for seven years. On June 24, 2004, the Supreme Court upheld the initial verdict on appeal. A set of messages conveyed by the three courts seemed clear: the courts set a high value upon a careful and contemplative attitude, essentially requiring a reasonable and moral decision that allowed for no options other than the termination of treatment. The wife should have sought enough information from the doctors to outline the care plan, prognosis, and the expected medical expenses. She should have mobilized all the resources she had. If she found out that, regardless of her desperate efforts, there was no way to support her husband’s treatment, the court would have been willing to be generous to the wife.

In regard to the doctors, they should have tried their best to identify the patient’s presumptive intention in a careful manner. The court held that the doctors should have recognized this action as against their professional consciences, and that the doctors should have recognized that what they were doing was unethical. They should have consulted other professionals, rather than allow one single doctor to make the decision. The court, in conclusion, called the doctors' and the wife's attitudes toward life into question, because to terminate the treatment was ultimately a decision between life and death. As Hyo-Sung Jung, a doctor and jurist, states, "If the doctors had discharged the patient from the hospital in a critical condition following conscientious consideration of the patient's interests and intentions, the court could have respected the professional's decision" (2008: 467).

The Aftermath of the Boramae Hospital Case

It is clear that the verdict in the Boramae Hospital Case was not an unconditional rejection of treatment withdrawal. Within this case, the possibility of recovery was arguable, and the patient's intention was also unidentifiable. Nevertheless, the decision made by the Supreme Court scared the Korean medical community (Choi Kyungsuk 2016; Jung Hyo-sung 2008). They could not hide their shock that their professional practice could entail criminal liability. As the attending doctor and the resident stated to the police, discharging a patient at the family's request had been a customary practice in Korean hospitals, which no one had problematized and for which no legal precedents had previously questioned. Korean doctors were very accustomed to facing the relatives of patients who made decisions on treatment in general. In particular, it was common to talk with the patient's family members when a patient was a senior citizen. In the same manner, if a patient or relatives of a patient strongly demanded, doctors customarily allowed the patient to be removed from the hospital. This was especially true when a patient was dying of terminal diseases.[15]

In part, this practice was related to a concept of *gaeksa*, which refers to dying in places other than home, as I discussed in the Introduction. Dying in a hospital was deemed as *gaeksa*, and patients and their families often asked doctors to discharge patients so as to let them die at home (rather than undergoing a futile "heroic" intervention), surrounded by their relatives. If a patient and/or a patient's family requested discharge, an intern would accompany the patient on a portable ventilator and ambu-bag via an ambulance, remove the ventilator after arriving at the home, and declare the death of the patient, which is exactly the same as what the intern had done in the Boramae Hospital Case. This death would be recorded on the medical chart as a "hopeless discharge," "moribund discharge," "DAMA (discharge against medical advice)," etc. (Jung Hyo-sung 2008).

The Boramae Hospital Case was actually not about a desperate request from family members to make the death good, but about the burden of medical expenses. The courts, too, problematized the lack of self-determination and the fact that the wife did not seem to be acting on behalf of the patient. However, it seemed that only a partial truth, taken out of context, circulated in the Korean medical community: a doctor accepted a family's request to turn off a

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[15] An identical practice with the same reason is observed in Taiwan as well (Lin Heng-Yi et al. 2017). Stonington (2012) reports the same practice in Thailand, and he analyzes that the two places—a home and a hospital—are considered different ethical locations in Thailand.

ventilator and he became a criminal! Doctors and nurses became reluctant to risk legal action by withdrawing treatment and discharging patients.[16] Consequently, this produced a new practice: defensive medicine (Jung Hyo-sung 2008: 463; Kang, Hyun-Hee et al. 2008). It became an unwritten rule that no withdrawal of treatment would be permitted, regardless of a patient's condition or wish.[17] A newspaper[18] reported:

> A bad scuffle between family members of a patient and a doctor happened in an ICU in the S Hospital because the family members tried to strip off a ventilator—a patient's lifeline—from the patient, which may be punished as patricide/matricide. The background of this terrible situation is that the total cost of treatment for the patient, who lost her consciousness by cerebral infarction, was $16,000, and $14,000 of the total cost remained unpaid. As doctors have already learned from the Boramae Hospital Case, granting a patient's request[19] would end in a charge of homicide, they cannot help but continue the treatment. The tragedy of this case is so common that it occurs in every hospital day after day. Some doctors are grabbed by their collars; tussles between patients' families trying to carry a patient to a van and the medical staff restraining them from it; and some critically ill patients cannot receive necessary intensive care at the proper moment because patients who have lost consciousness cannot be removed to open up needed beds.

The scene the newspaper described matched the story I had heard from Dr. Jee. Many of the doctors and nurses whom I have met told me that they had learned from their seniors— from the time they were students in medical and nursing schools—to never extubate tubes from dying patients and to avoid working in the departments where critically ill patients would be admitted.

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[16] For instance, "Strong backlash from the medical community," *Yonhap News Agency*, 1998. 5. 15. https://news.naver.com/main/read.nhn?mode=LSD&mid=sec&sid1=102&oid=001&aid=0004363290

[17] "The Last 10 Years of Koreans, " *The Chosunilbo* 2014. 9. 4. http://news.chosun.com/site/data/html_dir/2014/09/04/2014090400346.html

[18] *Joongang Ilbo*, 2001. 4. 19. Jung Hyo-Sung 2008: 479.

[19] Strictly speaking, it was the patient's wife, not the patient himself, who requested the discharge in the Boramae Hospital Case. However, to the doctors, a distinction between a patient and a patient's relative was not important because, in the Korean clinical setting, a patient and her relatives are treated as one. I will address this issue in Chapter Six. Usually, doctors and nurses say "*hwanja cheuk*" (환자 측), which encompasses both the patient and her relatives. I cannot find a corresponding translation word in English for *cheuk*.

As one doctor confessed in a conference, it was almost like a case of “victim mentality”: the fear of lawsuits paralyzed the medical community. The doctors’ strong refusal to stop life-sustaining treatment discouraged the previous practices that avoided *gaeksa*, and lay people could not help but accept this change anad let their family members die in hospitals. Consequently, the medical practice of hopeless discharge has faded away.[20]

Nowadays, the Boramae Hospital Case has been become widely known to the public. Particularly, since it was reported that the judge in the case, who found the doctors guilty, agreed to halt his mother’s life-sustaining treatment, this verdict tends to be negatively assessed as a verdict that set end-of-life care back decades in Korea. However, the verdict of Boramae Hospital Case has been misstated in part, because what the court called into question was not the termination of treatment per se, but rather that the wife and the doctors’ decision were not based on the patient’s self-determination and consideration of the patient’s best interest. Indeed, the verdict included a precondition that could allow for the termination of life-sustaining-treatment, which was very much consistent with the terms of the Act adopted in 2016 to allow for termination of life-prolonging treatment. This verdict did not intend to aggravate the quality of end-of-life care, but rather proposed the foundational conditions for it. If the ending of artificial life-support systems was not based on a patient’s wish or presumptive intention, then, the verdict implied, it was an unlawful taking of life.

In sum, since the Boramae Hospital Case of 1997, it had become an implicit code of the

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[20] Yet, still, but rarely, some relatives of patients, especially elderly people, request a discharge of the dying patient so that the patient can die at her home.

medical community not to allow the withdrawal of life-sustaining treatment. This practice bred many misunderstandings among lay people, who thought that the reason doctors and hospitals refused to terminate futile treatment was so they could profit off of imprisoned patients. Doctors were insulted by having their collars physically grabbed by the angry relatives of terminally ill patients. For the hospital's finances, it is like a "black hole," in that a less-profitable patient may occupy a bed without any guarantee of when the situation will end. For the government, the prevalence of meaningless life-sustaining treatments causes a significant medical expenditure (Kim Hye-Lim et al. 2017); and for human beings, it harms the right to die with dignity.

However, these troubles would not be fixed until a turning point surfaced through an event in Severance Hospital in 2008, which resulted in a second transition in the medical practice of end-of-life care.

The Grandmother Kim Case in 2008[21]

A 76-year-old woman visited her doctor due to cold symptoms. A pharmacist told her to go to a tertiary hospital, suspecting her symptoms might indicate pneumonia. The woman visited Severance Hospital and the doctor told her that lung cancer was suspected. In order to identify lung cancer, she underwent a lung biopsy via bronchoscopy in the hospital on February 18, 2008.

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[21] I consulted the rulings (2008GAHAB6977(2008가합6977), 2008NA116869(2008나116869), 2009DA17417(2009다17417)), "The Law of Dying with Dignity Began from this Grandmother" https://www.huffingtonpost.kr/2017/10/25/story_n_18381834.html, and "Interview with Grandmother Kim's eldest son-in-law, Mr. Chisung Shim" (*Lady Kyunghyang*, August, 2009.) http://lady.khan.co.kr/khlady.html?mode=view&code=4&artid=200908051731391&pt=nv#csidxfac3fc516d04c028d9f9523900368ae

During the examination, excessive bleeding occurred and, consequently, she went into cardiac arrest. The medical staff administered CPR, and her heartbeat resumed. The patient was put on a ventilator and was carried into the hospital’s ICU. She was subsequently diagnosed with hypoxic brain injury and had lapsed into a persistent vegetative state. According to a medical chart presented to the court at a later date, the patient was not able to sustain her breathing without the assistance of a ventilator. With a loss of cognitive function, she was without consciousness and was thus unable to communicate. The patient demonstrated only limited reflexes; she spontaneously opened her eyes and rolled her eyes in response to external stimuli. A brain wave examination, which was run on April 19, 2008, showed abnormal findings of diffuse brain function. One month later, the doctor in charge in the ICU informed her family that the patient had brain death and proposed to have the ethics committee of the hospital review the case.

The three daughters, a son, and their spouses had difficulty accepting this reality because the patient had been visibly healthy right up to the initial examination. They wanted to know what the patient wanted, but she was unable to tell them. They thought back to previous moments when she had discussed ways of dying, and remembered the events leading up to her husband’s death three years earlier. When the patient’s husband was near the end of life in 2005 in the same hospital, all of the family members were waiting for the son to return from his business trip to the U.S. so that the dying patient could see his son before his demise. The doctor in charge asked if the family members wanted to insert a tube into the patient’s trachea, which would prolong his life until the son came back. The wife—i.e., the current patient—at that time flatly rejected the suggestion, saying, “It is God who rules breathing. Prolonging a life by machine is meaningless. If the same event happens to me, do not put me on a ventilator."

The family members told the hospital that they wanted to terminate the ventilator and believed it to be the patient's wish. The hospital informed them that not only the ventilator but all of the sustaining measures should be terminated. While the family members debated, the doctors learned that the family had sued the hospital for medical malpractice, and the meeting of the ethics committee was canceled. The family members then sought assistance from a judge to remove the ventilator by filing for an injunction to stop the life-sustaining treatment for their mother. Since the patient was a senior citizen whose surname was Kim, the mass media referred to this case as "the Grandmother Kim case."

The patient's family asserted at the trial that (1) there was no reasonable possibility of the patient returning to a cognitive state; thus the current treatment merely prolonged her vital symptoms, which was medically meaningless; and that (2) the patient had previously expressed to her family her wish to die naturally. The family testified that, in addition to what the patient had said when her husband was dying, when the patient had been watching a scene of a patient lying in a bed on TV, she had said, "I don't want to live like that, troubling others. I want to finish my life in a neat manner." Furthermore, the family members testified regarding the personality of the patient that she was so concerned to look neat and proper that she always—even in summers—wore long-sleeved tops and long skirts because she did not want to reveal the little scars on her arms from a car accident some 15 years prior.

The testimonies of family members as to the patient's presumptive intention were all upheld by the Seoul Western District Court. It held that life-sustaining treatment caused physical pain and mental suffering to patients without prospect of recovery and that this meaninglessly prolonged suffering harmed the dignity and value of human beings. In this circumstance, the court held, the benefit of dying outweighed the benefit of maintaining life. The court held that if treatment was futile and if the patient's intention to terminate treatment could be presumed, the exercise of self-determination of a patient should be respected. The verdict professed that, under such conditions, terminating the use of an artificial ventilator would be without criminal or civil liability on the part of any parties, whether family members, physicians, or hospital.

Severance Hospital appealed to the Appeals Court and the Supreme Court, and both courts rejected the appeals of the hospital. The hospital argued that (1) the patient was not in an irreversible dying process and that (2) the testimonies of the family members were not enough to presume the patient's intention to stop the treatment. Both the Appeals Court and the Supreme Court rejected the appeal on the grounds that the evidence exhibited to the lower court proved the patient's irreversible state and the courts upheld the testimonies of the family members as to the patient's presumptive intention. Also, the two upper courts asserted that the treatment using the mechanical ventilator was not necessary treatment because it did not alleviate the patient's pain or contribute to respecting the dignity of the patient.

After the Supreme Court dismissed the appeals and confirmed the decision of the lower court, the ventilator was finally removed from the patient. It was 492 days after she lost consciousness during the examination. Yet, even after the removal of the ventilator, the patient did not pass away. Nor did she regain consciousness or vital function. She just remained in the grey area between life and death for an additional 141 days with spontaneous breathing, before passing away on January 10, 2010.

The Grandmother Kim case is often likened to the Quinlan case in the U.S. Both cases granted the medical profession freedom from criminal prosecution when removing life support from patients with no possibility of recovery (Choi Kyungsuk 2016; Hirsch and Donovan 1976; Stevens 1996). As Stevens pointed out, the crux of the Quinlan case was not about new technology imprisoning a patient in her body, but the professional fears the medical community had over criminal liability (1996: 352). With respect to the Grandmother Kim case, I believe it was the Korean medical community that most welcomed this legal action.[22] This social group had longed for some form of legal guidance to help navigate their practices regarding life-sustaining treatment.

A New Agenda: Death with Dignity

Compared to the Boramae Hospital Case, which essentially called the withdrawal of life-sustaining treatment a form of passive euthanasia, the Grandmother Kim Case utilized the phrase, “death with dignity” for the first time. All the mass media that covered this case reported that the Supreme Court respected the right to die with dignity and framed this verdict as a triumph of self-determination over the right to life. The medical community, too, actively participated in producing a discourse of death with dignity, and this action was not a coincidence, but a

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[22] For instance, “Medical Community’s Positive Remarks about Passive Euthanasia,” *Munhwa Ilbo*, 2008. 9. 1. https://news.naver.com/main/read.nhn?mode=LSD&mid=sec&sid1=102&oid=021&aid=0001963131.

calculated strategy of language politics. Rhetorically, “death with dignity” conveyed less controversial and more acceptable implications than did “passive euthanasia.” While euthanasia is controversial enough to provoke heated ethical debates—calling for input from a range of professionals from jurists, religious professionals, and ethicists—death with dignity implies a natural right due to all humans that no one can disagree with. By labelling the withdrawal of life-sustaining treatment as death with dignity, a group of people came together to advocate for a law that would allow for the termination of life-sustaining treatment, without precipitating emotional resistance from the public. Thus, a series of legal cases, beginning with the Boramae Hospital Case to the Grandmother Kim Case provided the historical background by which withdrawal of treatment came to be called death with dignity instead of passive euthanasia.

Toward Legislation of End-of-Life Care

With the Supreme Court decision, the collective efforts to legislate the use of life-sustaining treatment came to fruition (Korea National Institute for Bioethics Policy 2018). The Social Consultative Body was organized in December 2009; the Korean National Institute for Bioethics Policy (KoNIBP) published their Recommendation in July 2013; and the Ministry of Health and Welfare held a public hearing. Finally, the Act on Hospice and Palliative Care and Decisions on Life-sustaining Treatment for Patients at the End of Life was passed by the National Assembly on January 8, 2016, with 203 out of 204 votes, and has been in force since

August 4, 2017.[23]

The General Provisions of the Act[24] states its purpose:

> The purpose of this Act is to prescribe matters necessary for hospice and palliative care and life-sustaining treatment for patients at the end of life, determination to terminate or withhold, such life-sustaining treatment, and the implementation thereof, and thereby to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination.

That is, by this Act, patients at the end of life may determine whether to continue, withhold, or withdraw life-sustaining treatment, and the patients' best interest and self-determination may be assured and protected in the process. In doing so, the dignity and value of human beings are meant to be protected.

The key terms were defined as follows:[25]

> 1. end-of-life process: a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly;
>
> 2. patient at the end of life: a person who has received a medical prognosis under Article 16 from the doctor in charge and one medical specialist in the relevant field that he/she is in the end-of-life process;
>
> 3. terminal patient: a patient who has been diagnosed as expected to die within a few months by the doctor in charge and one medical specialist in the relevant field in accordance with the procedures and guidelines prescribed by Ordinance of the Ministry of Health and Welfare, because there is no possibility of a fundamental recovery, and the symptoms gradually worsen despite proactive treatment of any of the following diseases: (a) cancer; (b) acquired immune deficiency syndrome (AIDS); (c) chronic obstructive respiratory disease; (d) chronic liver cirrhosis; (e) any other disease prescribed by Ordinance of the Ministry of Health and Welfare;

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[23] Only one member abstained.

[24] See Appendix for more details of the Act.

[25] Some key terms were revised in 2019, and I will deal with this revision in Chapter Seven.

> 4. life-sustaining treatment: medical treatment by cardiopulmonary resuscitation, hemodialysis, administering anticancer drugs, and mechanical ventilation to a patient at the end of life, which merely extends the duration of the end-of-life process without curative effect.

Putting the key terms together, end-of-life and life-sustaining treatment in the Act were narrowly construed as four technological measures which were used in "a state of imminent death" of a patient.

The heart of the Act is to provide a prescribed process to assist in implementing the withholding and withdrawing of life-saving measures. First, the Act offers two official forms for patients to enunciate their intentions regarding an end-of-life care plan: (1) Physician Orders for Life-Sustaining Treatment (POLST)[26] and (2) Advance Directives (AD). In order to manage general affairs regarding life-sustaining treatment, the Act prescribed the establishment of the National Agency for Management of life-sustaining treatment and directed the Minister of Health and Welfare to designate registration agencies to supervise the registration of ADs. Also, each medical institution shall establish an institutional ethics committee in order to perform the services concerning determination and implementation of withholding/withdrawing of life-sustaining treatment.

The details of how to implement the withholding and withdrawing of life-sustaining treatment are as follows. (1) A doctor in charge provides a terminal patient/patient at the end of life with relevant information on a POLST. (2) A patient may request the doctor in charge

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[26] According to the National Law Information Center, which provides the official English version of Korean Law, the Act denominated the English name POLST as a "life-sustaining plan," and an AD as "advance statement on life-sustaining treatment," Instead of POLST and AD.

prepare the POLST. (3) The doctor in charge explains the status of the patient's disease, care plan, life-sustaining treatment, matters concerning determination to withhold or terminate the treatments, information on using hospice care, and the overall process of POLST. The prepared POLST is registered and kept in a medical institution where the patient signs it. (4) The doctor in charge and a medical specialist diagnose whether a patient is in the end-of-life process. (5) The doctor in charge verifies the patient's intention by (a) POLST written in advance, (b) an AD, or (c) two or more identical statements of the patient's family members regarding the patient's intention that was consistently expressed if a patient is not able to express her intention; (d) and if it is impossible to verify a patient's intention, all members of the patient's family should reach an agreement. (6) The doctor in charge immediately implements the determination. Yet, the medical care for relieving pain and the simple provision of nutrients, water, and oxygen shall be provided indefinitely. (7) A person who implements a determination to terminate treatments to a patient not subject to the Act, is in violation of Article 15 and shall be punished by imprisonment with labor for up to three years, or by a fine not exceeding 30 million won.

According to the Article 2 of the Act, which defined the key terminology of the Act, "end-of-life process (*imjong-gi*, 임종기)" means a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly, and "terminal patient (*malgi*, 말기)" means a patient who has been diagnosed as expected to die within a few months because there is no possibility of a fundamental recovery, and the symptoms gradually worsen despite proactive treatment. That is, this Act segmented the last months of a person into a terminal stage and an end-of-life process. Both periods are the time of irreversibility, but one spans a few months and the symptoms gradually worsen, whereas another is defined as imminent death with a rapid pace of symptoms progression.

The whole process of end-of-life care decision-making is outlined in the following chart (Figure 1).

Responses to the Act

This Act can be read as a very ambitious attempt to pursue two seemingly conflicting values simultaneously—the best interest of the patients and the right of self-determination (Lee Seok-Bae 2017). From the point-of-view of medical ethics, these two values often are regarded as contradictory because it is the physician who judges the best interest of the patient, whereas self-determination stresses the right of the patient to decide what she wants, even if what she wants is against her best interest.

Scholars, medical professionals, and religious figures, who had been involved in the legislative process, in part welcomed the Act as it opened a door to the termination of unwanted, meaningless interventions. For example, Kyungsuk Choi, a professor in bioethics who had participated in the legislation, assessed the Act as an achievement that, on the one hand, makes possible the termination of treatments, and upholds "life," on the other hand (2016: 122-123).

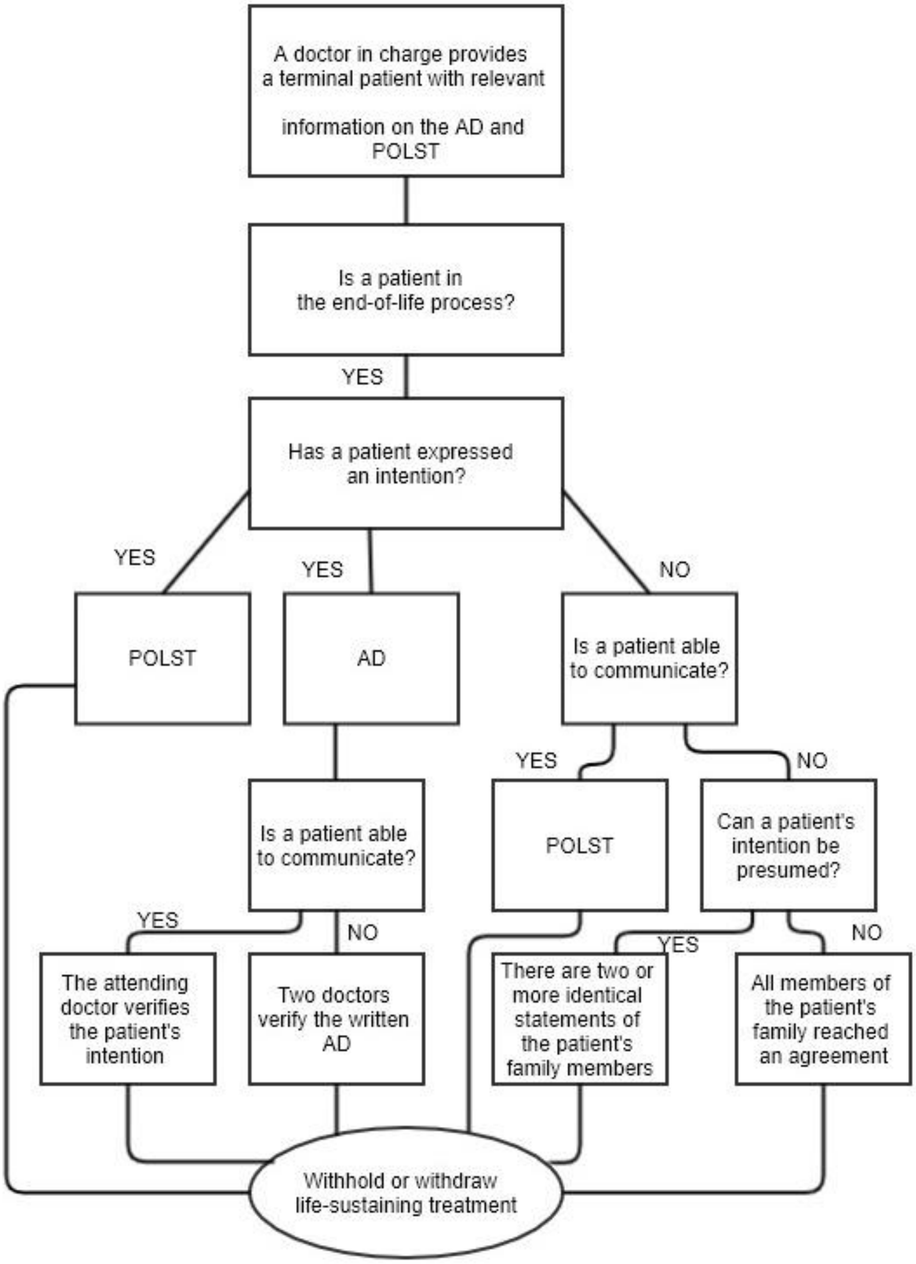

Figure 1. Flow Chart of the Act

Yet, the Act did not end all the uncertainties and anxieties held by some involved parties. It is worth illustrating some scenes I observed at a conference that was held on April 26, 2017, right before the announcement of the forthcoming legislation. Presenters, discussants, and participants on the floor—ranging from doctors, nurses, and social workers, to professors—expressed their concerns regarding the details of the Act from diverse viewpoints. Their concerns, in fact, converged upon one salient question: Can this Act really contribute to the ultimate goal of the Act, i.e., dying with dignity? For instance, many participants were concerned that this Act seemed to aim to *regulate* what practitioners did in the clinical field rather than to *promote* better end-of-life care. In order to withdraw life-sustaining treatment, doctors were supposed to fill out and register a total of seven legal documents, which the medical professionals at the conference believed to be too demanding. Although a presenter who came from the Ministry of Health and Welfare tried to relieve the concerns by saying that "this Act provides a conversation channel between doctors and patients/families, and this Act will protect the medical practice that is conducted within the framework the Act offers," it seemed to fail to dispel these worries. The worries the medical professionals expressed in the conference were reasonable because reality is always more complicated than can be captured by a neat flow chart that schematically outlines the articles of the Act.

Conclusion

I have described in this chapter two legal cases and their consequences. In the time that the emergence of some technologies and the avoidance of *gaeksa* together created a medical practice that allowed transfer the dying body to their homes, the Boramae Hospital Case intervened in this situation and resulted in doctors’ refusal to withdraw any life-prolonging measures. The second case, the Grandmother Kim Case in 2008, defined a way of dying free from aggressive measures and, invoking the rhetoric of ‘death with dignity,’ led to legislation that ratified the decision in this case. By defining the scope of life-sustaining treatment and the diseases involved, the Act succeeded in charting a process for the implementation of withdrawal of treatment, which, however, engendered some additional worries and concerns, some of which had been voiced before the law was in force. The two cases did not merely provide the legal background for hospital death; they also provided powerful elements of the structure that determined what practices can be provided in hospitals. The Act, which framed when and who could do what, was an additional structure that would overlap with a number of other already-existing hospital structures. In the following chapters, I explore the ways in which the palliative care team shaped a way of dying within the context of the multi-layered structures in S Hospital. In so doing, the entailments of the two legal cases and the Act intersected on and off with the other structures that doctors, nurses, and family caregivers had to navigate during the end-of-life process in S Hospital. In the next chapter, I show how the Act and its articles were articulated within the existing hospital system and moral and material conditions for good dying as the palliative care team endeavored to institutionalize the new way of dying that the Act had engendered.

Chapter Three

Institutionalization of New Form of Dying

Introduction: Demonstration Projects

One day in October 2017, Nurse Kim, with a bright smile, distributed pretty pocket notebooks to the team members who attended a regular staff meeting. The notebook, on which the emblem of the palliative care team was imprinted, contained sticky notes and a ball-point pen. It was a custom-built souvenir for the palliative care team that the team itself had ordered, and, indeed, it was a high-quality souvenir.

A week later, Nurse Kim announced in a morning briefing that each volunteer team would receive money—a one-time subsidy—with which the volunteers could go out for a dinner. This had never happened before. The volunteers were surprised by the news, and a volunteer asked, "How did we become so rich all of a sudden? We have always been poor." The volunteer laughed and continued, "Is it ok for us to take this money?"

Nurse Kim answered, "We were picked for a demonstration project concerning consultation-based hospice, and the government gave us some money for the project. Now hospice consultation is reimbursed by the government. So far we have occupied a place outside the system, but finally we have been given a place within the institutionalized system."

The demonstration project that Nurse Kim mentioned was a government-led pilot program initiated prior to the enactment of the Act. The Ministry of Health and Welfare began a number of demonstration projects at the time the Act was adopted, for the purpose of testing if the Articles of the Act could be smoothly implemented in the clinical settings. S Hospital had been designated for two projects: a demonstration project of consultation-based hospice and a demonstration project of life-sustaining treatment in August 2017 and October 2017, respectively. Consultation-based hospice is one form of hospice.[27] Unlike at-home hospice care, where the end-of-life care is conducted in the patient's home, or inpatient hospice, where the dying patient receives care in a hospice ward (whether in a hospital or in a hospice), in consultation-based hospice, a palliative care team visits patients in general wards and provides services needed in those wards. A palliative care team consists of hospice-trained physicians, nurses, social workers, spiritual caregivers, and volunteers, and provides both palliative care services and psychological and spiritual consultations. Because it does not require an independent hospice ward, this form of hospice can be understood as a compromise to implement hospice care in large-scale hospitals—such as the tertiary hospitals—in South Korea. The main purpose of the consultation-based hospice project was to institute a pilot project relating to reimbursement fees—that is, to determine how the participant institutions would be reimbursed for consultation fees, management of death fees, and fees for the *imjongbang* (the private room only for the dying).[28]

The life-sustaining treatment demonstration project focused on the two parts of the Act: Advance Directives (AD) and Physician Orders Life-Sustaining Treatment (POLST). Following

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[27] It is also called a palliative care consultation team (Sasahara et al. 2009) and a consultation-based hospice and palliative care (Hu Youn Jung 2013). In Korea, it is called *jamunhyeong* hospice (자문형 호스피스).

[28] "Four among the Big-Five hospitals participate in the consultation-based hospice service." *Kukminilbo*. 2017. 7. 6. http://news.kmib.co.kr/article/view.asp?arcid=0923779260

evaluations by the Selection and Assessment Committee, a total of 13 institutions had been designated in August 2017; five institutions for AD, and ten institutions for POLST. S Hospital was one of the ten institutions chosen for POLST. In these designated institutions, patients were able to decide whether to withhold or withdraw the four types of life-sustaining treatment via AD or POLST before the Act was initiated in 2018. In the cases in which patients were unconscious, family members were able to make decisions via statements of agreement.[29] The period of the demonstration project ran from October 23, 2017 to January 15, 2018.

Incorporation of Palliative Care in the Hospital System

The launching of the demonstration projects symbolized an entry of the palliative care team into the hospital system and the national health care bureaucracy. The palliative care team had occupied a marginal area in the whole hospital system before the demonstration projects. One reason for the marginalization of palliative care came from its unprofitability. Until the demonstration projects were initiated, consultation was not a medical intervention reimbursed by the government. In other words, the consultations that the nurses provided to their patients and families were not deemed as a form of labor that created countable and reimbursable values. Outside the reimbursement system, all the activities that consumed the time and effort of the nurses remained unreimbursed volunteering for good will.

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[29] However, the case of family members' agreement was excluded in the demonstration project since the Act had not yet come into force.

Besides, the purpose of palliative care is to provide relief from symptoms, pain, physical stress, and mental stress, while not requiring patients to receive invasive and aggressive treatment that would not do them any good. This purpose is, in fact, contrary to that of any for-profit acute care tertiary hospital. There was no reason to let a patient stay in a tertiary hospital if the patient did not need complicated medical interventions. Thus, it was not surprising that the palliative care team had not been given much systemic attention. In every way, the team had depended upon charity and volunteers. Its staff had struggled with a chronic shortage of money for operating expenses,[30] and that was why the veteran volunteers, who had witnessed these difficulties, were surprised by the news of the subsidy.

At this turning point, when the center was finally institutionalized through the demonstration projects, it was allocated money from the government. Though the sum they received was likely a pittance compared to that of mainstream projects in medicine, it was enough to cover the souvenirs and provide a subsidy for the dedicated volunteers. Indeed, the two items—the small pocket notebooks and some money for a special dinner—stood as a sign of the incorporation of the palliative care team into the hospital-governmental system.

Along with the budget, a few openings for additional personnel were also allocated to the palliative care team. The palliative care team had previously been run by Nurse Kim, Nurse Roh, and Nurse Shim, while Nurse Roh and Nurse Shim occupied part-time positions. Further, the two nurses' salaries had come out of charitable resources, not from the hospital, according to

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[30] According to hearsay, the palliative care team's annual budget that was allocated by the hospital was about $12,000, which was far from enough.

what I heard from a member of the team. Now Nurse Heo, Nurse Lee, Nurse Choi, and Social Worker Woo joined the team; Doctor Yim also joined as an affiliated position in the palliative care team. In order to accommodate the new employees, the team members were busy rearranging the office and the furniture. That a service becomes a part of the health system means that the system recognizes this service as a productive activity that warranted additional money and staff. Before the demonstration projects, the palliative care team operated as if it was, itself, on life support; and only the members' dedication had maintained the existence of the palliative care service in the interstices of the hospital structure.

The enactment of the Act and launching the two demonstration projects in the S Hospital meant that a certain type of dying, which had not existed in the hospital before, came to be a part of the system of this institution. The hospital system is fundamentally punctual and regulatory. It governs time and space in order to put everything under its control, and all actors are given specific roles. In contrast to the nature of the hospital system, death is fundamentally a kind of chaotic process, which signals a failure of medicine (Ariès 2016[1974]). The presence of the dying bewilders doctors, nurses, other patients, and their visitors. Yet death does occur here, every day, and modern hospitals have developed coping strategies for routinizing death (Chambliss 1996; Moon Jae Young 2012): full code, slow code/Show-PR, ceasing, withholding, or limiting further treatment, Do-Not-Resuscitate orders (DNR), the withdrawal of life-prolonging treatment, and discretionary use of medications. Some of these methods are done in an explicit way, while others are done as unofficial practices. Hospital insiders know how to approve and implement death in hospital, but no one speaks about these methods (Chambliss

1996).

Before the legislation of the Act, only full code had been publicly recognized in Korea, while other strategies had remained outside an official system and had been carried on quietly, invisibly, and individually. The Act now authorized withholding and withdrawing of treatments; and it was necessary to determine the proper timing, place, and personnel for the implementation of the cessation of life-sustaining treatment within the existing system. It was the backstage work of the palliative care team that institutionalized these once unofficial ways of dying in the hospital. This work was much more delicate than imagined. In the following section, I unpack the ways in which the palliative care team standardized a new way of dying in the hospital. The process of standardization was not only an implantation of a form of dying in the hospital system but also an attempt to change the previous practices that had hampered a good dying in Korean hospitals. In so doing, the palliative care team played a bridging role between experts and lay people by lowering the barriers lay people faced when wanting to stop futile treatments.

The Standardization of a Form of Dying

Every Friday afternoon, we had regular meetings in which the palliative care team members developed educational materials and discussed how to institutionalize the Act in S Hospital. This was one of two regular meetings preparing the date the Act would take effect that I was allowed to attend. One day in October, the palliative care team members were revising a guideline for withdrawal of life-sustaining treatment, which targeted the medical staff working in

ICUs.

> Nurse Choi: I think this phrase, "Unnecessary administration of medicine should be canceled," sounds problematic.
>
> Doctor Jin: I was told that unnecessary medicine is very often given to dying patients in the field because doctors do not change the previous order. For example, even ABG[31] at times continues for a dying patient, I was told.
>
> Nurse Choi: I think this expression, "unnecessary" could make doctors feel uncomfortable. They are like, "What? So, what I have done to my patient that was something unnecessary?"
>
> All: (laughed)
>
> Nurse Choi: How about this: "Only imperatively necessary medicine may be administered."
>
> Doctor Jin: That's very nice!
>
> Nurse Choi: We'd better use some positive words. When one is told "unnecessary administration of medicine may be canceled," the negative words can make her feel uncomfortable. So we can say, "Only imperatively necessary medicine and exams may be done."
>
> Nurse Lee: It's not what you said, it's the WAY you said it.
>
> Doctor Jin: I think we can get rid of "exams," too, because exams should not be done to the dying anyway.

In this conversation, Doctor Jin addressed the fact that residents, in many cases, left the pre-given orders unchanged even when a care plan had obviously been changed once the patient had entered the dying phase. To be clear, the previous orders had remained not because the doctor in change was negligent, but because the resident did not know what order would be considered necessary or unnecessary.

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[31] An arterial blood gas (ABG) test, which measures oxygen and carbon dioxide levels and PH levels in blood. (https://www.healthline.com/health/blood-gases)

A resident I met during my fieldwork bitterly clarified this very issue. She confessed that running carbon dioxide exams on elderly patients whose death was imminent was torture to her. Contracting pneumonia is very common in elderly patients with underlying diseases because of their debilitated immune system. In order to examine a patient's difficulty breathing, the resident was required to collect arterial blood. Collecting blood every six hours was routine, she recalled. The resident felt awful as the patient's arms were riddled with needle marks. She wondered, "If running this exam would not be beneficial, but even harmful, to the patient, why am I supposed to torture my patient?"

Similar events occurred very often. When she was on night duty, the resident found a doctor in charge had ordered the collection of arterial blood. "It was ridiculous because at that point the exam was entirely meaningless unless they would want to do research on how much carbon dioxide in blood was needed to cause death." She could not stand it anymore and was determined not to run this exam again. On her way to explain to the patient that this exam only imposed pain to the patient, she learned of the patient's death. She said:

> In school, we only learn how to save patients. We don't know how to deal with the dying. I have never talked with professors about when is the right time for DNR. No guidelines for dealing with the dying.… The resident might casually order the arterial blood exam, I don't know. But many (doctors) would feel like they're doing nothing without ordering an exam. So they order meaningless exams.

According to her, in medical education, caring for terminal patients is rarely taught, and physicians have little sense of how to alter treatment according to the changed care plan. As a part of hospital culture, doctors feel pressure to do something, thus leading to the continued ordering of meaningless exams. Doctors may be reprimanded for not ordering an exam, but would likely face no repercussions for ordering an unnecessary exam.

A nurse who worked in the terminal-cancer ward also complained to me about the practices of some doctors. Patients with cancer can experience extreme suffering from cancerous pain. If a patient's death was imminently expected and the patient complained of severe pain, the nurse wanted to make the patient comfortable. Yet, according to her, the residents rotating in the terminal-cancer ward, at times, ordered medications based upon a patient's breathing rate, weight, and interval of medication as they had learned from textbooks. The nurse believed that, if the residents truly understood how much pain the patients were in and what the dying process was like, they would never have based their ordering of painkillers solely on such data.

What I heard from physicians and nurses about the existing problematic practices echoed what Doctor Jin said in the meeting. Doctors did not understand how to care for the dying in practical ways, thus making these guidelines mandatory. Doctor Jin wanted to change doctors' practices by clarifying that the unnecessary medication and exams should be withdrawn.

What Nurse Choi wanted to address was in the same vein as what Doctor Jin intended, but Nurse Choi considered it from a perspective of rhetoric. She tried to change the word 'unnecessary,' which contained a negative connotation, to "imperatively necessary," which tightly restricted the use of medication. When the goal of a care plan changes, medications and procedures that have been previously given to a patient become unnecessary, or even, harmful to the patient. New care goals require the implementation of new treatments. However, the timing of a care plan's change and whether a treatment is necessary are not clear-cut; patients wax and wane, and goals of care can swing back and forth. The patient's health status and the subsequent care plans do not always follow a trajectory of stages that clearly demarcates the moment when a particular plan is useless. From the point of view of the medical staff overseeing a patient's treatment, the guideline for ceasing unnecessary treatment may be offensive to the doctor or nurse, as if someone else defines the treatment they prescribed as unnecessary. Nurse Choi's thoughtful revision was thus oriented toward the doctors and nurses who would read this guideline. She did not want to frustrate them by implying that the treatment they had already administered was unneeded.

After the conversation regarding the phrase "necessary," the discussion moved to the issue of "lines"—any external tubes and lines that are connected to a patient, including intravenous (IV) lines, an L-tube (a plastic tube which is usually used for nasogastric intubation for the purpose of feeding), and an A-line (a thin catheter that is inserted into an artery and commonly used both to monitor blood pressure in real-time and to obtain samples for arterial blood gas analysis).

> Nurse Choi: Ok, "unnecessary lines" too can be changed to "only necessary lines may be left." Unnecessary lines would be L-tubes and A-lines. What kind of lines would the patients have?
>
> Nurse Kim: They have main fluid lines.
>
> Nurse Choi: Then, how about highlighting only what doctors should do? "Leave only main fluid lines." One should take a moment and think about what would be unnecessary when one is told to remove unnecessary things. One might think, "This and that also will be needed until this patient dies."
>
> Nurse Kim: So, "Remove all but main fluid lines?" It might be more confusing. What about Foley catheters? A patient might have to keep a Foley catheter[32] until the end.

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[32] An indwelling urinary catheter

> Nurse Choi: Then, "Remove all but IV fluid lines and Foley catheters."
>
> Nurse Kim: Last time, the ICU removed even Foley catheters and main fluid lines from a patient. They removed too much.
>
> All: (laughed)
>
> Nurse Choi: So, how long did it take for the patient to pass away?
>
> Nurse Kim: Two-to-three hours after the patient was moved to the *imjongbang*. It was the right thing, but…
>
> Doctor Jin: But I think it is right to remove the main fluid lines as well.
>
> Nurse Choi: So, let patients have the minimal lines as specified in the Act. See, when we directed "Remove unnecessary lines," people removed all of them.
>
> Doctor Jin: I think it's right to remove Foley catheters, too.
>
> Nurse Kim: But some patients hang in up there [the terminal-cancer ward upstairs] for two days.
>
> Doctor Jin: Oh…
>
> Nurse Kim: And family members can't handle it. If a patient leaks after leaving the ICU, the relatives can't manage the situation.
>
> Doctor Jin: You are right.

Inpatients are usually attached to many kinds of lines. In particular, patients who have stayed in ICUs certainly are. When the time arrives to let the patient go, the lines attached to the patient must be removed. Nurse Kim and Nurse Choi thought feeding and monitoring of blood pressure to be unnecessary for dying patients, but individual doctors and nurses may have different concepts of "unnecessary lines" for the dying, as Nurse Choi's concern was supported by the anecdote of ICU professionals who "removed too much." In order to minimize discrepancies that might occur in the field, Nurse Choi suggested highlighting the few lines needed—main fluid lines and Foley catheters.

In terms of lines, Doctor Jin took a position that all lines should be removed if possible. She valued lessening the time of suffering for the dying. Death is imminent and irreversible. Thus, in Doctor Jin's opinion, intervention through attached lines only contributes to lengthening a patient's dying process. Nurse Kim agreed with Doctor Jin's idea that lessening the suffering time of a patient would be a virtue. However, Nurse Kim was also considerate of the affairs of the patient's relatives. Two to three hours would not be enough time for them to say good-bye to one another, she thought. As all body fluids threaten a boundary of purity and danger (Douglass 2003[1966]), and as managing one's body fluids plays a part in judging the person's hygiene and the degree of civilization (Elias 1996[1939]), leaking urine would embarrass the people around the patient, and hurt the patient's dignity.

Their discussion continued.

> Nurse Kim: Let's make it "main fluid lines and Foley catheters." (pause) Hmm, some patients don't even have Foley catheters.
>
> Nurse Choi: Then we don't need to include Foley catheters in the direction.
>
> Nurse Kim: So, are we going to keep 'unnecessary?'
>
> Nurse Lee: In some cases, patients are moved from the ICU with painkillers and Vasopressors, aren't they?
>
> Nurse Choi: Even with Vasopressors?
>
> Nurse Kim: It depends on the situation. What patients are left with depends on the situation.
>
> All: Then, let's make it "it depends on the situation."
>
> Nurse Kim: For certain, L-tubes and A-lines are unnecessary.
>
> Nurse Choi: It is rare for patients to have L-tubes for drainage, isn't it?

> Nurse Kim: Usually L-tubes are for feeding.
>
> Nurse Choi: If it is for drainage, doctors will leave the L-tube.
>
> Doctor Jin: Then, keep ‘unnecessary lines.’ L-tubes and A-lines are the ones that are most commonly used, right? They will surely leave necessary L-tubes even though it says ‘unnecessary.’

Reality is complicated. Exceptions and variables always surface: ideas about treating the dying vary among individual doctors and nurses, patient conditions vary, and the medical interventions available vary. Systems require standardization. The essence of a system is that it continues regardless of member replacement. It should produce the same result regardless of who is in charge. What the palliative care team discussed through this long conversation in the meeting was how to standardize a process of dealing with dying in the ICU after withdrawal of treatment was determined. They took into consideration all the chaotic variations, both from their lived experiences and from various imaginable scenarios, and then tried to find a way to minimize confusion by providing consistent directions that anyone could easily follow.

While they paid careful attention to the language so as not to hurt colleagues’ sense of professional responsibility, the team members simultaneously delved into what would be the best for patients and their relatives.

Details of the Conditions for Good Dying

Many people celebrated that patient autonomy finally came to be embedded in the Act, but self-determination was not the sole necessary and sufficient condition of good dying. In reality, many more details needed attention in order to realize good dying in hospitals. As seen in the above discussions, the meetings to produce a guideline for stopping life-sustaining treatment reflected the delicate and diverse conditions for good dying—such as a reduction in suffering time, having enough time to say good-bye, and controlling the dying body's fluid emissions—all of which the veteran doctors and nurses had learned over their long careers, as seen in the next scene, which came from another day's meeting, In this meeting, the nurses and doctor discussed how to deal with a dying patient's oxygen supply in the ICU.

> Nurse Kim: (reviewing the draft of the guideline) In the case of the ICU death… Will the ICU employees keep ambu-bagging? Hmm… I think ambu-bagging is not necessary. So, "Turn off the ventilator and then connect a T-piece to a patient."
>
> Nurse Choi: No ambu-bagging?
>
> Nurse Kim: Yes, maximal oxygen is delivered to a patient through the T-piece.
>
> Doctor Jin: Yeah, because we don't move the patient outside the ICU.
>
> Nurse Choi: Oh, what about in the case where we move the patient to the terminal-cancer ward…?
>
> Doctor Jin: In that case, we do ambu-bagging, but in the ICU, no ambu-bagging.
>
> Nurse Kim: So, "First, confirm that the family members have gathered, give them time to say good-bye to the patient, get the family's consent to turn off the ventilator, and then supply oxygen via a T-piece." The purpose of ambu-bagging is to prevent the occurrence of an event during transfer. And, it's not good when a patient passes away too quickly after arriving at the *imjongbang*. If they have time to spare, the residents give some time to the patients and their relatives to say good-bye by continuing ambu-bagging for a while. The thing is, the residents are too busy and they always hustle off. I feel nervous and wish they would do ambu-bagging a little longer. Anyway, in the ICU, the guys don't need to do ambu-bagging. Have family members prepare themselves to let the patient go, switch off the ventilator, and then deliver 100% FiO2[33] to the patient. I'm also not sure if 100% FiO2 is necessary. Maybe just off-vent is enough.
>
> Nurse Lee: From the family members' point of view, even though they have prepared themselves, the patient has already been off the vent. So, it is better for the relatives to see oxygen supplied to the patient than see a patient just lying with nothing.

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[33] The doctors and nurses in S Hospital said "O2-full," but I translated this insider term to an expression common in American hospitals.

> Nurse Kim: Right. So, 100% FiO2 for the purpose of preparing family members rather than a requirement of the dying process. 100% FiO2 will help both medical staff and family members to feel less burdened.
>
> Doctor Jin: They don't need to extubate, do they?
>
> Nurse Kim: The residents might ask a question about extubation. I clarified the issue in a Q&A section. Question: "if withdrawal of treatment is determined, does extubation follow?" Answer: "If the airway has trouble and a patient seems uncomfortable, or if suction would be needed after extubation, then extubation is not necessary."
>
> Doctor Jin: With being extubated, a patient might be in pain… Well, at that moment, the patient would already be unconscious [and not feel any pain].
>
> Nurse Kim: If [the dying process] lingers too long, we'd better extubate.

The main issue addressed in this conversation is a way of supplying oxygen to a dying patient. If a patient is to move to another place for dying, such as the *imjongbang*, a resident in ICU accompanies the patient to the room while squeezing an ambu-bag. The purpose of ambu-bagging here is not medical, but moral. As Nurse Kim indicated, it is not *right* that a patient dies on the move. Accordingly, in order to earn some time for a patient to remain "alive" until she arrives at the right place—the private room for the dying—an ICU staff member pumps the ambu-bag attached to the patient. To put it another way, it is acceptable for a patient to die in the ICU or in rooms of the wards; yet it is not appropriate for a patient to die en route to a private place prepared for her. Can the relatives have enough time to say good-bye to the patient in a corridor or an elevator? If the relatives cry out, this scene and sound would upset the well-organized and quiet space and cause anxiety to other patients and visitors around the relatives by awakening them to the fact that death is so close to them. If the relatives refrain from expressing their emotion at such a sad moment, it is not right, either. To die in motion is like *gaeksa* in that this death occurs in an unexpected place at an unexpected time, without enough attention.

Second, until the last moment, the patient should be taken care of by the medical staff. In most cases, the dying patient is without consciousness and, as Doctor Jin pointed out in relation to extubation, she or he would not feel uncomfortable—this is a medical fact. However, regardless of the scientific truth, the living who watch the dying may feel uncomfortable. As Nurse Lee addressed, it would hurt the family members to watch the dying be provided with nothing to ease the process, and they might feel that the patient has been abandoned. The medical professionals likewise might feel guilty or feel pressure from the relatives around them. Thus, 100% FiO2 supply is positioned as a technology by which a patient is taken care of and, by extension, both the relatives and the medical staff are made to feel more comfortable.

Thirdly, the length of time of a patient's death should be balanced between two temporal values: lessening the suffering time of dying and giving the patient and their relatives enough time to appreciate their last moment together: neither too short nor too long. In order to attain a balance between two contradictory goals, the team members mobilized four types of technology and technique: an ambu-bag, the maximum concentration of oxygen, a ventilator, and extubation. On the one hand, to ensure a patient is not suffering too long—a main goal of palliative medicine—the team guided the medical staff to turn off a respirator and to consider an extubation depending on the time the dying process took. On the other hand, to ensure that the patient's family members are given a chance to express their love, gratitude, and sorrow before their final farewell is also important. For this aim, Nurse Kim directed using 100% FiO2 at the same time that she expressed regret that the interns of ICUs stopped squeezing the ambu-bag too early. This direction illustrates the ways in which the doctors and nurses providing palliative care took advantage of medical technology in flexible ways in order to realize a range of good dying.

Bridge between the Law and Lay people

The primary task of these series of meetings was to advertise how to execute the withdrawal of life-sustaining treatment, and the targets of this campaign were two groups: the medical staff of S Hospital, and patients and their relatives. In general, lay people are placed in a vulnerable position in relation to medical professionals due to the power asymmetry caused by their lack of control over medical knowledge (Taussig 1980; Zola 1985). The imbalanced power over medical knowledge includes language barriers. If a physician explains an exam result or the prognosis of a disease to a patient through the jargon with which she communicates with her colleagues, the patient likely would not be satisfied with her explanation. Experts are obligated to "translate" the jargon into plain, colloquial language. In light of the newly introduced law, lay people would face a double barrier—the jargon of both the law and of medicine. Producing brochures and pamphlets for patients and their families thus involved bridging both between the law and lay people, and between the medical staff and lay people.

As one way of lowering a hurdle for lay people, the palliative care team adapted an FAQ format in the educational materials for patients and their families. The nurses, physicians, and social workers of the team took quite a while to ponder potential questions that patients and their relatives would likely have. Since the Ministry of Health and Welfare had already announced that life-sustaining treatment could now be terminated, many critically ill patients and their relatives already had some insight, but their knowledge remained vague. Through a long and arduous meeting, Nurse Kim decided to place some major questions and answers in the front of the brochure, such as “What is POLST?” and “How can I stop receiving life-sustaining treatment?” Since Nurse Choi claimed that legal expressions inhibited patients and their relatives from easy access to the Act, Nurse Kim placed a summarized explanation of the Act at the very end of the material. What the law said was a less intriguing point to the lay people. Only what they could do mattered.

The palliative care team members struggled with translating the legal and medical terminology into language used at an eighth-grade reading level. Nurse Kim thought, ‘life-sustaining treatment’ was not easy for the public to understand, since *yeonmyeong yiryo,* which translates to life-prolonging treatment in English, is a combination of Chinese characters (延命醫療). The word was not something intuitively understandable, she believed. In addition, *yeonmyeong yiryo* was unfamiliar terminology to many health professionals as well. Previously, *yeonmyeong* (life-prolonging) *chiryo* (treatment) had been widely accepted. Yet, the Social Consultative Body (p. 63) proposed a newly-coined word, *yeonmyeong* (life-prolonging) *yiryo* (medicine) on the grounds that the medical intervention related to life-prolonging did not actually *treat* patients, but rather prolonged the end-of-life period. The Social Consultative Body in 2009 did not want to offer a misimpression to the public that an artificial ventilator could bring back the dying. Given this background, Nurse Kim’s point was reasonable. However, after a debate, the members concluded that arbitrarily changing an officially-published word would be inappropriate and they decided to retain the terminology.

Similar attempts to find more understandable words often appeared in the discussions. They decided to use "stop" (*jungdan*) instead of "withdraw" (*cheolhoi*), and "postpone" (*boryu*) instead of "withhold" (*yubo*); they agreed not to use the English abbreviations AD and POLST.[34] Instead, they intentionally replaced AD with "advance statement" (*gyehoikseo*) and POLST with "plan" (*yihyangseo*) in the brochures and pamphlets.

The team members exerted considerable effort to lessen any chance that lay people might misunderstand. Miscommunication comes from language, so, accordingly, they tried to carefully replace specific words within the materials. For example, in Korean, a doctor and an intention are homonyms. Thus, with the direction "Verify an intention of a patient," people might be confused with whether it means "verify the patient's intentions" or "verify the doctor in charge of a patient." Some of the team members suggested using a different expression for "decision-making capacity" in order to avoid a communicative barrier. After a discussion, Doctor Jin opposed the suggestion because it was an established terminology in ethics and the Act.

Nurse Choi seemed to be the most interested in language usage. While reviewing the guidelines for stopping life-sustaining treatment, she suggested:

> This might be trivial, but I have always been bothered by it. It says "call the medical staff and confirm *imjong* (passing away of a patient) through EKG (electrocardiogram)." Here, *jong* means end and *imjong* means that death is imminent, right? I have always been bothered by this. We usually use *imjong* since we are reluctant to use the straight word, death. We can use euphemisms with patients, but with medical staff we need to use an exact expression.

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[34] Medicine is one of the fields where using English terminology most prevails in Korea, and the palliative care team used AD and POLST as mundane words. However, most Koreans would not know what AD and POLST mean.

Her suggestion echoed the attempt to recast the avoidance of talking about death within Korean culture. Many health professionals had claimed avoiding disclosure harmed the quality of life of patients with end-stage disease (e.g., Ahn Eunmi et al. 2013), and the palliative care team shared the same opinion on the matter. The nurses tended to encourage the family members to talk about the care plan with the patient although the medical staff very often faced their resistance and refusal. What Nurse Choi tried to do in this instance was to call attention to one of the small and subtle words that made it difficult to speak out about the elephant in the room—death.

Whereas Nurse Choi tried to cast the guidelines as an opportunity to exercise a subtle language politics, Doctor Jin endeavored to enlighten lay people in a more direct and explicit way. As a member of the hospice care team, Doctor Jin believed that receiving life-prolonging treatment was a torture for the dying, and her objective was to reduce the number of cases of futile medical intervention. She knew that patients' relatives often made the decision to do "everything" on behalf of their loved one because they really had no idea of what applying heroic measures—such as cardiopulmonary resuscitation (CPR)—to the dying would be like. From this stance, Doctor Jin suggested inserting an explanation as to what it would be like to receive life-sustaining treatment.

> We must insert the contents of what the four types of life-sustaining treatment are. Because lay people have no idea of what they are, it takes a long time for a resident to explain them. There is a study, and according to the study, the rate of writing DNR increased when patients watched a video of CPR. Showing a video would be impossible for now, but a brief explanation must be included. Both the resident's and the patient's time would be saved.

Her suggestion was, on the one hand, a practical one to save the time it took for busy residents to explain what life-sustaining treatment would be. Yet, on the other hand, her fundamental aim was to persuade the patient not to pursue life-sustaining treatment at the end of life. The ultimate goal of the team was not merely to assist patients and their relatives to make *a* decision, but rather to help them to make a *good* decision. And they had a concrete idea of what a good decision was.

Negotiations and Strategies

Although I have demonstrated the significance of a great number of meetings and the work to implement the Act so far, I do not want to romanticize the notorious intensity of the labor necessary to carry out the demonstration projects, or the real-world constraints that hampered the palliative care team members. While preparing for the enforcement of the Act, they very often worked overtime at night. On the face of it, they looked exhausted, especially Nurse Kim, who was responsible for all of the business. In addition, the broad, institutional level-support for the team was still insufficient. For instance, the budget that was allocated to the team was so tight that the members rescheduled the time of regular meetings, which had previously been held during lunch break, because having a meeting during lunchtime meant they needed to provide meals to the members who attended. In these poor circumstances, the palliative care team members mobilized a range of strategies to attain their aim as well as to protect themselves.

One of the strategies they employed was to utilize some unofficial routes to obtain what they needed. The Act could not be implemented until an individual doctor executed the provisions of the Act. Yet making the doctors and nurses follow the Act was not easy, because they had long been habituated to carry out their practices in a particular fashion, and these practices were tightly coupled with the medical system. For example, to take the time to discuss the significance of writing an AD with a patient might be a virtue. However, even if an individual doctor hoped to follow this virtue, the clinical circumstance would not allow the doctor to do so: indeed, the clinic was so crowded that each patient could have only three to five minutes to see her doctor. In addition, some physicians, who are otherwise fully cooperative with the palliative care team, also frowned upon the idea of obtaining a POLST from a patient in outpatient clinics. In this situation, in which the environment of the clinic had not been optimized to discuss the withdrawal of life-sustaining treatment, as Doctor Jin said, the team could not just push the doctors and nurses when they were not ready for the change. Providing guidelines for the doctors and nurses was one strategy, while mobilizing their private relationship was another. The team members detected who would be in favor of what they were doing and the philosophical ideas that guided the implementation of the new practices, and they specifically targeted those doctors. The team members personally contacted the doctors in several departments and asked for their cooperation in trying to attain POLST from patients, and in explaining how to write POLST to their colleagues and trainees.

The team members also tried to adjust the amount of the work as much as they could handle. The governmental institutions leading the demonstration projects (the Ministry of Health and Welfare and the Korean National Institute for Bioethics Policy) wanted each participant institution to educate all of the patients and families who visited the hospital, but the team members were well aware of the fact that they were unable to manage the situation. Thus, they focused on patients who visited their office and were admitted in the terminal-cancer ward, that is, “those who might be keenly interested in POLST.” The attempt to control the amount of the work mirrored the priority they set for themselves: these backstage tasks must not overshadow the onstage, on-going process of caring. Also, it was a struggle to protect themselves from burning-out under these difficult conditions.

Conclusion

The initiation of the Act made the heretofore marginalized end-of-life care visible by placing the palliative care in the hospital-national health system. The legalization of treatment cessation was a ratification of one form of hospital dying, which had been possible in secret and unofficial ways. In order to give this form of dying a visible place within the hospital system, the palliative care staff endeavored to establish a standard protocol so that an identical result could be produced no matter who implemented the termination of life-sustaining treatment.

Obviously, the ethical principles of self-determination and the best interest of the patient as well as the articles of the law were not enough, in themselves, to realize the new form of dying nor were they the only values required to make a good death within a hospital. On the path of dying, multiple technologies, techniques, spaces, and moral values were contested. As seen in the discussions regarding oxygen provision and ambu-bagging on the way to *imjongbang*, the action of turning off the respirator machine was not a key step in good dying. In the discussions about the right place and right time for dying, considerations important not only to the dying but also for the relatives and the medical practitioners were taken into account, as were issues relating to the management of the dying body and lessening the suffering time; and the doctor, nurses, and social worker struggled to find the right balance among these different conditions for good dying. What they attempted to do—in the midst of their otherwise overloaded work schedule—was to “reflect not only different values but also different ways of ordering reality” (Mol, Moser, and Pols 2010: 13). In their work, medical technologies were appropriated in flexible ways, and the meanings of the technologies remained unsettled along with the moral values and idiosyncratic circumstances.

Chapter Four

The Activation of the Terminal Stage and the Time Called "End-of-Life"

Introduction: Location of Terminal-Stage and Timing of Terminal-Cancer Ward

So far, I have used three terminologies—palliative care, hospice care, and end-of-life care—as if they are interchangeable. Also, I have called the ward in which the palliative care staff members work the terminal-cancer ward as if it is a ward where a patient who has been diagnosed as in the terminal stage is hospitalized. However, palliative care and hospice care are not synonyms for each other, nor come only the terminal-stage patients to this ward. WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (Sepúlveda et al. 2002: 94). Palliative care is not confined to a specific disease stage, but rather, theoretically, its early intervention is stressed. In contrast, hospice care and end-of-life care more explicitly target terminally-ill patients.

Moreover, in S Hospital, the terminal-cancer ward is not the official name of this ward. The official name consists of just three digits following the naming ward rule of S Hospital. Both patients with advanced cancer and patients with terminal cancer are hospitalized in this ward. In most cases, when a patient with advanced cancer is carried to the ER due to some acute problems, the ER staff sends the patient to this ward. and the patient is likely to be diagnosed as in the terminal stage during her stay. Thus, this ward is a place where palliative care and hospice care are blended and anti-cancer regimens and end-of-life care coexist. These blending and coexistence is partly attributed to the indeterminacy of terminality. Contrary to common belief, terminal stage is not clear-cut, but rather is constructed and activated through diverse operational definitions, paperwork, and communications among the medical staff, patient, and her relatives. On the other hand, these blending and coexistence emerges from the tertiary hospital system. Unlike hospices, where a patient goes after the untreatability is determined, a tertiary hospital is a place where patients come to for treatment. Accordingly, the nature and contents of care that the end-of-life care specialists provide is very different from those of specialists working in hospices. Chapters Four and Five address how the temporal notions of terminal period and the space of terminal-cancer ward are intertwined and coproduce special configuration of end-of-life care in this hospital system.

Because the sense of time, space, and self are deeply entangled with one another (Plugge 2017: 236-240), a doctor's declaration that a case has reached the 'terminal stage' does not merely mean "no time," but rather implies an irreversible change in the ways in which a person is related to the world. Probably since we all understand the grave effect of the declaration of terminal stage, we have developed a particular type of care, i.e., an end-of-life care. In this chapter, I first how this specific time unit is produced in the terminal-cancer ward and what a terminal stage means to health practitioners, patients and their relatives, and the Act, respectively. First, I focus on how the terminal stage is configured in the biomedical scheme of cancer trajectory and how the end-of-life care is activated through care plans and the end-of-life care documents. Second, the way that the doctors and nurses understand the terminal stage contrasts with the patients and their relatives' perspective on this period in relation to their life history. On the one hand, the palliative staff's mission aligns with the biomedical understanding of irreversibility, but, on the other, the team challenges the idea that there is nothing left to be done for the patient. By describing the specificity of care in this chapter, I explore the ways in which the palliative care team strives to make their patients' end of life meaningful. Finally, I will show how the multi-layered temporal dimensions of the end of life converge on the reality of the chaos and unpredictability of death in a way that often makes it impossible to achieve a "good death" in either a hospital or a hospice.

The Cancer Trajectory and Care Plan in the Terminal-Cancer Ward

In a particular way, the oncologists and palliative care staff of S Hospital conceptualized what a patient would go through and established some strategies for responding to terminal cancer cases. Figure 2 visualizes the illness trajectory of cancer that the biomedical practitioners understand.

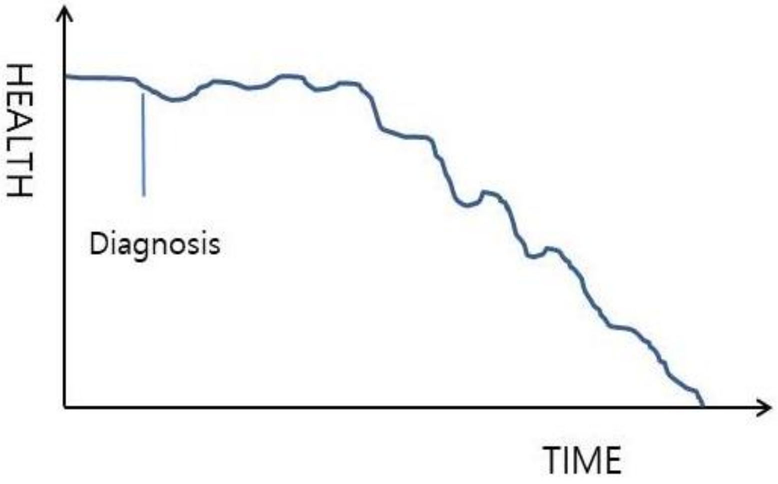

Figure 2. Cancer Trajectory in the Terminal-Cancer Ward

The horizontal axis marks time, while the vertical axis marks the health status of a patient. The doctors and nurses used expressions such as the “condition,” “stamina,” and “performance”[35] of patients to refer to the health status of patients in the broad sense. This indicates the extent to which a patient conducts her own daily life without any of the inconveniences of cancer per se or of the cancer treatment’s side effects—i.e., nausea, pain, fatigue, loss of appetite, etc. As a patient’s “condition” and “performance” declines in the graph, the health status of a patient points to ill-health, with the zero point of health status indicating death.

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[35] “Condition,” “stamina,” and “performance” all are my informants’ terms. “Condition” and “performance” come directly from English (that is, my informants say “condition”), whereas “stamina” is a translation of *giryeok* which refers to energy and vigor.

At the onset, a patient’s health status is more or less considered “okay”—except in the case of a too-late diagnosis—and the doctor establishes a plan according to the diagnostic findings in order to begin therapeutic interventions. As time goes by, the patient’s “condition” declines, partly due to several symptoms of cancer, and partly due to the side effects of medical interventions that the patient received. If the first intervention works well, the patient may return to her initial health condition. If the patient is lucky, her tumor may be eradicated by the first or second intervention—whether anti-cancer medication or surgery—but not everyone has such luck. Many patients repeat these small-scale roller coasters like the first curve while going through consecutive treatments and recoveries from the side effects of the treatments. The fifth year from the onset date of cancer is used as a reference point. If a five-year follow-up finds no more cancer, the patient will be declared fully recovered. This is the best ending patients can dream of. In many cases, however, cancer has recurred or metastasized. Once a recurrence or metastasis of cancer is found, the prognoses that the oncologist can give generally get more depressing. Over the course of this roller-coaster-like trajectory, a patient’s “condition” can improve, but, in the long term, the patient’s health status gradually declines as the efficacy of interventions decreases.

A care plan, an oncologist’s strategy to bring the patient’s condition back to the previous point on the vertical axis of the cancer trajectory, is an essential part of the temporal logics employed by the palliative care team members. Setting aside definitions of care plan that one finds in medical and nursing text books, the concept of care plan that I encountered during my field work is a problem-solving scheme that is organized along a lineal timeline, which is parallel to the cancer trajectory. In the case of cancer, problems include: cancer, complications of cancer, adverse effects of anti-cancer treatment, the patient's condition, recurrence, and metastasis of cancer, and these problems are the underlying causes that make the line on the graph go down. Resolutions for the problems will be: chemotherapy (medication or injection), radiation therapy, surgery, antibiotics, drainages, lab tests, and the like. With the exception of countermeasures (e.g., antibiotics), anti-cancer treatments follow a drug use trajectory, starting from more efficient, inexpensive, and less invasive drugs and then moving to less efficient and more expensive ones. Physicians will try a first-line chemo drug when a patient is diagnosed with cancer. If it fails, they try a second-line drug; if it fails again, they move on to a third-line drug.[36] If all fail, doctors sometimes suggest that a patient participate in a clinical trial. For oncologists, the care plan is analogous to determining what kind of bullets and how many bullets are available to a patient in order to fight particular cancer. When a patient's condition gets worse or a complication is severe, any remaining bullets can no longer be used.

Once the doctor utilizes the last available intervention (i.e., there is no other anti-cancer drug to treat the patient's disease) and finds that "the patient's body is no longer responsive to the drug"[37] (i.e., the erstwhile intervention fails to remove or shrink the tumor, or fails to prevent the metastasized area of the body part from spreading), it indicates that the patient now is entering the terminal stage of cancer: the "bullets" the physician has for the patient are used up. The available treatment options have been played out, and a doctor says to other staff members,

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[36] During my fieldwork, I never heard of fourth-line and more.

[37] Note that the reason for treatment failure is attributed to the body of the patient in the doctors and nurses' idioms.

“There is no further care plan.” Given that a “plan” is about the future, the doctor’s statement of “no further care plan” is another expression of “no future” for this patient. From this point, the patient is considered as a terminal-stage patient.

From now on, this patient’s condition will only worsen. The “active” treatment is over, and the medical staff will focus on “conservative” treatment and “supportive care.” Some patients will have years more to live, while others will have only a couple of weeks. What is certain is that, regardless of the length of time patients have to live, all of them will meet death. This is why many oncologists I have met said to me, “Patients in the terminal-cancer ward will eventually die.”

I heard very similar expressions regarding cancer from the residents and attending doctors I met during my fieldwork. One day, I shadowed a resident rounding the terminal-cancer ward. One of his patients with advanced breast cancer was reluctant to leave the hospital since there was no caregiver at home for her. To persuade the patient to be discharged, the resident said to her, “Eventually, your cancer will progress. I would say that you have a limited length of time. Let’s say you have ‘ten’ left. You need to decide how to spend the time given to you. For example, you can decide to remain in this hospital for two to three of your ten and to stay in your home for the remaining seven. Medically speaking, your condition does not require hospitalization. Don’t you think time is too precious for you to stay in the hospital?” His expressions—cancer that will eventually progress, a limited length of time, and the condition that does not need hospitalization (because there is nothing the doctors can do for her)—were associated with the properties of terminal cancer.

The resident's ideas of non-preventable cancer progression and finite time as given to the patient were reiterated in the words of other residents and nurses. For example, a resident, who rotated into the ward one or two months after the resident above, said to me, "Cancer is a disease that inevitably progresses, and the timeline is already established. I hate that there is nothing I can do for them. My patients ask me, 'What should I do?' and there is nothing I can say." The feeling of powerlessness the resident mentioned was rephrased by a third resident as "unproductive."

A fourth resident expressed her opinion in more explicit, bitter terms. She said:

> Honestly, I really do not like oncology[38] because I do not think "palliative care patients" benefit from anti-cancer treatments. From the moment of their transition to palliative care, any intervention [except palliative and hospice care] will only torture them. I don't see a good reason for clinical trials.[39] I am a member of the medical community, but, if this was happening to a member of my family, I would not let my family member undergo a clinical trial. Once a doctor calls for palliative care for a patient, the doctor at outpatient clinics should tell the patient objectively that she is in this situation, ask if she wants to receive anti-cancer treatment, and explain that her life will only be extended to one or two months despite the anti-cancer treatment. However, doctors avoid this conversation. Even if the doctors provide such an explanation, most patients seem to believe they will live forever, just with their cancer. It is necessary to give patients a clear explanation that their cancer eventually will get worse, and they will ultimately pass away.

By all accounts, the doctors and nurses understand cancer as an obstinate disease, with a few possibilities for full recovery. Despite desperate treatment-seeking efforts, cancer will

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[38] All residents were rotating through every department in S Hospital during the training period.

[39] Due to the nature of Korean, she omitted the subject of this sentence. Since both a doctor and a patient can be a subject of this sentence, this sentence could indicate either that she meant to blame doctors who involve a patient in a clinical trial in which a good result was hardly expected or that she meant to express pity for a patient who tried to grasp this tenuous hope.

always advance, whether in the long- or short-term, while anti-cancer treatment causes critical damage and burdens to both the patient's body and their financial affairs. The unproductivity and powerlessness that the residents felt reflect their inability to stop the progression of cancer, as symbolized by the downward trajectory on the chart. In many cases, medical interventions only contribute to extending the patient's life a bit longer without guaranteeing the quality of life. The terminal stage thus officially signifies the irreversibility of cancer, which in turn reaffirms that there is nothing the doctors and nurses can do for the patient. In other words, it is at this moment that biomedicine admits its defeat in the face of cancer.

The following instance provides an example of how a patient's terminality is first arrived at in a discussion among the doctors, nurses, social worker, and referral staff in the weekly staff meeting.

> [Scene: Switching to terminal stage (1)]
> Resident: (Briefing a patient's treatment history and the results) He has undergone a whole brain radiation therapy. Nevertheless, he had fever yesterday. His urine was too turbid. Sepsis is suspected. He was going to be transferred today [but he seems not to be able to go].
>
> Nurse Kim: I think you need to request a hospice consultation.
>
> Doctor Park: His performance will likely be bad, and the urine problem seems to indicate sepsis. It looks like antibiotics can't make a big change.

In this conversation, whole brain radiation therapy was the last "bullet" the physicians had. Despite this attempt, the patient had a fever, and turbid urine was found, both of which were bad signs that he was entering an unstoppable decline. The resident, Nurse Kim, and Doctor Park implicitly understood what the failure of radiation therapy, the urine problem, and fever meant: "there was no positive expectation for this patient," as Doctor Park often said. This patient needed to prepare for his last time in the world, and the hospice consultation was about to begin as the first step of such preparation. The goal of treatment for this patient now was supposed to make a transition to palliative and hospice care, and the resident's action of calling for a hospice consultation ratified this transition. Also, the nurse's action of initiating consultation signified an official announcement of the patient's having entered the terminal stage.[40]

Most patients staying in the terminal-cancer ward were either likely to decline or had already reached this terminal stage. From this point on, the health status of a patient may more rapidly decline than before, and this downward trajectory is both unstoppable and irreversible. There is no question about the untreatability of terminal-stage cancer per se. However, a question remains as to what is defined as "untreatability"—a quality that demarcates the starting point of terminal stage of cancer—and when a patient is actually *treated* as a terminal-stage patient. The ways in which patients were classified in the terminal-cancer ward might offer an answer to these two questions. In the morning briefings and staff meetings, a patient list was circulated to the volunteers and the medical staff. The patient list divided those in the terminal-cancer ward into two categories: "anti-cancer" and "palliative care." The former indicated that the patient was on a treatment regimen, or had planned to use another therapeutic intervention. Those falling under the "anti-cancer" category were not under the care of the palliative care team, and, it was only after a patient was classified to "palliative care" that the palliative care team members began to intervene in the patient's treatment.[41]

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[40] Simultaneously, the patient was supposed to leave this ward and to move to another place, where the "preparation" would be realized, which I will elaborate in the next chapter.

[41] The volunteers' basic care service was provided to all patients.

When does a patient's status change from "anti-cancer" to "palliative care"? The key criteria were whether the patient had been administered *any* anti-cancer drug or was receiving *any* radiation therapy or surgery. In other words, whether or not there was an anti-cancer regimen that doctors could prescribe to the patient—*regardless of its probability of success*—played a key role in classifying a patient. For example, the patient with breast cancer in the earlier anecdote was marked as "anti-cancer" because she was on chemotherapy, despite the nuanced suggestion by the resident that she did not have much time. The scene below illustrates well how the kind of thinking that precipitated the transition from "anti-cancer" to "palliative care" occurred in the terminal-cancer ward.

> [Scene: Switching to terminal stage (2)]
>
> (In a staff meeting)
>
> Resident: (briefing a patient's treatment plan that an attending doctor established)
>
> Doctor Park: (frowning) Have you obtained a POLST from her?
>
> Resident: Only verbally.
>
> Doctor Park: Do you think there is a chance of reversibility for this patient? Do you think she will get better if you renew Iressa [an anti-cancer drug] for her? In a long-term perspective, her prognosis is not good…. You should make that clear to the patient. Given her "condition," it's no wonder you were able to obtain a POLST from her. What if she suddenly gets worse? Are *you* going to administer CPR to her?

Both Doctor Park and the resident (and other participants in the meeting, too) were aware of the patient's hopeless prognosis, and Doctor Park recognized that an emergency could lead to the need to administer CPR, which was not his favorite situation. Nevertheless, the patient's status had not yet shifted to "palliative care" because her attending doctor planned to prescribe the anti-cancer drug, Iressa, to her, even though this drug was not expected to reverse this patient's outcome.

The implicit practice that a patient remained in the "anti-cancer" sector as long as a treatment plan existed was extended to those who were participating in trial experiments as well. Theoretically, an experimental clinical trial is not deemed "treatment." For example, a website that provides the public with healthcare information, http://www.healthline.com, explains that terminal cancer is incurable, and suggests a few options that a patient with terminal cancer could consider. This website regards clinical trials as follows:

> Others may choose to take part in experimental clinical trials. The treatments used in these trials likely won't cure terminal cancer, but they contribute to the medical community's greater understanding of cancer treatment. They can potentially help future generations. This can be a powerful way for someone to ensure their final days have a lasting impact.[42]

According to this explanation, clinical trials do not aim to cure an individual patient, but rather aim to contribute to developing more effective and powerful anti-cancer drugs that may one day defeat cancer. However, in the local reality, a patient who is enrolled in a clinical trial is not transitioned to the "palliative care" category. As long as a doctor has any course of action to suggest to the patient, the patient is not treated as in the terminal stage.

One might argue that marking a patient as "anti-cancer" or "palliative care" on the patient list is merely paperwork; the doctors and nurses know that a patient is entering a terminal-stage, regardless of how they are classified on paper. This is absolutely true. I am not arguing that the resident or Doctor Park was ignorant of this so-called international standard. The doctors and nurses *knew* that, under the textbook definition, the patient would be classified as in

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[42] https://www.healthline.com/health/terminal-cancer#treatment

the terminal stage. They *knew* that the patient was desperately hanging on during the clinical trial, even though the chance of recovery was slim. Yet, what matters here is that the paperwork relates to the question, “When is palliative care *activated*?” and “When is a patient *treated* as a terminal-stage patient?” If the designation of “anti-cancer” and “palliative care” has actual power to direct people’s actions, this is not merely paperwork.

In contrast with the fact that a care plan included even trial participation, the doctors’ statement, “There is no further care plan,” excluded end-of-life care from the typical “care.” Strictly speaking, the declaration of terminal-stage did not mean an end of care plan, but rather a transition from curative treatment to palliative and hospice care, and thus, the resident should have said, “We have to change the care plan for this patient.” The statement that was adopted by the physicians at all times in the terminal-cancer ward reveals that the mainstream biomedicine, in an unconscious way, does not count palliative and hospice care as an integral part of the ordinary medical care plan: palliative and hospice care is regarded as something separate and special, which does not belong to the general work of doctors and nurses; other *specialists* will take responsibility for the terminal-stage patients, not us.

The Activation of End-of-Life Care

Once the categorization of a patient on the patient list has transitioned from “anti-cancer” to “palliative care,” due to the absence of available drugs that a doctor can prescribe, the patient is officially considered to have entered the terminal stage. Usually, the official marker of this transition was accompanied by a doctor's verbal request to the social worker and/or the nurses in the staff meeting. The residents or Doctor Park would say to Social Worker Shin or Nurse Kim and Nurse Heo, "Could you begin an initial consultation (or hospice consultation) with this patient?" This sentence signaled the shift of the patient's status to "palliative care."

An initial consultation was one of Social Worker Shin's jobs. As the name of it inferred, the goal of the consultation was to contact a patient and/or her relatives before the discussion surrounding end-of-life care began in earnest. This consultation was intended to explore the family's social and economic background, as well as to establish a comfortable rapport with the family so as to ease the inevitable conversation with the palliative care team. Through a consultation with a patient or her family members, Social Worker Shin identified family matters (family relations, strong or weak family network, and the like), social status, and economic circumstances that might affect the patient's future care. If it turned out that a patient was economically encumbered, Mr. Shin searched for any available financial support programs for the patient and assisted in the application process. His intervention signified that, when biomedicine no longer had solutions to offer the body, the case was handed over to social welfare services.

The nurses began a hospice consultation based upon the patient information Social Worker Shin had gathered and shared with the team members, and the information that had been collected through informal channels (e.g., conversations between a patient and/or the patient's relative(s) and the volunteers during the programs offered by the palliative care team), and with the request from the doctors. Unlike the initial consultation that primarily focused on the family relations and socio-economic state of a patient, this consultation was used by the three nurses to establish an end-of-life care plan with the patient and/or her family members.

Although I remark “and/or” here, but, except a few cases, almost every initial consultation and hospice consultation was done between the palliative care staff and a patient’s relative. In general, the patient’s family members played the role of gatekeeper in the encounters with doctors and nurses.[43] Usually the residents or the attending doctors would convey to the patient and/or the patient’s relatives that there were no more available treatments, but this disclosure was hardly expected to be a long-enough and in-depth conversation, considering the time constraints of the clinical environment of South Korea. Since the first hospice consultation would likely be the first meaningful conversation regarding end-of-life care, this work required more time and a more careful approach than ever, as is evident in the case I present below.

> [Scene: An Example of a First Hospice Consultation]
>
> (In the tea-making room located in the corner of the terminal-cancer ward, Nurse Heo began a hospice consultation with Mr. Lee Minki’s wife. After a short greeting,)
>
> Nurse Heo: I wanted to see you to ask if there is anything we can help with, such as pain control. Is there anything you want us to do for you?
>
> Mr. Lee’s wife: I want him to be cured. It is okay if it is not a full recovery, but…
>
> Nurse Heo: What did the doctor say? Did he say anything about further treatment?
>
> Wife: My daughters must have heard something.
>
> Nurse Heo: Your daughters met the doctor and did not convey his words to you?

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[43] Chapter Six will deal with why and how family members of a patient became so deeply engaged in the conversations with the medical staff.

> Wife: They handle everything themselves.
>
> Nurse Heo: Do you and your husband want to continue with a treatment and get him feeling better?
>
> Wife: I think he can get better, and he also thinks he will be able to go home on his own.

Nurse Heo always began with the question of what the patient and the relative had heard from their doctor, in order to determine if they had a true understanding of the terminal stage. It was not uncommon to encounter a patient and their relatives who had not been explicitly told of their poor prognosis, because the doctor employed various indirect euphemisms in order to avoid the uncomfortable conversation. This case, however, was not a matter of disclosure, but rather a matter of a denial, which is also a quite common reaction among patients and their families, and it was the nurses' job to navigate this denial into an acceptance of reality.

Nurse Heo asked the wife what time her daughters usually visited the patient, since the daughters appeared to be the primary decision-makers. The wife answered that her daughters came to the ward in the very early mornings and late at night. Nurse Heo learned that it would be hard to find an opportunity to speak to the daughters. The wife was proud of her devoted daughters, and Nurse Heo talked up their filial duty. The conversation continued.

> Wife: My daughters scour a fish market and bring food every day. It is only due to them that the patient ate anything today. He says he has no appetite. I have no energy to nurse him anymore. It is too burdensome.
>
> Nurse Heo: What is the greatest burden to you now?
>
> Wife: Bathing him, because his abdomen is swollen.

> Nurse Heo: Due to ascites.[44] It must be difficult for him to eat.
>
> Wife: Yes, and his legs are very swollen.
>
> Nurse Heo: As a palliative care team we were requested to control his symptoms and pain actively. The thing is, how we approach a patient depends on their individual treatment plan.
>
> Wife: I heard from the doctor that we can’t expect a full recovery. The doctor said that my husband can continue with anti-cancer treatment only when his jaundice is fixed. But his jaundice is not controlled well; the drainage tube doesn’t work well. Yesterday it leaked again and he is going to have to have the procedure again today.
>
> Nurse Heo: His doctor said that we can’t expect a full recovery?
>
> Wife: Yes. He said that my husband can only begin the anti-cancer treatment and take protective drugs for liver once his jaundice is gone, but his jaundice is not fixed. Since my husband can’t eat now, he won’t be able to consume the protective drugs for his liver, either.
>
> Nurse Heo: *So you heard from the doctor that a complete recovery is not expected, didn’t you? The doctor asked for this consultation with us so that your husband, too, can hear this with ease. You didn’t hear anything about a discharge plan, did you?*
>
> Wife: No.

Nurse Heo finally succeeded in having Mr. Lee’s wife accept that, at this point, Mr. Lee would not experience a full recovery. Also, she redefined the implication of a hospice consultation as allowing a patient to take part in their (end-of-life care) discussion. Nurse Heo asked for the daughters’ contact information.

> Nurse Heo: I will call her or drop by when she is in the ward, if possible. Regarding the washing issue, some volunteers visit the ward every day to help with shampooing, bathing, and cleaning the beds.
>
> Wife: Ok. My husband keeps asking for a bath.

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[44] The accumulation of fluid in the peritoneal cavity, causing abdominal swelling. https://www.lexico.com/en/definition/ascites

> Nurse Heo: Bath. Anything else?
>
> Wife: Bath, because the patient can't move. I can't lift him alone. When he defecates, I have to lift him but I can't. Changing diapers is challenging.
>
> (Nurse Heo explained the volunteer's activities)
>
> Wife: What if we are told that further treatment is not possible and we should go back home? What are we supposed to do?
>
> Nurse Heo: Then the doctor will ask us to search for suitable palliative care institutions. I will talk to your daughter and give guidance to her. (Nurse Heo continued to explain the consultation-based hospice process to the wife.)
>
> Wife: (after a short silence, sobbing) We are not ready. When we arrived, we thought he could go home fully recovered. We wanted to live in the countryside and do farming. I wish the hospital had let us stay a bit longer to give my husband relief. We went to J Hospital, but his condition was aggravated there.
>
> Nurse Heo: We referred him to J Hospital and his condition worsened there?
>
> Wife: Yes. After I told him he could be hospitalized here, he began to eat and brush his teeth again. He says that he wants to die here if he is going to die. He believes that he will die if we leave this hospital.
>
> Nurse Heo: Why did the staff in this hospital refer you to J Hospital?
>
> Wife: They said there was no bed for him here. We were very anxious. That hospital's process for controlling infections is very different from here. The nurses in that hospital were different. We found dirt in the food there. People [the patients and the families staying in that hospital] said that they were abandoned there. (She continued complaining about that hospital.) We were so happy when we heard a bed had become available here in S Hospital.

Nurse Heo identified the urgent problem that Mr. Lee and his wife hoped to fix. Mr. Lee's wife finally opened up and shared her concerns with Nurse Heo. Although Mr. Lee's wife had hoped for his full recovery, she had a hunch that what they had dreamt of together was unlikely to come to fruition. In the views of Mr. Lee and his wife, S Hospital was the last faint hope for his recovery, and this belief was reinforced by their bad experience with another hospital. In the wife's account, the referral to another hospital gave the couple a feeling of being *abandoned*: they had been asked to leave the place that had anchored their hope to be provided with the best, and only, care. If S Hospital were to stop treatment and ask them to leave again, there would be nothing left for them to rely on. The sentence "He believes that he will die if we leave this hospital" in the wife's account was a common concern I heard from many patients' relatives.[45] Nurse Heo displayed empathy and gave information on how to apply for the government's support for consultation-based hospice.

> Wife: I don't want my husband to know about it.
>
> Nurse Heo: I understand; I will talk to your daughter.
>
> Wife: [If my husband learns of his poor prognosis] He may hurt himself.... When he had his first surgery, I should have managed the after-surgery better. Every day he says that he will kill himself instead of suffering if he learns his cancer is incurable. He knows how to hurt himself.
>
> Nurse Heo: Right. That's why I used the phrase "palliative consultation" when speaking in front of him. When I send our volunteers to you tomorrow, I will advise them to be careful.
>
> Wife: Thank you.

Mr. Lee's wife was worried the patient would attempt suicide if he found out that the palliative care team began intervening and that there would be no further treatment option.[46] Many relatives of patients took seriously any possible consequence from disclosure. Despair might negate the efficacy of treatment or, even worse, affect the patient's morale to such an extent that the patient might decide to end the suffering on his own. Because a patient's suicide could lead to a lawsuit—not to mention the shock the medical staff and family would experience—the concern regarding a patient's giving-up led the palliative care staff to contact a family member first, and

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[45] Chapter Five will address the significance of S Hospital for patients and their family members.

[46] During my fieldwork, I could observe such a case.

then only contact the patient with the family's agreement.

This consultation with Mr. Lee Yinwoo's wife took a total of 45 minutes. When one considers the time-constrained environment of Korean hospitals, in which the idiom "three-hour wait for three-minutes with the doctor" exists, such a long medical consultation is extraordinary. As she did with Mr. Lee's wife, Nurse Heo tried to prepare all her patients and their relatives for what would happen during the terminal stage, and she offered each a chance to consider what would soon be a very real scenario. Yet this intention requires a very fine-tuned approach. She explored if the patient and his wife were properly informed of the bad prognosis by the doctor, figured out what difficulties they were undergoing, and helped the wife to admit the irreversibility of the patient's decline by rephrasing the wife's words. Also, in order to minimize any emotional resistance to the palliative care team's intervention, she highlighted one part of palliative care (pain control) and defined the aim of palliative care as facilitating the patient's participation in the conversation.

With the first hospice consultation as a steppingstone, Nurse Heo took her time and established a strong rapport with her patients and their relatives. She visited her patients daily and had small chats with them, even when nothing particular had happened. Her visit continued every day until the patient left the hospital, either due to a referral or due to death.

Through the subsequent consultations, the nurses helped the patients and their families in many areas, including pain control, decision-making on life-sustaining treatment, selecting a hospice, arranging a funeral, and coping with emotional reactions to the final farewell. Also, the volunteers of the team began to spend more time and paid more attention to the patient. The physicians who worked with the palliative care team were able to order the necessary medication and drugs to control the terminal-stage symptoms. The patient now was treated as a terminal-stage patient.

Placing End-of-Life Care Documents

In the weekly staff meeting, the doctors, nurses, and social worker always asked if a patient had signed their Advance Directive (AD), Physician Orders for Life-Sustaining Treatment (POLST), and/or Do-Not-Resuscitate order (DNR). “Has the patient signed her AD?” “Who signed the patient’s POLST?” and the like were the main agenda items brought up among the medical staff. It is worth asking at what point end-of-life documents (AD, POLST, and DNR) appear in the activated care for terminal-stage patients, and what it means for terminally-ill patients to sign these documents. Before seeking answers to these questions, I shall first clarify the definitions and brief histories of each form within South Korea.

In South Korea, the concept of an AD was introduced by civil organizations, such as Society of People Thinking about Life and Death (삶과 죽음을 생각하는 회), with a mission to promote a “well-dying culture” within the country.[47] This document had had no legal authority, nor was it a standard form. Rather, the document served as a symbol of a civil campaign that urged civilians to think about their own death in advance and to plan dying with dignity—that is,

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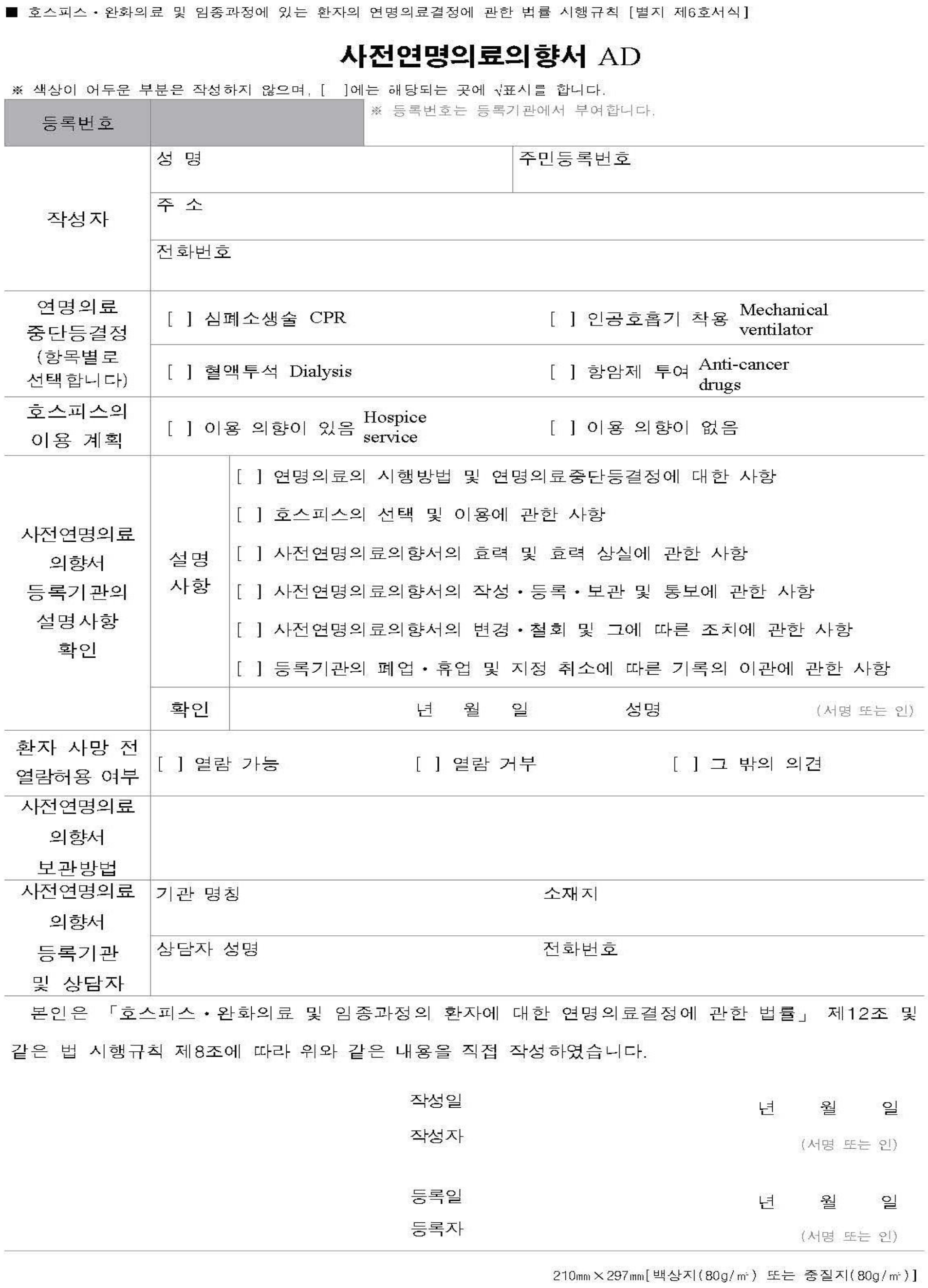
[47] “Well-dying” is a Koreanized English term that is prevalent in Korea. This term appeared as a counterpart of well-being, to evoke a social atmosphere in which people think over what kind of death they would want to realize.

without life-sustaining treatment. Very few people had written their ADs, and due to its lack of legal force, the document could not have guaranteed that the person’s wishes would be observed. It was only in January of 2018 that the AD gained legal authority, as the Act prescribed the definition and functions of AD, and designated the Ministry of Health and Welfare as the institution that would manage AD enrollments.

According to Article 11 of the Act, people can enroll their ADs (Figure 3) in a regional healthcare institution, a medical institution, or a non-profit organization that provided services concerning AD. A worker in the registration agency will provide details concerning the methods of implementing life-sustaining treatment, decision-making on using life-sustaining treatment, matters concerning selecting and using hospice care, matters concerning the validity and invalidity of advance statements on life-sustaining treatment, matters concerning preparing, registering, keeping and notifying the advance statement on life-sustaining treatment, and matters concerning amending and withdrawing advance statements on life-sustaining treatment, as well as subsequent measures.



■ 호스피스ㆍ완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 시행규칙 [별지 제6호서식]

사전연명의료의향서 AD

※ 색상이 어두운 부분은 작성하지 않으며, [ ]에는 해당되는 곳에 √표시를 합니다.

등록번호		※ 등록번호는 등록기관에서 부여합니다.	
작성자	성 명		주민등록번호
	주 소		
	전화번호		
연명의료 중단등결정 (항목별로 선택합니다)	[ ] 심폐소생술 CPR		[ ] 인공호흡기 착용 Mechanical ventilator
	[ ] 혈액투석 Dialysis		[ ] 항암제 투여 Anti-cancer drugs
호스피스의 이용 계획	[ ] 이용 의향이 있음 Hospice service		[ ] 이용 의향이 없음
사전연명의료 의향서 등록기관의 설명사항 확인	설명 사항	[ ] 연명의료의 시행방법 및 연명의료중단등결정에 대한 사항 [ ] 호스피스의 선택 및 이용에 관한 사항 [ ] 사전연명의료의향서의 효력 및 효력 상실에 관한 사항 [ ] 사전연명의료의향서의 작성ㆍ등록ㆍ보관 및 통보에 관한 사항 [ ] 사전연명의료의향서의 변경ㆍ철회 및 그에 따른 조치에 관한 사항 [ ] 등록기관의 폐업ㆍ휴업 및 지정 취소에 따른 기록의 이관에 관한 사항	
	확인	년 월 일	성명 (서명 또는 인)
환자 사망 전 열람허용 여부	[ ] 열람 가능	[ ] 열람 거부	[ ] 그 밖의 의견
사전연명의료 의향서 보관방법			
사전연명의료 의향서 등록기관 및 상담자	기관 명칭		소재지
	상담자 성명		전화번호

본인은 「호스피스ㆍ완화의료 및 임종과정의 환자에 대한 연명의료결정에 관한 법률」 제12조 및 같은 법 시행규칙 제8조에 따라 위와 같은 내용을 직접 작성하였습니다.

작성일 년 월 일
작성자 (서명 또는 인)

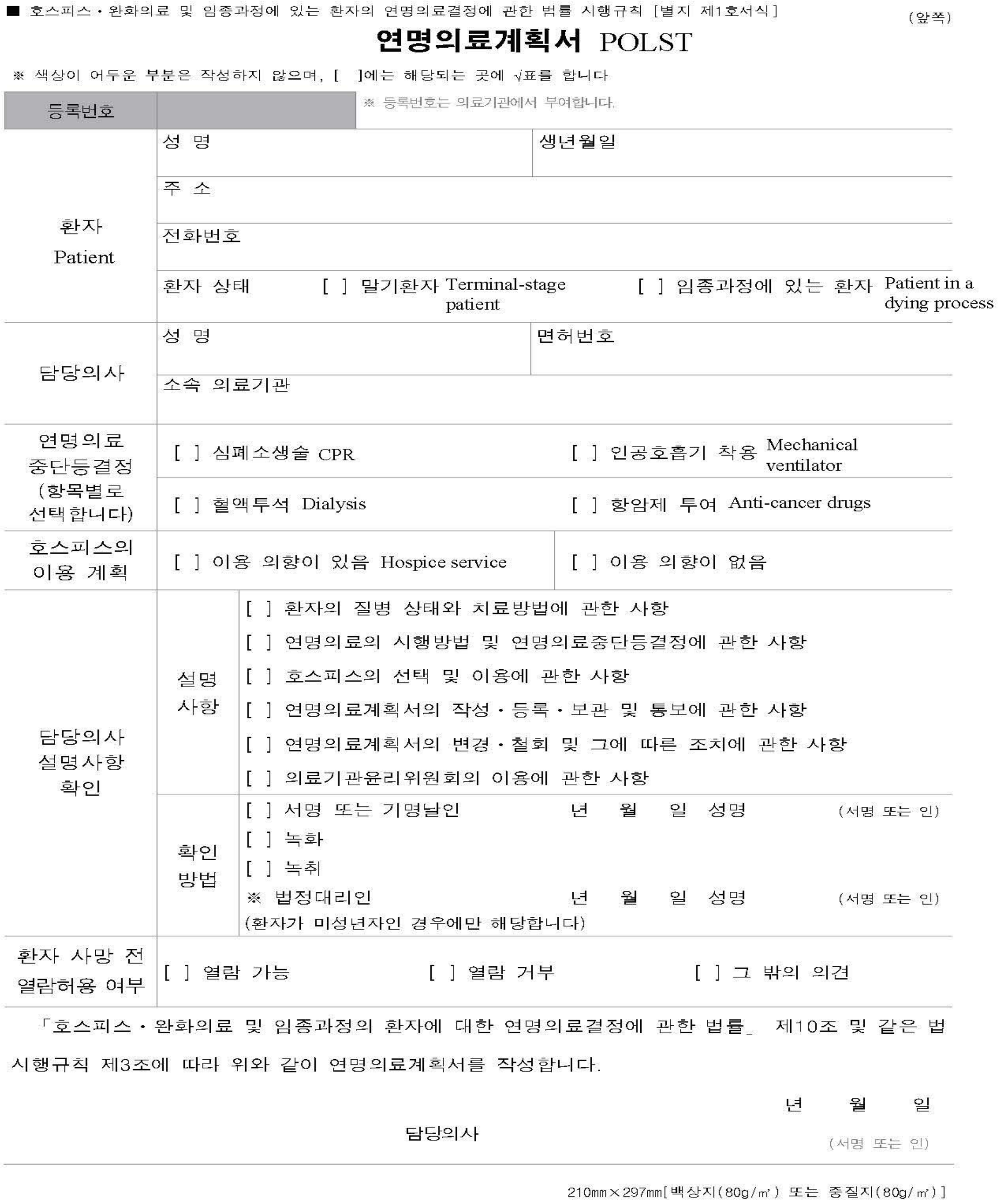
등록일 년 월 일
등록자 (서명 또는 인)

210㎜×297㎜[백상지(80g/㎡) 또는 중질지(80g/㎡)]

Figure 3. AD Form

Neither did a DNR document have a legal basis in Korea. Each hospital had developed its own form of DNR and had obtained it from those whose deaths were imminent. Theoretically, there is no designated time in which one should sign a DNR: it can be signed by both healthy and seriously-ill patients. Yet, in South Korea, it had been a customary practice for a doctor to obtain a DNR from one whose death was imminent. However, during this period, a patient usually lacked consciousness or was incapacitated, and, consequentially, it was very natural that a family member would sign a DNR on behalf of the patient (Kim Do Yeun et al. 2007). Though a DNR order is limited only to decisions regarding CPR, in actual practice, obtaining a DNR implied that the medical staff, the patient, and the patient’s family all agreed to let the patient die without further interventions.

POLST (Figure 4) was a new form introduced by the Act in 2018. According to Article 10 of the Act, a doctor in charge must provide a terminal patient with information regarding (1) the status of patient's disease and matters concerning the methods of treatment; (2) matters concerning the methods of providing life-sustaining treatment and matters concerning determination to terminate or withhold life-sustaining treatment; (3) matters concerning selecting and using hospice care; (4) matters concerning preparing, registering, keeping, and notifying life-sustaining treatment plans; and (5) matters concerning amending and withdrawing life-sustaining treatment plans and subsequent measures. In contrast to the AD, which is written by the individual, POLST is written by a doctor with a patient’s signature.



■ 호스피스 · 완화의료 및 임종과정에 있는 환자의 연명의료결정에 관한 법률 시행규칙 [별지 제1호서식]

(앞쪽)

연명의료계획서 POLST

※ 색상이 어두운 부분은 작성하지 않으며, [ ]에는 해당되는 곳에 √표를 합니다

등록번호		※ 등록번호는 의료기관에서 부여합니다.	
환자 Patient	성 명		생년월일
	주 소		
	전화번호		
	환자 상태	□ 말기환자 Terminal-stage patient	□ 임종과정에 있는 환자 Patient in a dying process
담당의사	성 명		면허번호
	소속 의료기관		
연명의료 중단등결정 (항목별로 선택합니다)	□ 심폐소생술 CPR		□ 인공호흡기 착용 Mechanical ventilator
	□ 혈액투석 Dialysis		□ 항암제 투여 Anti-cancer drugs
호스피스의 이용 계획	□ 이용 의향이 있음 Hospice service		□ 이용 의향이 없음
담당의사 설명사항 확인	설명 사항	□ 환자의 질병 상태와 치료방법에 관한 사항 □ 연명의료의 시행방법 및 연명의료중단등결정에 관한 사항 □ 호스피스의 선택 및 이용에 관한 사항 □ 연명의료계획서의 작성 · 등록 · 보관 및 통보에 관한 사항 □ 연명의료계획서의 변경 · 철회 및 그에 따른 조치에 관한 사항 □ 의료기관윤리위원회의 이용에 관한 사항	
	확인 방법	□ 서명 또는 기명날인 년 월 일 성명 (서명 또는 인) □ 녹화 □ 녹취 ※ 법정대리인 년 월 일 성명 (서명 또는 인) (환자가 미성년자인 경우에만 해당합니다)	
환자 사망 전 열람허용 여부	□ 열람 가능	□ 열람 거부	□ 그 밖의 의견

「호스피스 · 완화의료 및 임종과정의 환자에 대한 연명의료결정에 관한 법률」 제10조 및 같은 법 시행규칙 제3조에 따라 위와 같이 연명의료계획서를 작성합니다.

년 월 일

담당의사 (서명 또는 인)

210mm×297mm[백상지(80g/㎡) 또는 중질지(80g/㎡)]

Figure 4. POLST Form

AD, POLST, and DNR all concern how a person wishes to spend their final moments in regard to medical interventions, but the recommended timing for writing each document is slightly different. Theoretically, the AD mainly targets those whose death is not imminent. The raison d'être of AD is to provide people with an opportunity to think over their last moments in advance while still *compos mentis* in the case that they unexpectedly lose their capacity to make critical decisions when their death is imminent. POLST, in contrast, is filled in when a person becomes seriously ill and is nearing the terminal stage. When one's life expectancy is a few months, the patient becomes eligible to sign her POLST. Customarily, the DNR, too, had been written during a patient's end-of-life stage. For example, some nurses I met in my field expressed curiosity as to why a patient may be on the DNR code, and thus assumed something was wrong if they thought a patient's status as "too good to write a DNR" (Figure 5).

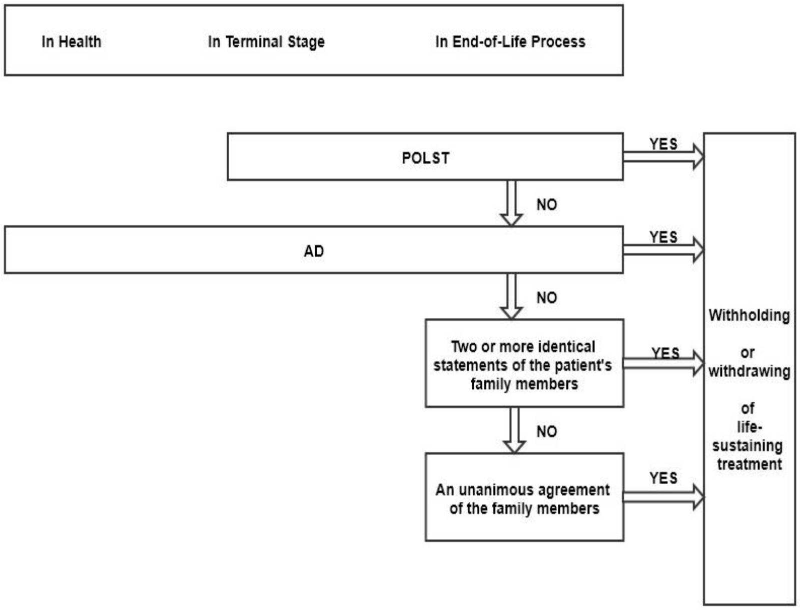


Figure 5. The Steps to Withholding or Withdrawing of Life-Sustaining Treatment

As I outlined in Chapter Two, the Act distinguishes an “end-of-life process” and a terminal-stage. Both periods refer to a time of irreversibility, but the terminal-stage means that a patient is expected to die within a few months because there is no possibility of a fundamental recovery, while the end-of-life process means a state of imminent death.

This specification of the minimum length of remaining time for end-of-life care service through governmental regulations is found elsewhere, too. For example, in the U.S., Medicare patients must acquire a doctor’s certification that the patient has less than six months to live in order for them to be referred to hospices (Christakis 1999:10). Under insurance policy regimes and the legal authority of documents, the end of life goes through a process of bureaucratization, on the basis of prediction (Christakis 1999).

Previous studies have addressed some collateral problems to this bureaucratization of end-of-life care. First, any prediction made by human beings is inevitably incomplete (Christakis 1999). The laws—not only those of the Act in South Korea, but also any law throughout the world—presuppose a doctor’s ability to accurately pinpoint the timeline of a patient’s final months. Yet, previous studies have demonstrated that any prognosis regarding life expectancy is not perfect (Glare et al. 2003; Maltoni et al. 2005). In the Grandmother Kim case, for instance, the three courts judged that she had been in the dying process on the basis of the medical records and the brainwave exam. However, the patient had survived with spontaneous breath for over 141 days after the mechanical respirator was withdrawn by the court’s order. all that humans can do is only make a prediction and then see if the prediction was right or wrong after the death occurs.

The Act of 2018 required physicians in Korea to predict more specific life expectancy. Since the Act distinguished the end-of-life process from the terminal stage and allowed only those in the end-of-life process to withdraw or withhold life-sustaining treatment, the doctors were supposed to determine which patients were in the end-of-life process, and which were in the terminal stage.

Regardless of the theoretical and temporal segmentation of AD and POLST/DNR, in actuality, the uses of these three end-of-life care documents were often improvised. The three documents all appeared in the terminal-cancer ward—in the morning brief, in the staff meeting, and in the consultation between the medical practitioner and the patients and their relatives, regardless of the recommended time to write each form.

> [Case: Ms. Lee Inyeong]
>
> Ms. Lee Inyeong was admitted to the terminal-cancer ward on November 8th as she began her new chemotherapy. Her first diagnosis with breast cancer had been two years prior, but all of her family members—Ms. Lee herself, her mother, and her husband—would not consider stopping the anti-cancer treatment. Ms. Lee was a young woman in her thirties with two little daughters, a two- and a four-year-old.
>
> However, her attending doctor did not seem to expect this round of chemotherapy to work well. On November 8th, when her new round was scheduled, the attending doctor already believed Ms. Lee's life expectancy would not be long. Her tumor had spread over her lung, which signaled a bad prognosis. Ms. Lee and Ms. Lee's mother were those who had the strongest desire to fight against the disease. Initially, both the patient and her mother refused to speak with Nurse Kim. It was in the third week of November that their attitudes changed—likely due to their realization that the drug was not working well. For the first time, Ms. Lee considered bringing her little girls to see her in the hospital. It was common in South Korea that young children were often prohibited from visiting family in the hospital, as it was considered a bad experience for young children.
>
> Among the medical staff, there was an implicit understanding that Ms. Lee's

> prognosis had worsened since her hospitalization. However, it was not until the fourth week of November that an end-of-life document was suggested. Her resident prognosticated in the staff meeting that her demise was imminent—less than two weeks. Since Ms. Lee was so ill, the staff members gave up referring the patient to a hospice. Her family members were informed of this unfavorable prognosis, and Ms. Lee's little girls came to the ward to see their mother before her condition worsened further. Ms. Lee already could not sit upright by herself in bed, yet she had not signed her end-of-life care document. In the staff meeting, when Doctor Park asked why an AD had not been obtained from Ms. Lee, the resident in charge answered, "It is because she was scheduled to get chemo yesterday. It was only today that the final decision not to continue with chemo was made." Ms. Lee passed away on the last day of November.

Ms. Lee's story demonstrates that the end-of-life care document was not obtained while chemotherapy was still scheduled. Theoretically, it would not be surprising for Ms. Lee to have written her own AD with a physician's counsel because she had long struggled against breast cancer and the AD was a document that any adult could complete. However, just as the doctors and nurses did not shift a patient's status from "anti-cancer" to "palliative care" unless they had stopped a patient's treatment, they did not bring up signing any end-of-life care document to Ms. Lee and her husband because she was scheduled to try another anti-cancer treatment. There was no significant difference in pragmatics between AD and POLST/DNR in the terminal-cancer ward of S Hospital, as neither document was suggested to the patients until all available treatment measures were eliminated.

A conversation I had with Ms. Kang Wuju also buttressed this fact. Ms. Kang Wuju was one of the patients I could not forget. Although she had struggled with breast cancer for years and had experienced a recurrence and metastasis of the tumor, Ms. Kang remained strong. She volunteered at S Hospital as a "senior patient." S Hospital provided some educational programs to patients with cancer—such as "how to handle pain," "dietary recommendations for cancer," and psychological therapy sessions—and the “conversation with senior patients” was one of these programs. Some “exemplary” patients who had fought against cancer with a stable mind and positive attitudes shared their own strategies to live with cancer and their emotional support with “newbies.” The fact that Ms. Kang played a part in the program as a “senior patient” demonstrated her courage and strong will to maintain her dignity. When I asked her if she had written an AD or POLST, she answered, “I wanted to write an AD because I really do not want to bother people around me. I asked my professor (her attending doctor) to write the document, but she turned it down.”

“Why did she refuse to write an AD or POLST?” I asked. Ms. Kang said, “She said it was too early to write it.”

Her attending doctor was a typical oncologist. Why did the doctor dissuade Ms. Kang, and what did she mean by “too early to write it”? On the one hand, oncologists, in general, wanted their patients to understand the cancer trajectory and not to be “obsessed” by the idea of seeking any available treatment. Yet, on the other hand, an individual doctor might want an individual patient to hold out hope at least during an anti-cancer treatment period. To put it another way, writing the end-of-life care document meant that, regardless of the type of document, now it was the time to abandon every possible hope.

What type of document was written did not make a big difference in terms of the implication of the document, but it seemed clear that the doctors felt fewer burdens when they suggested writing an AD to a patient and their relatives, than they did mentioning a POLST or DNR, as was evident in Mr. Woo’s case.

> [Case: Mr. Woo Daegeon]
>
> Mr. Woo was admitted to the terminal-cancer ward through the ER of S Hospital. He had long suffered from both Parkinson's disease and cancer. Due to his breathing difficulty, a member of the ER staff performed a tracheotomy on him, obtained an AD from his wife, and sent Mr. Woo to the ICU. After a few days in the ICU, his breathing problem somewhat improved, and Mr. Woo was moved to the terminal-cancer ward. In a staff meeting, a resident remarked, "Because he was a new patient, the ER staff member obtained just an AD and sent him up to the ward." Doctor Park ordered the resident to obtain a DNR from the family members on behalf of Mr. Woo.

In Mr. Woo's case, the AD appeared as a cushion before obtaining the DNR. To the resident in the ER, it was uncomfortable to mention a DNR with the patient perhaps because the resident felt that it was improper to initiate the topic to the family members when the resident had not had a rapport relationship with the patient, who had been just carried to the ER unconscious. Or, the resident might have felt that the hustle and bustle milieu of the ER was not a suitable setting to bring up much serious topic as a DNR. Or, it could be that both reasons explained why the ER resident obtained an AD instead of POLST or DNR.

With regard to the perceived difference of the emotional burden between AD and POLST/DNR, one ER resident had similar opinions to that of Mr. Woo's ER staff. She said, "Imagine: Your professor of oncology[48] has never told you about this, and a young kid in the ER, whom you have never met before, tells you that there is nothing left you can do and that you should *give up*. This is wrong, isn't it?" To put it another way, obtaining POLST/DNR undeniably signifies "giving-up," but, in terms of an AD, there is a room for doctors to manipulate a way of explaining this document's implication so that an AD seems less serious

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[48] She called oncology specialists professors because she was a resident.

than POLST or DNR. In sum, obtaining an AD is less time consuming and less of an emotional burden to the residents than obtaining a POLST or DNR due to its implication of grave consequences. For instance, Nurse Lee Juwon and an instructor, who belonged to an NGO that had promoted the "well-dying" culture, gave a lecture to the volunteers of the team in a monthly workshop. Nurse Lee explained:

> This Act does not aim for giving-up anti-cancer treatment in stage two or three. You receive all treatments as best you can. Just you leave your will in a document that you will not receive unnecessary life-prolonging treatment when you are not responsive to treatment in the terminal stage or in the dying process.... Any adult over 19 can write an AD at any time. If you are carried into an ER without a written AD, it is really hard for the medical staff not to start life-sustaining treatment even if both you and your relative do not want the doctor to do so because now we have this Act.

The second presenter said regarding the necessity of writing an AD:

> An AD is necessary not as a patient but as a human. As humans, we must contemplate the quality of life and the quality of death: this is the original purpose of AD. Whether or not to write it is just a petty problem. It is important to think whether or not the "happiness index" will be high at the end of life.

As long as an AD is defined as a document that "any adult over 19 years of age can write," just in case, and a document to think about the quality of life and death in advance as "humans," it is easier to persuade people to write this form. The doctors often adopted a rhetorical strategy of highlighting this aspect of the AD—that anyone, including the doctor herself, might write one without signifying imminent death—in order to reassure the patients and their relatives

Moving up the Time of Disclosure

How long is it proper for a terminal-period to last? The Act defined the terminal-stage as a few months before death; the oncologists also thought a few months to be the general time length for a terminal-stage, but the declaration of terminal-stage in reality tended to be much delayed while the “final” treatment was completed.

The phenomenon of late referral to palliative care was not limited to hospitals in South Korea. Bruera and Hui (2010)—covering palliative care in Canada, where the first palliative care unit opened in 1976—stressed the importance of early referral to palliative care. They asserted that early referral could facilitate timely diagnosis and treatment of symptoms, longitudinal psychosocial support, and counseling, as well as a gradual transition of care (2010: 4014). However, the timing of referral to palliative care that the authors criticized as “too late” in this study was an average of 30 to 60 days before death (2010: 4014). In contrast, according to the statistics of the palliative care team in S Hospital, the patients in the terminal-cancer ward, on average, stayed one month before death. Nurse Kim thought the ideal period of palliative care would be two to three months. She said:

> I think it is really necessary for a patient to look back on their life. Two to three months are needed. The remaining time should be enough, but not too long. If you have two to three months to live, you can see what you want to do and put your affairs in order. If the remaining time is too short, you don’t have any energy to do it. At least you are able to be mobile.

It was obvious that the activation of end-of-life care should be done earlier than is done presently.

However, considering that the doctor had the authority to announce the terminal stage and to allow the palliative care team to intervene in care for the patient, and also considering that whether or not the information on the terminal period was conveyed to the patient depended entirely on the patient’s relatives, there was not much the nurses could do to move up the time of activation of the end-of-life care. Whenever they seized a chance, the palliative care team earnestly urged the patient’s family members to talk with the patient regarding the future. A more fundamental and important mission of the palliative care team was to urge the medical staff—the doctors and residents in charge—to call for the palliative care earlier than the time when all the bullets had been exhausted because they could not bring up any conversation regarding an end-of-life care without the doctor’s order. Once the doctor called for a hospice consultation, there was at least a chance to persuade the family members to have a conversation with the patient together. The nurses and social worker of the team usually adopted a strategy of slightly nudging the doctors in charge to call for hospice consultation before it was too late. This persuasion was generally done in the staff meetings in which the residents who were rotating into the ward and Doctor Park, who directed the ward, were gathered. This persuasion was nuanced and not aggressive. For instance, they might say: “If you call for a hospice consultation, we will see and talk to the patient.” This persuasion strategy, which did not “offend” the doctors, seemed very natural in the Korean medical community, where there was a clear hierarchy between doctors and nurses.

Time as Recognized by Patients and their Family

In comparison with my medical practitioner interviewees, who were more or less a homogeneous group in terms of educational level, occupation, and ideas relating to "good dying," my patient interviewees varied in age, type of cancer, gender, social status, family support, occupation, religion, and attitude toward the reality they were facing. Among the patients I met, some could not accept their fate and refused to talk about it; some practiced institutional religions that suggested some kind of life after death; some strongly maintained the scientific position that there was nothing after death; some wished for their suffering to end quickly; and some had already put their affairs in order. It is impossible to generalize a single way in which patients handled their pasts, presents, and futures given the heterogeneity of patients and their respective beliefs and circumstances.

Yet, at least in terms of how each group understood the terminal stage timeline, there seemed a clear demarcation between the medical staff and the patients and their families. While the medical staff produced a time frame within both the larger frame of a care plan for each patient and the fundamental idea of cancer progression, the patients and family members obviously perceived a different time frame from that of the medical staff, as related to their individual life histories. Mr. Lee Minsu's case, which I relate below, shows the chasm between the doctors and nurses and the patients and their families in regard to giving meaning to the terminal stage.

> [Case of Mr. Lee Minsu]
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> Mr. Lee Minsu was a young male patient in his forties. He was a "strong-willed patient," in a negative sense of being obstinate,[49] who was determined to try any

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[49] In English, strong-will connotes a positive assessment. In Korean, too, it is used as a positive expression. However, in this terminal-cancer ward, strong-will can have both positive and negative implications. In such cases

> available option regardless of its faint success rate. Mr. Lee even refused to communicate with any of the palliative care team, including the volunteers, as if simply speaking with them would bring him bad luck.
>
> According to Social Worker Shin, who was the only one in the team who had succeeded in approaching the patient, Mr. Lee and his parents had seen much hardship in life. His father had lost all his property, and Mr. Lee and his mother had had a difficult life reconstructing their household. Mr. Lee worked so hard that he missed the opportunity to get married, and just a few years before his cancer diagnosis, Mr. Lee finally bought a house for himself and his parents. Unsurprisingly, Mr. Lee was shocked by the news of cancer and was desperate to try anything. In Mr. Lee's perspective, it was finally supposed to be time for him to enjoy the fruits of his labor after his life of hardship. When his resident brought up a referral to a hospice, Mr. Lee was very disappointed and refused to speak.
>
> That said, the resident had not even mentioned hospice in a straightforward manner. Because Mr. Lee was so determined to continue with anti-cancer treatment, the resident could not bear to tell Mr. Lee that the treatments were not working. Rather, the resident chose Mr. Lee's mother as a main interlocutor. Thus, Mr. Lee refused to talk when his mother conveyed to him the doctor's suggestion of transferring to hospice. When I asked how Mr. Lee was doing, the resident said, "Mr. Lee expressed his dismay and asked why his doctors always say no. Yet, I think it would be better for him to know the truth. If I were him, I would want to know. Cancer will develop, regardless of whatever you try."

While the medical staff had placed Mr. Lee's cancer on an irreversible downward trajectory, Mr. Lee only considered his life history, which had been plagued with economic predicaments and struggles to rise from poverty, and he believed it was time for his life to finally improve. To him, this was not the right time to die; he was not concerned with truth or avoidance, but rather with possibility and miracles.

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like that of Mr. Lee, whose prognosis clearly seemed bad but the patient would not embrace that reality, the palliative care team could use this expression as a euphemism for the patient's denial.

Tension was thus created by the three perspectives of the attending doctor and the resident (“Strong will does not make the tumor grow slowly.”), Mr. Lee’s mother (“My poor son. I want him to stop, but I can’t talk to him.”), and Mr. Lee (“Why do you doctors always say no?”). Due to the patient’s refusal to speak with the palliative care team, Nurse Kim was limited in her ability to intervene. As the three stakeholders could not communicate openly with one another, the final decision to transfer to hospice occurred too late. It was not until right before he was referred to a hospice—that is, when his “condition” conspicuously exacerbated—that his resident obtained a POLST from his mother. Mr. Lee passed away right after the transfer, which was after two months of Mr. Lee’s last hospitalization in S Hospital. As with Mr. Lee, the patients who believed that their lives were unfinished often refused a transition from curative treatment to palliative and hospice care until the end.

Unlike these patients, some patients smoothly accepted the fact that their remaining time was not so long. Mr. Kim Ilhan was one of the patients that the palliative care team regarded as an exemplary case of well-prepared dying. He was ready to talk to the nurses and the volunteers.

> [Case: Mr. Kim Ilhan’s narrative]
>
> Mr. Kim Ilhan was in his late sixties. His cancer had spread to his left eye. His doctor had recommended he receive surgery on the eye that had been affected by a tumor, but he had rejected the idea as he did not want to live without his eyesight. Instead, he focused only on anti-cancer treatment and radiation therapy. He positioned himself as a compliant patient who did not even take vitamins without the doctor’s direction.
>
> He liked rock climbing. Every time one of his friends from rock climbing passed away, he would carry the friend’s coffin. After carrying the coffin and covering the coffin with earth, he would pour a cup of *soju* on the grave[50] and say, “Take

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[50] A part of memorial practices that are done in front of one’s grave. *Soju* is a kind of liquor.

> care. I am not going to come back and see you." It was the way that he made his farewells to his people. Since he had experienced the deaths of many of his friends, he was not afraid of his own.
>
> Mr. Kim was also not afraid of his own death because he believed he had fulfilled his parental duty. He had put two children through college and they were now self-sufficient. Because of his strict parenting, his two children had gotten along very well. He had treated his daughter and granddaughter without gender discrimination, which was not common at his age.
>
> He had many good friends who asked after him every morning and came to have a meal with him.[51] He believed that having good friends was crucial in elderly life, and he had good ones. So, he had experienced a good life. He signed his POLST and was transferred to a hospice, where he passed away.

Mr. Kim exemplified a patient who relatively easily accepted his fate. According to his narrative, this smooth embrace of death was possible because he felt it was now his turn to die. He recalled many friends and family members whom he had lost during his lifetime and knew that no one could escape death. Also, because he thought he had completed important projects in his life as a father, he was ready to leave without regret. He placed his cancer in a time of natural order and completeness in his life.

As with patients, their family members also viewed the terminal stage within the context of their life histories. When I met Ms. Ryu Inhee in S Hospital, she was enmeshed in grief from watching her only daughter slowly die. Her daughter, Ms. Hah Yejin, was in her mid-thirties and had a husband and young daughter. At a glance, she seemed to have entered the dying process. Ms. Ryu provided around-the-clock care for Ms. Hah. I visited Ms. Hah to massage her swollen

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[51] Eating together symbolizes communality and friendship anywhere (Julier, 2013), but this is especially true in Korea as evidenced in mundane idioms. One of mundane greeting and farewell is "We should eat a meal together someday"; and an expression, "He has no one to eat a meal together," indicates social isolation and loneliness. Mr. Kim might mean that some friends actually visited him and shared food together or that he had many loyal friends who took care of him.

limbs, and Ms. Ryu always welcomed my visit. One day, we talked for a long time about Ms. Ryu's lovely daughter and her own life. In our conversation, Ms. Ryu constructed her own narrative on why her lovely daughter had attracted this awful disease within Ms. Hah's married life.

> [Case: Ms. Ryu Inhee's narrative]
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> To Ms. Ryu Inhee, Ms. Hah was the greatest daughter, and Ms. Ryu was incredibly proud of her daughter. Ms. Hah had done well in school, had been elected the class representative, and had been a juvenile athlete. Ms. Ryu recalled that Ms. Hah was a daughter who always made her a better mother and, in turn, "made her heart beat."[52]
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> Although she remarked that her daughter's illness occurred as it was supposed to occur, Ms. Ryu believed that her son-in-law was responsible for this misfortune. Like her daughter, her son-in-law was a handsome and clever man with a promising future. However, it was only after this seemingly reliable son-in-law had quit his job, had studied for the bar exam, and had repeatedly failed the exam for six years, that Ms. Hah's cancer developed.
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> "They should have lived their life to its fullest, just being healthy and joyful. Excessive greed exacts a price. Your husband stays at home to prepare for the exam, and you go to work even when you are pregnant, how can't your liver melt?[53] One year after childbirth, she was diagnosed with cancer."
>
> When we met, it had already been two and a half years since Ms. Hah's attending doctor had predicted that Ms. Hah would have only six months to live. The error in this prediction was interpreted by Ms. Ryu as Ms. Hah's strong will to live. At the same time, this two-year-long struggle against cancer was a time of shame from Ms. Ryu's point of view. It is common that remaining family members, in particular the parents who have lost their young (adult) children and wives who have lost their husbands at a young age, feel shame. Ms. Ryu recounted, "It is heartbreaking to watch my daughter be critically ill. It is a disgrace to watch your

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[52] This idiom means that someone or something makes a person feel alive and delights the person.

[53] This idiom refers to a person who cares too much, who is stressed out, and who longs for something so much that he or she becomes ill.

> daughter die. If she lived ten years more, I would probably die within that time [and would not have to go through this]. If a mother of a dying daughter is sane… I eat only one meal a day. I can't swallow food and I feel shame when I eat. I feel that sleeping is too good for me and I always sit up when the nurses come in."
>
> Ms. Ryu, on the one hand, wished for this time of misery to come to an end, both for herself and for her daughter. On the other hand, however, Ms. Ryu of course wished for her daughter to live longer. When the attending doctors asked, "For how long do you want her to remain alive?" Ms. Ryu answered, "Until my granddaughter goes to a primary school." She knew her wish would not be realized. But when the doctor added, "I think she is not likely to live through this fall," Ms. Ryu thought of the family trip which was scheduled in September. They were going to go on a trip to Canada. Ms. Ryu sincerely wished her daughter would make it to that trip.[54]

In her long narrative, Ms. Ryu thought about two life trajectories: her own and her daughter's. When she thought of Ms. Hah's life, Ms. Ryu believed that many things went wrong after Ms. Hah's marriage and the birth of her child. In her thought, the son-in-law should not have quit his job to try the bar-exam: after being a husband, a man has a duty as a head of household (*gajang*, 가장) to support his family. It was the wrong time to pursue his late dream. Her resentment grew when she thought of her daughter who had to be a breadwinner and take care of her husband during her pregnancy. Being pregnant meant to Ms. Ryu a time to be protected and supported by all family members, especially by her husband. Ms. Ryu pointed to Ms. Hah's overwork, which was caused by the son-in-law's irresponsibility as a head of household, as the fundamental reason for the cancer and suffering that both Ms. Ryu and Ms. Hah went through.

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[54] Very sadly, however, Ms. Hah passed away in S Hospital at the end of June.

At the same time, Ms. Ryu understood this tragedy in relation to her own life trajectory: it is like a natural law to Ms. Ryu that an elderly parent should die before his or her child(ren) dies. It should have been Ms. Ryu, not her daughter, who got sick, was nursed by the family members, and died in the presence of her children. This idea of normal death is sometimes associated with a specific morality imposed on parents who have lost their children. According to an account, which is generally accepted by Koreans, there is no word in Korean to refer to parents who have lost their children, whereas a wife or a husband who have lost his or her spouse is called *guabu*, *mimang-in* (both mean a widow), *hol-abi* (a widower), etc., and a child who lost his or her parents is called *goa* (an orphan). The account attributes the absence of the word for parents who have lost their child to the fact that the sadness of losing children is too overwhelming to be described by a word; since this is a tragedy beyond words, it is not surprising that parents who have lost their children cannot maintain themselves and their everyday lives any more. Further, a parent who has lost her child but maintains herself and her everyday life as if nothing happened is likely to be judged harshly. It is by this very line of thought that Ms. Ryu felt shame when she conducted her daily activities.

What Should the End of Life Be Like?

The temporal imagining of the terminal stage held by the palliative care team members resided at the intersection of the biomedical scheme and the life-historical sense. Although palliative care was part of biomedicine, the team's position was distinctive within S Hospital. On the one hand, as members of the medical community and as specialists caring for the dying, they regarded the cancer trajectory as an indisputable, natural fact. Given that the team members considered the cancer trajectory and care plan scheme as something beyond question, they did not disagree with other doctors and nurses in broad terms. Yet the position that the team members took was distinguished from mainstream biomedicine in that they *questioned* the central idea of the biomedical world view that there was nothing to do for those who could no longer sustain a care plan. The team members knew that there *were* many things they could still give their patients even after all treatment options were exhausted.

Pain Control

From the team members' point of view, even though the tumor could not be entirely removed from the patient's body, the patient still needed many things for comfort—in particular, pain control. Biomedicine must serve until the end to relieve the terminal-stage patient's pain, via a range of medication, from painkillers to sedation, if necessary. No single patient, the team members believed, must suffer from cancerous pain.

Severe pain indeed hurts human dignity. I learned this when I took care of Ms. Kim Hana. When she was referred to the palliative care team, Ms. Kim's main complaint was pain in her abdomen. In the first hospice consultation with Nurse Heo, Ms. Kim wanted to select a hospice on her own where she would meet her end. We could see that she was an autonomous and strong person. Two days after the first hospice consultation was initiated, however, I was bewildered to encounter her in extreme pain beyond expression when I visited her to see if she needed anything. Ms. Kim was sweating to the extent that her clothes were entirely soaked through. She could not withstand the pain and was writhing in agony. In suffering from both cancer pain and delirium, she looked like she had no idea what to do or how to handle this pain. Ms. Kim grabbed a bottle of water and poured it on her neck. At this sight, I, as a new volunteer, did not know what to do either and asked for help from other volunteers. Nurse Kim and a couple of veteran volunteers ran down to her room from upstairs. Her husband, who had left the patient just for ten minutes or so, came back, too. While we tried to change her wet clothes, Ms. Kim kicked her feet and hurled verbal abuse at her husband. The woman who had made her own choices and had struggled to maintain her dignity had disappeared. This disturbance finally ended when a nurse administered an increased dose of morphine sulfate to her.

In fact, Ms. Kim had been prescribed a patient-controlled analgesia (PCA) by Doctor Yim of the palliative care team. This device allows a patient to self-administer predetermined doses of analgesic medication to relieve pain. In the first consultation, Nurse Heo said to Ms. Kim, “If pain strikes you, just push this [PCA] button.” Ms. Kim said, “But I was told not to push the button too many times.” “Not too many times? Who said that? Doctor Yim?” The last sentence of Nurse Heo implied that it could not have been Doctor Yim who had directed it and that Ms. Kim did not need to listen to anyone other than Doctor Yim. Nurse Heo added, “If you feel pain, just push it. It is ok.”

We could not identify who had said to Ms. Kim that she should limit pushing the PCA button, but it was obvious that this advice came from a popular misunderstanding that prevailed in South Korea regarding narcotic analgesics. It was not uncommon to hear a story that a family member restricted a patient—regardless of the illness stage—from taking painkillers, especially opioid painkillers. When the palliative care team asked why she or he did it, the family member would mention concerns about drug addiction.[55] "What if the patient becomes addicted? What if the patient becomes resistant to all painkillers in the market and no drug relieves her pain in the end?" This popular fear of drug addiction was one of the many misconceptions that the palliative care team fought against.

Health professionals outside of the palliative care team, too, tended to be very tight in their prescriptions of painkillers needed to save a terminal-stage patient from harsh pain. One of the nurses who worked in the terminal-cancer ward said to me that she was very irritated when physicians ordered pain controls in a mechanical way, being obsessed with theories that they learned from textbooks. From her point of view, relieving the extreme pain that the terminal-stage patients experienced was the most important duty of the medical staff. However, some of the physicians still clung to directions regarding time interval, breathing rate, and body weight of a patient when prescribing dosages.

As seen in the case of Ms. Kim Hana, palliative care underscores the importance of pain control for those who suffer from extreme cancerous pain. This production of biomedical knowledge and technology can be easily utilized even in S Hospital, where other conditions for good dying are hardly realized. However, it was the prescribers and caregivers who obstructed

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[55] It would be of help to note here that an implication of drug addiction would be different in Korea from that of the U.S. Korea is one of the countries that maintain the strictest policy on drugs to the extent that even marijuana is prohibited. Drug addiction is highly stigmatized so that celebrities who are known to be drug addicts are hard to return to their careers. Meanwhile, this extremely conservative attitude toward applying narcotic analgesics to patients may imply a culturally different perception of pain, but this is beyond the scope of this dissertation.

the patients' access to the analgesics, on the basis of an inflexible application of the dose of the opioid analgesics and a misunderstanding of drug addiction. The palliative care team members believed that no one had to suffer from pain, especially at the end of life, when humans are the most vulnerable, and they fought against the misleading ideas on behalf of their patients.

Natural Death: Contested Meanings

The central philosophy of palliative and hospice care is encapsulated as natural death—the dying process must not be intentionally cut short(euthanasia) or prolonged (life-prolonging treatment) by interventions; we should let nature take its course. This doctrine seems so simple and clear that anyone would agree if the one understood the irreversibility of death. Yet, just as the concept of nature in the terrain of reproduction is contested along with assisted reproductive technologies (Franklin and Ragone 1998; Kang Jiyeon 2012), what natural death means, too, is continuously negotiated.

Basically, the palliative care team members personally were prone to the position that any intervention, except pain control, was excessive in the terminal stage. For instance, when I asked about using vasopressors, IV, and nutrition with dying patients, Nurse Roh answered:

> The purpose of giving vasopressor to a patient is to sustain the patient's blood pressure. In S Hospital or other hospitals, when a patient's blood pressure drops, the medical staff increases the pace or the volume of IV fluid to increase the blood pressure. When these ways fail, vasopressors are used. We [palliative care specialists] see this as against natural dying, and the vasopressor is not used in hospices…. In hospices, it is regarded as better to let nature take its course if your blood pressure drops.

The drop of blood pressure is a sign of the imminence of death, which is non-stoppable. Death will eventually occur, thus administering a vasopressor only prolongs the dying process. Nurse Roh utilized an analogy when explaining this principle to me: “Transfusion is like shoveling sand against the tide; nutrition eventually causes gridlock in the circulation system. It causes edema and burdens the heart. A coffin is smaller than you think. If the dead body is swollen too much, it is hard to put the body into a coffin.”

If we draw a line and mark the left end as “do everything” and the right end as “let nature take its course,” diverse ideas regarding good dying would lie in between the two points on the line. Nurse Roh made clear that their position was toward the right side of the line. Many patients and their relatives, even though they needed some time to accept it, eventually agreed upon the idea of natural death, because this seemed better than the alternative of dying attached to an artificial ventilator. However, when it comes to the low-technologies, especially transfusion, IV, and nutrition, the boundary between natural death and abandonment of the dying becomes blurred.

> [Scene: Discussion on Transfusion in Hospices]
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> The participants in the meeting discussed Ms. Lee Eunjeong, who would be referred to D Hospital’s free-charge hospice ward soon. They confirmed the process of using a paid caregiver service for Ms. Lee; and then they turned to the transfusion issue. Nurse Kim said,
>
> “Does D Hospital provide transfusions? She might occasionally need a transfusion.”
>
> Doctor Park wanted to make clear the implication of going to a hospice.
>
> “We need to see the situation with a cool head. Patients in hospice actually don’t need transfusion. If a patient keeps bleeding, that itself is a sign of the dying

> process.”
>
> A member of the referral staff, Ms. Yun, interjected.
>
> “If you stop transfusion as soon as a patient goes to a hospice, you will face strong resistance. You need to gradually stop transfusion. If you stop transfusion suddenly, you can’t transfer a patient to a hospice.”
>
> Doctor Park joked, “So, realistically, half-and-half?”
>
> Ms. Yun continued, “When a patient goes to a hospice and consults the staff members, they say ‘We don’t provide this, we don’t provide that.’ The patient would ask, ‘Then, what on earth do you provide?’ ‘We do only pain control.’ The patient would be upset, saying ‘You are saying that I am supposed to just wait for death?’”

This discussion took place prior to the enactment of the Act and the introduction of the end-of-life care documents into the clinical setting. Yet, even if this conversation occurred after the demonstration project of life-sustaining treatment had been initiated, the contents of the conversation would not be different, because the Act stipulated only that CPR, dialysis, mechanical ventilators, and anti-cancer drugs could not be used in hospices, and the use of low technology had been and continued to be contested before and after the enactment of the Act.

The last remark of Ms. Yun captured the discrepancy between the hospice philosophy and the patients and their family members regarding natural death. The patient’s decision to die in a hospice did not mean that the patient refused all medical interventions. The absence of provision of IV and nutrition was assessed as starving a patient; the cessation of transfusion was considered to be letting a patient die by bleeding. From the patients’ and their relatives’ point of view, the non-intervention doctrine that excluded low and simple technologies was not a natural death but rather an abandonment of the dying.

In this incongruence between the specialists and the patients and their relatives, the palliative and hospice institutions had to compromise with reality: a small number of hospices provided transfusion, and the majority of hospices administered IV and nutrition to a patient if the patient and/or her family members strongly requested it despite the doctors and nurses' persuasion. Working in the medical field, they also recognized the disagreement about what constituted mandatory care, regardless of their personal beliefs, and they were aware of the necessity to reconcile their views with reality. As McNamara (2004; Seale and van der Geest 2004: 884) has shown, "the original conceptions of dying well may have been compromised with a more realistic recognition of a "good enough" death by palliative care practitioners." In the Act, the scope of life-sustaining treatment is limited to four types of intervention—CPR, mechanical respirator, dialysis, and anti-cancer drugs—was a reflection of the strong resistance of lay people (and some religious groups) to the idea that IV, nutrition, oxygen, and transfusion should be stopped in the terminal-stage. By stating that the supply of nutrition, oxygen, and IV could not be suspended under any condition, the Act contended that these low technologies are part of essential care that must be given to all humans.[56]

To Untie the Knots

During the period in which I worked with the palliative care team in S Hospital, Nurse

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[56] Thus, for the first time, the Act made illegal the care practice of hospice institutions that had minimized the provision of transfusion, IV, and nutrition. Further study is needed to explore if the hospice specialists have changed their practices against their hospice philosophy in order to observe provisions of the Act. According to the users of the online community of cancer patients and their families, transfusion is provided depending on the patient's situation, and nutrition is gradually reduced under the family members' agreement.

Heo gave me various versions of what she believed good dying entailed. One day, she defined her goal as “to let them know their life was not meaningless.” Meaningfulness and meaninglessness appeared on and off in my field notes as one of the central themes penetrating the services of the palliative care team. This idea of meaningfulness included both the past and the future. On the one hand, the team members hoped that their patients would realize that the paths they had walked were full of dazzling moments and good relationships, and that they had accomplished many achievements in their lives. On the other hand, the team members also hoped their patients would spend their last weeks and months in this world in a meaningful way. Thus, it was at this very point that the value the palliative care team pursued intersected with the wishes of patients and their families. As the patients and their relatives thought of their tragic illness in the context of their life histories, the palliative care team members assisted them in looking back on their lives in order to give them meaning and value and to complete their stories in a beautiful way. The team members hoped that their patients would remember, “I have been loved through my entire life,” as in Nurse Heo’s words.

With regard to the crucial way of making lives meaningful at the end of life, Nurse Heo used the expression of a “knot.”

> If you repress something in your mind, it can hurt not only you but also those who will remain in this world after you leave. Unspoken words and events can engender a problem and create a knot in the relationship. I wish to help my patients to untie their knots. It is not right to keep something upsetting to yourself and to further agitate yourself. It is much better to express what is in your mind and to recognize each other’s feelings. When you have something on your mind, and if you truly love someone, isn’t it good for you to express these things and to resolve the problem between you and your loved one?

To put it another way, a patient’s last weeks and months should be spent not in desperation to extend their lives, but in unpacking what the patient and their relatives have kept in their minds—whether a positive or negative issue—because this would be the real last chance for them to do so. This action of speaking out would make the patient feel better and help the relative of the patient to accept their farewell in a smoother way.

Most programs the palliative care team offered were designed to serve this goal. For example, a team of some young filmmakers helped patients to produce video letters. If a patient expressed her wish to participate, the filmmaker team came to the hospital and visited the patient. They set up the room, directed the patient, and recorded a video. Once they finished editing the film, the video was delivered to the patient or the patient's family. Two art therapists also served this goal of making the last time meaningful. Their therapeutic activities of using photos and drawings elicited some stories that the patients and their relatives had kept buried in their minds.[57]

Along with the video letter and the art therapy, Ms. Hah Kyeongmin carried out an activity—called "Interview with My Soul"—that also exemplified the kind of quality-time care that the palliative care team endeavored to provide. Ms. Hah, who had gotten her master's degree in psychology, was devoted to this volunteer activity. Having worked with the palliative care team for a long time, and having proved her sincerity, compassion, and competence, she gained a strong sense of respect among the medical staff, not to mention the volunteers.

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[57] Unlike the film team that visited only when a patient wanted to do this work, the art therapists came to the ward on regular days and made rounds through the entire ward. They visited each bed and explained what the art therapy was and what the activity aimed for. As with the other palliative care team's programs, it was not easy to involve patients in the art therapy activities.

Ms. Hah visited the terminal-cancer ward every Wednesday. Before she came, the nurses would identify who had a desire or need to talk to her. For instance, if a patient seemed to be upset with her husband or if a patient seemed to have made many mistakes with his family members, Nurse Kim would visit the patient and advertise the program. If the patient showed an interest, Nurse Kim introduced Ms. Hah to the patient. Before meeting the patient, Ms. Hah was informed of relevant information regarding the patient's care plan, prognosis, "insight," and family matters.[58]

The basic format of this program was to interview a patient and then to transform the interview into a letter. The letter was delivered to the relevant recipient—the patient and/or the family members. The interview continued for twenty to thirty minutes. When a patient was willing to talk about her story, the time could be extended as much as the patient liked, but in most cases, the patient's condition did not allow her to talk for a long time. Ms. Hah would begin by asking questions to elicit a story from the patient. Mostly, they talked about the patient's relationship with her family members—whether it was positive (gratitude, love, wishes, and forgiveness) or negative (anger and sadness). After finishing the interview, Ms. Hah rewrote the contents of the interview into a letter, doing her best to recreate the patient's own voice and locution. She was also careful to pay attention to the letter's font size in order to guarantee an elderly terminal-stage patient could still read it.

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[58] In order to protect the conversations when patients shared private secrets, I did not shadow Ms. Hah as she conducted her interview sessions. All the stories I will present below were relayed to me by Ms. Hah in our long conversations. Some of the stories were presented by Ms. Hah in a conference and a workshop organized by the palliative care team.

> [Case: Reconciliation of a Couple in the Face of Death (Ms. Hah's narration)]
>
> There was a male patient in his sixties whose ending was imminent. He had a poor relationship with his wife, and there were many reasons for the bad relationship. He was the kind of Korean man who did not get along well with his wife, and instead spent most of his time working hard. So to speak, he was a *wangdda* (outcast) in the family. He could not openly communicate with his adult children, either.
>
> Together we wrote a letter. He spoke and I wrote down his thoughts to later form into a letter. The next week, I called both the husband and wife to this room [the meeting room in the terminal-cancer ward] and suggested that he read what he wrote to his wife. The wife did not like the idea, saying, "Why on earth should I listen to it?" I almost begged her just to pretend to listen to him. She even sat with her back to her husband, which showed her strong denial. Once the husband began to read through the letter, however, she started crying, and they hugged one another tightly.

To borrow a line from Nurse Heo, this couple succeeded in untying the knot that they had accumulated during their life together. Ms. Hah assessed that this reconciliation helped the patient to take a load off his mind and to leave this world, and helped the wife to live her life without anger and remorse. One might question the effectiveness of this one-off event as a way to "reconcile" such long-standing conflicts between a wife and a husband, or between a parent and a child. This kind of conflict is hardly expected to be resolved even through ten sixty-minute sessions of therapy. How much would this at best thirty-minute long interview and a letter really resolve any tension?

This critique is absolutely valid. However, the palliative care team's goal was not to resolve the tension, but to provide any chance to *express* what the patients wanted to and any chance to hear what they wanted from their family members. To put it in her own words, Ms. Hah did not try to "pull out something that people have stuck in their inside attic" but to reduce what patients and their family members would regret in the future. She aimed to elicit from him at least one word that would be meaningful to their relationship. Even if it was just one word, that word would help the wife to live her life in peace after her husband passed. It was enough to assist her patients to express their story even if the story seemed to lie just on the surface.

Although she did not cling to one specific format or content with her interviews, Ms. Hah always followed one principle: to end the interviews with a positive memory. It was crucial to complete an interview with a piece of good memory and a good remark so that the patient knew that they had accumulated some shining moments during their life, and the remaining relative could cherish and remember the patient's good words. The action of speaking out was valued, but the expression must not create yet another knot for anyone.

Through the Interview with My Soul, by narrating their life histories, the patients also participated in a kind of self-fashioning, and, at times, this self-making was oriented toward the others beyond the patients themselves.

> [Case: A Life Lesson That a Young Man Learned (Ms. Hah's narration)]
>
> A young male patient was one of my initially non-cooperative interviewees. He was perverse from the beginning. In order to strike up a conversation with him, I threw him an unexpected question: "What is the first memory you remember?" He answered, "When I was young, I poked a socket with a chopstick, and the chopsticks burnt." I said, "You are kind of curious and daring, aren't you?" It was at this moment that 'a click' occurred with him. The patient began to talk. At the end of the interview, I asked, "This is unfair, isn't it?" (I do not avoid these kinds of conversations.) The patient answered, "Someone encounters infelicity in the name of poverty; someone encounters infelicity in the name of bad family relations. For me, infelicity came to me as a face of illness. That's all."
>
> I learned he was a fan of Bernard Werber, a French writer, and I asked, "If you were Bernard Werber, what would you do during hospitalization?" He answered,

> "I would find something fun with curiosity." "Then, you tell me what you find next week." However, this young male patient passed away before "the next week" came. In the interview with him, I did not try to elicit from him a word regarding his parents. He talked about himself and arranged his thought about his fate. That was enough.

Ms. Hah confessed that it was not easy to "click" with this young man. With several questions to get him involved in the interview, Ms. Hah seized the moment in which his eyes sparkled with the memory of the chopstick episode, and she deepened their conversation regarding his curious nature, which led her to discover his interest in Bernard Werber's novel. Recalling the old memory of a chopstick and a socket, the patient reconstructed himself as an optimistic and curious young man, not as a cancer patient, but as a person who would be able to find something fun even in the dreary and monotonous environment of the hospital. Further, he escaped from the typical pity for a young patient in the terminal stage by positioning his illness at an early age in the mundaneness of infelicity. Everyone has her own worry and misfortune, and there was nothing special in his illness, too. By positioning himself as one among all other humans, he took his cancer in stride. Although he could not see what he said in the form of a letter, the work process—discovering his own nature, defining his fate beyond the biological entity of a tumor that labeled him as a patient in the ward, and narrating these thoughts to Ms. Hah—must have contributed to his self-care. This interview, after being rewritten by Ms. Hah in the form of a monologue, was posted on the palliative care team's website as one example of an "Interview with My Soul." This young man left his life lessons to all of us, along with a self-portrait of himself.

This sort of practice of preparing for one's death in advance is found in other East Asian countries as well. For example, in Japan, where the super-aging population has emerged as a concern of the whole society, a practice of writing an “ending note” has prevailed (Kim Heekyoung 2018). As evidenced in a catch-phrase *pinpin korori*—which means to live healthily (*pinpin*) just until death and then die promptly (*korori*)—the Japanese elderly population is exhorted to discipline their aging bodies and health in order not to burden their families, neighborhoods, and the state. The elderly Japanese, on the one hand, are subjectively involved in the self-discipline for *pinpin korori*, at times cynically, at times strategically, but they always recognize the undesirable possibility of *nennen korori*, or meeting death while bedridden. To gird themselves up for the situation where they are not able to manage their last period in this world on their own due to degenerative diseases or any other misfortune, the elderly Japanese prepare for their death in advance via a new form of writing: an ending note. This note comprises one’s wishes regarding after-death matters, ranging from the scope of life-sustaining treatment they want to or do not want to receive to the form, the guest list, and the specific music and shroud for their own funeral. Kim Heekyoung analyzes this writing practice as a way that the elderly look back at their individual past, explore the question of “Who am I?”, and practice what they want to be in the end.

The practices I have outlined above—the “Interview with My Soul,” the art therapy, the video letter in the terminal-cancer ward of S Hospital, and the ending note in Japan—are ways of making selves that are driven by the existential crisis of death. The Japanese ending note is an activity done by oneself in which one looks inward and of which the main purpose is to ask their relatives to deal with everything regarding their passing in a more or less practical manner.

The underlying idea of ending note is not to burden others, which penetrates the Japanese collective ethos. In contrast, the programs offered by the palliative care team straightforwardly rely on the power of speaking out and narrating the relationship between me and family, further, between me and the world. The ultimate objective of these programs is to untie knots in relationships. The palliative care team wished to support their patients in (re)finding meanings and values in their social relationships—past, present, and future. In doing so, the terminal stage, no matter how short, could become meaningful rather than simply being a time of waiting for death.

The Reality: Dissonance of Multiple Modes of Time

So far I have unfolded the multiple ways that the temporal order of the terminal stage of cancer was imagined, realized, and oriented by heterogeneous participants in the terminal-cancer ward—the oncologists, patients and their family members, and the palliative care staff. In reality, each time frame overlapped and conflicted, while creating chaos and improvisations, partly due to the uncertainty of death, which often frustrated those who were involved in end-of-life care.

> [Case: Overlapping Multiple Time Frames and Uncertainty of Death]
>
> Mr. Jeon Keunwoo was a professor at a university in Seoul. When he came to Doctor Park, his tumor had progressed to such an extent that he did not have a choice regarding treatment. From the beginning, Doctor Park had expected Mr. Jung's life expectancy to only be one month. As a Christian, Mr. Jeon and his family believed that God had given him some time to complete his calling, and they deemed that calling was a book on which he had been working.
>
> The palliative care team members were very fond of Mr. Jeon and his family. His

family was a so-called "decent family," whose members were sophisticated with refined demeanors. Further, the palliative care team admired that this family "had prepared" for Mr. Jeon's death in a very organized manner; his two daughters and his wife nursed him all the time; Mr. Jeon voluntarily applied for Ms. Hah's "Interview with My Soul" program and left a letter to his lovely wife and daughters; also, Mr. Jeon had written his DNR. In the morning briefings, Nurse Kim at times explained, "This is a very well-prepared family. The patient is such a strong man."

After finishing the book, however, his last moment did not come. Nobody in the world, including Doctor Park and Mr. Jeon himself, could tell Mr. Jeon how long he would have now. His tumor had continued growing in his trachea to such an extent that his airway had become as narrow as pencil lead. Surgery was not a possible option, and radiation therapy did not work. Yet his condition in general was very good, aside from the tumor. He did not even contract pneumonia, as was common with cancer patients, and his lab results always indicated no infection. Only his trachea had been intruded upon by the tumor, and, although this caused him difficulties in breathing, he continued to retain his sanity. Mr. Jeon came to be very anxious about what would happen to him in the end.

Three months after his hospitalization in the terminal-cancer ward, everyone—Mr. Jeon, his wife, and Doctor Park—were exhausted by "preparing." Mr. Jeon's wife became a greater expert on airway suction than many interns; Mr. Jeon asked Doctor Park for euthanasia, which was not allowed in Korea; and Doctor Park could not find a single word to say during rounds anymore.

Nobody knew what would happen to Mr. Jeon, or when his end would come. However, they continued discussing how to handle this eventual end. Mr. Jeon wanted Doctor Park to sedate him using midazolam so as not to die due to choking. Doctor Park's concern was that, even if he sedated Mr. Jeon, the patient's sedated status could continue for one week or so if they still suctioned him. Mr. Jeon's wife clearly disagreed with the idea of stopping airway suction. She regarded the action of withdrawing airway suction as aiding and abetting suicide.

Only two days after Doctor Park expressed concerns to the palliative care team, Mr. Jeon passed away. Nobody had expected his ending to come at that moment. Even though Mr. Jeon's family had prepared themselves for over three months, Mr. Jeon's wife could not help but ask, "Could you do anything for him, please?"

> to Doctor Park in her husband's last moments. After he passed away, Nurse Kim informed the staff of his passing away in the morning briefing and said, "He had prepared too early."

In Mr. Jeon's case, I can draw out several sets of ideas about the temporal process of dying that did not always play out as intended and that often contradicted one another. For Mr. Jeon, since he had been absorbed in self-discipline through working-out, the onset of cancer frustrated him. He was in late his fifties, with strong vigor and energy, and in the prime of his career. This was not the right time. Yet, with his religion and the emotional support from his family, he could accept his fate, giving meaning to his last weeks as a time to complete his book.

For Doctor Park, the first prognosis was incorrect, which, in itself, was not a problem. All patients and families hope for a patient to live longer than their prognosis. It was clear to Doctor Park that Mr. Jeon had entered the late terminal stage, a time of irreversibility and incurability. Simultaneously, the patient's "condition" was good despite the continued growth of his tumor, which made it difficult for Doctor Park to make a prediction of the timing of the dying process.

For the palliative care team, Mr. Jeon's family was a model family. They were armed with love and gratitude, did not create dramatic scenes, and hoped that Mr. Jeon's ending would be in peace. Ms. Hah said to me several times how she was impressed by the interview with Mr. Jeon.

However, the terminal stage for Mr. Jeon was a bit longer than everyone had expected. Mr. Jeon could not find meaning from the time he continued to have after he completed writing his last book. Suffering from pain in his trachea and the psychological pressure of fears of suffocation, Mr. Jeon wanted to end this lingering time on his own terms, which could not be realized in a legal way in Korea. Both his wife and Doctor Park fully agreed with Mr. Jeon's wish to find a way to lessen the pain he went through, but Mr. Jeon's wife made clear her objection to the idea of stopping suction. As a Christian, she did not agree to artificially shorten her husband's life through the cessation of suctioning, because she felt that made her an accomplice in a suicide rather than an assistant in a natural death. Doctor Park was curious if it would be possible to lessen the suffering time without stopping suction. Since the patient's body was enduring very well, the sedation of the patient was probably not enough to lessen the time of suffering from pain and fear.

As seen in this case, "preparation for death" does not go as well as people planned and expected. Particularly, it is very hard to clarify the distinction between the end-of-life process and the terminal-stage because a patient's body does not always follow the cancer trajectory. Further, low-technologies, such as airway suction and sedation medication, often play a key role in life-prolonging measures, which are not contained in any law.

> [Case: His AD that did not work well][59]
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> Mr. Hahn Dongcheol was in his eighties with bladder cancer. Despite his age, Mr. Hahn's general condition was good enough that he came to Doctor Shin's office by himself without a family member's assistance. Mr. Hahn was alert and always expressed what he wanted. Mr. Hahn had a strong will to judge everything and to make every decision on his own. As such patients did, Mr. Hahn often did not

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[59] During my fieldwork, I had an opportunity of attending an Ethics Grand Round in another tertiary hospital, a branch of the S Hospital, and this Mr. Hahn's case was presented at this event.

show up at his appointment because he sought treatment in other hospitals. From a doctor's point of view, he was a typical non-compliant patient. From the patient's point of view, he just relied on his own judgment based on all information and experience he had gathered throughout his entire life.

Mr. Hahn came to Doctor Shin's office alone not only because of his personality but also because of his bad relationship with his sons. One had immigrated to the U.S., and another, who owned a big company, did not get along with his father. They had been estranged for a long time, and Mr. Hahn always tried to resolve any difficulty at any cost without his sons' support. When he had been diagnosed with cancer, Mr. Hahn had written an AD in another hospital. From the beginning, he refused both chemotherapy and surgery and received only radiation therapy. His bladder cancer recurred two years later, and he was admitted to this urology department for supportive care.

Mr. Hahn had been informed that his life expectancy would be less than three months. It was the first time that Doctor Shin met one of his sons, the chief of a company. This son asked Doctor Shin to do everything for his father. Mr. Hahn's health status rapidly worsened, and he became delirious as his "condition" declined. In his delirium, Mr. Hahn said to his son that he did not want to die. This son, who had just mended his bad relationship with his father, came to be so concerned that he abruptly visited Doctor Shin to ask about Mr. Hahn's prognosis. During his hospitalization, Mr. Hahn's acute problems temporarily improved and he went back home. This temporary recovery—which was just one small instance on the roller coaster of his cancer trajectory—made Mr. Hahn and his son rely heavily on this hospital and Doctor Shin. When Mr. Hahn was discharged in April, Doctor Shin told the son that now this patient needed palliative care and admission to this hospital was no longer of use to the patient.

Regardless of the doctor's declaration of the terminal stage, the son kept calling and asking Doctor Shin what to do while the patient's condition worsened again.[60] Even when Mr. Hahn was carried into the ER of the hospital, the son called Doctor Shin to help them, which burdened Doctor Shin.

Two weeks later, acute respiratory distress syndrome rapidly developed, and he was emergently intubated and transferred to an intensive care unit to be put on

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[60] This is an absolutely unusual situation. I assume that the son acquired Doctor Shin's personal contact number from his personal social network.

> mechanical ventilation. Doctor Shin thought this was the time to write POLST based upon the patient's wish—his AD. Yet, the son did not agree. The son argued that his father had changed his wish, given the words he spoke during his delirious state. It was very hard for Doctor Shin to convince the son that Mr. Hahn was in the end-of-life process. At the end of a long dispute, the son finally agreed to sign a POLST. While the family was preparing the document, a second critical event occurred, and the medical staff in the ICU had no choice but to apply CPR to the patient. In the meantime, the son convened the workers of his company for his father's funeral. Many people were waiting in the hospital for a funeral to be held. The son asked Doctor Shin, "You said to me that it is time for my father to leave. Why has the patient not left yet?" Mr. Hahn survived for another 20 hours before the certificate of family relations was ready, and life-sustaining therapies including ventilator and hemodynamic support could finally be removed.

At a glance, the preconditions of good dying for Mr. Hahn were prepared. Mr. Hahn had a long relationship with Doctor Shin, who knew what his patient wanted for end-of-life care. Mr. Hahn even had written his AD, which was not common at that time. Mr. Hahn was a strong-willed man who wanted to manage everything on his own terms.

During the last months, Mr. Hahn and his son restored their relationship. Mr. Hahn must have been happy about this. The son accompanied his father to the outpatient clinic and was so (too much, perhaps) eager to have his father live longer that he personally contacted the attending doctor.

Doctor Shin was certain that Mr. Hahn had entered the end-of-life process. However, he was not certain if the patient's AD was still effective or not. Who would be able to judge if the patient's changed wish should be negated due to his delirium? Further, despite the long-term relationship with Mr. Hahn, Doctor Shin did not feel safe to rely on their relationship due to the excessive intervention of the son—who had the social and economic power to file a suit against him later.

When they managed to replace the previous AD with a POLST, the medical staff was interrupted by the bureaucratic process of the law. While the family members worked to get the certificate of family relations issued, Mr. Hahn had to undergo CPR. After signing the POLST, the son could not understand that the dying time could span hours and days because at the moment he signed the POLST, he expected his father to die. In his mind, death could occur at once.

This case not only addresses the question, “Is the patient’s will at that moment of writing an AD the same as his presumed intention at the moment of the actual event?” This case also demonstrates that an end-of-life care document has limited power to ensure the dying’s wish. The powerlessness of the end-of-life care document was manifested in Mr. Woo Daegeon’s case, which I presented earlier as a comparison between AD and POLST/DNR. He had yet another story behind his admission to the terminal-cancer ward.

> [Case: Unknowability of Death]
>
> Mr. Woo had long suffered from Parkinson’s disease and regretted being a burden to his family. When he was diagnosed with cancer, he made clear to his family his wish not to receive any life-sustaining treatment, including a tracheotomy. All the family members agreed and respected his wish.
>
> Regardless of this intention, however, when Mr. Woo was carried into the ER due to an unidentified fever following his fifth trial participation, his family members allowed the ER staff to perform a tracheotomy on him. Even though they knew of Mr. Woo’s disease history and disease stage, not to mention his wish not to receive any life-sustaining treatment, his family members could not judge whether this was just one of the downward movements on the small-scale roller coaster—that is, whether it was the time to let their father rest in peace or the time to “prolong” his life. Nor did the ER staff know at that very moment

> whether the patient's condition was reversible or not. It was the duty of the ER staff to inform the patient's relatives of the urgent necessity for a tracheotomy in order to save the patient at the moment, and the family members found it impossible to say "No" to the medical staff when told, "The patient will pass away unless this procedure is done right now."
>
> Among the palliative care staff, Doctor Park felt particularly sorry for Mr. Woo. He asked, "What does this three-week-long hospitalization and tracheotomy mean to him now? Family members imagine a gradual and expected death, but most cases worsen suddenly. I am so sad to see this situation. This patient had an 'insight' and his will was very clear, but he is still being put through this. In my outpatient clinic, I warn patients and family members that the patient can deteriorate at any time and that the patient can just pass away. Young patients have a hard time accepting this fact, but elderly patients tend to accept it more smoothly since they have seen others die. Do not do anything to him. No antibiotics or lab tests."

In this case, the patient's will was determined, and the family members also respected his will. Even, Mr. Woo made clear his intention by filling out his AD in advance. There would be nothing he could do more than this. However, no one knew whether or not the moment right before performing the tracheotomy was his time to die. Mr. Woo's wife would not have let the ER staff do it if she really knew that this was the destined time for her husband. However, what if this was just another crisis that he would overcome as he had done? What if Mr. Woo could live a few more weeks and months due to this aggressive intervention? Especially some types of cancer, such as prostate cancer, are likely to continue for years in the "terminal-stage," and this unknowability of death often negated all the legal and medical power of the end-of-life document.

Conclusion

Any kind of activity that humans conduct is about time, but this is especially true about medicine. In being critically ill and seeking medical intervention, we ask ourselves to imagine different future scenarios for ourselves and our loved ones (Kaufman 2010: 195). However, sadly, these different scenarios are often not as powerful as we might wish. First, there is inconsistency in when the terminal stage is actually declared to begin. The Act defined the terminal-stage as a few months before death and the end-of-life process as an imminent death; and the AD and the POLST were meant to mark the distinction between these two timelines. However, in the clinical setting, the oncologists generally declared the terminal stage to begin when there was no further treatment option they could suggest, a point that often overlapped with the imminence of death. In the circumstance where both the doctors and the patients' relatives all hesitated or did not want to let the patients know the bad news, obtaining the end-of-life documents was delayed and the division between the AD and the POLST was not that meaningful.

Second, how the terminal time should be filled was at times contested. Emphasizing the ways in which the patients and their family members understood this time in relation to their individual life trajectories, the palliative care team members wished that their patients could untie the knots in their social relationship, without suffering from physical pain. When biomedicine handed off from the care for terminal-stage patients, the palliative care team members tried to help their patients to go through a natural death. However, there was a fine line between letting nature take its course and abandoning a patient to die, and the nurses had to negotiate with the patients' relatives who regarded low-level technologies as a part of the essential care for the dying.

In this chapter, I mainly focused on what happened in the terminal-cancer ward during the terminal period, but the care plan scheme produces a strong request for the patients to leave the ward once they are diagnosed as in the terminal-stage. In the next chapter, I will consider how and why the terminal-stage patients are moved to several places for good dying.

Chapter Five

Pathways of Dying

Introduction: The Place of Death Matters

Patients arrive at the terminal-cancer ward S Hospital via an ER and outpatient departments in S Hospital; and, upon entering the “end-of-life” period, they are offered three limited options for where to move and stay until the end. Why are the patients unable to stay in the terminal-cancer word and compelled to leave for another place? What values are embedded in each spatial option, and what regulations and elements of the hospital system allow, force, or stop a patient migrating to another place? How does the palliative care staff arrange this relocation, and can we call this displacement of patient care?

In exploring the entanglement of space and good dying, I first outline the possible end-of-life routes that the patients in the terminal-cancer ward can follow and explore the structure and internal rules of S Hospital that push the terminal-stage patients to leave this hospital by rendering the terminal-cancer ward as a station of the end-of-life route. Second, I scrutinize how the palliative care team members rank the available places for end-of-life care according to their ideas about what constitutes good dying. Third, however, the two best paths for good dying are often hampered by contradictory regulations, the lack of the governmental support, and the patients’ and their family members’ resistance to the referrals to hospices. The newly-introduced end-of-life care documents can facilitate the admission to the hospices and home death as well as the discharge from ICUs, in some sense, but the majority of medical institutions are still unable to implement the withdrawal of life-sustaining treatment and, as a result, some patients swing back and forth between tertiary hospitals and other facilities.

Possible Pathways of Dying

The majority of the patients arrived at the terminal-cancer ward via the ER of S Hospital, and a small percentage were admitted from the outpatient departments of S Hospital. At the moment of admission, not all patients recognized their bad prognosis, since it was likely that the doctors had not yet initiated the conversation regarding their bad prognosis. Yet, during hospitalization, many of them would have been informed that they were now entering the terminal stage, and the nurses would suggest that the patients and their family caregivers think about where they would like to spend their end-of-life time. When they were discharged from the terminal-cancer ward, some would return home, some would be referred to hospices, and some would be moved to an intensive care unit in the hospital. And some patients would not leave and eventually pass away in the terminal-cancer ward. These are the pathways of dying that patients with cancer move along (Figure 6).

Before following these pathways of dying, however, the first question must be, “Why do these patients come to S Hospital—a tertiary hospital in Seoul?” In Korea, there exists an expression: “big-five hospitals.” Though not every Korean can name the five hospitals that belong to this group, most Koreans would imagine one of these hospitals to be “a big hospital in Seoul.” In actuality, the big-five hospitals refer to five large tertiary hospitals located within

Seoul.

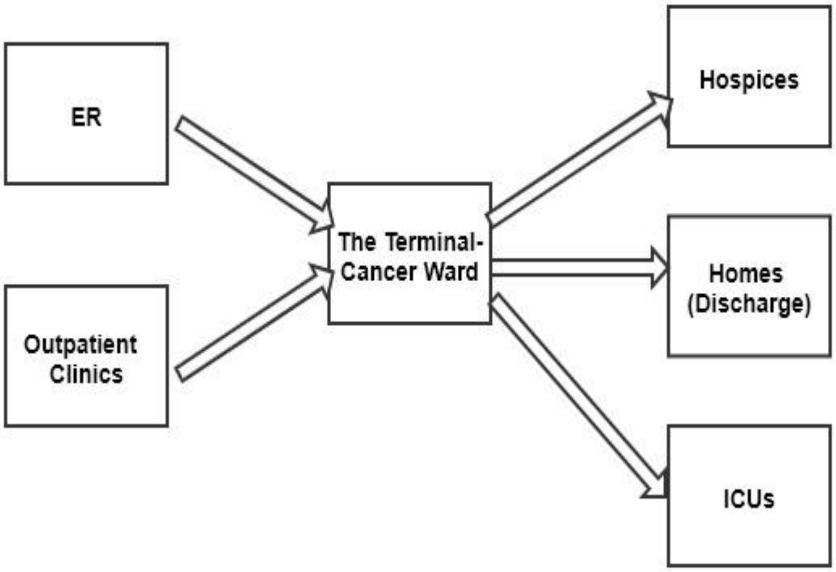

Figure 6. Pathways of dying

According to the Medical Service Act, medical institutions in Korea are largely divided between (1) a clinic-level medical institution, which provides medical services primarily to outpatients, and (2) a hospital-level medical institution, which provides medical services primarily to inpatients. Hospitals that are equipped with 200 to 800 beds and have at least seven specialized departments are classified as general hospitals. Among general hospitals, the Minister of Health and Welfare designates as "superior general hospitals" those that specialize in providing medical services requiring a high level of expertise for treating serious diseases. A superior general hospital must have not less than 20 specialized departments, and must provide training to people who intend to become medical specialists.[61] Although the Medical Service Act does not use the term “tertiary hospital,” a superior general hospital as defined in the Act accords with WHO’s definition of a tertiary-level hospital: a hospital with highly specialized staff and technical equipment—including, for example, a cardiology unit, an intensive care unit, and specialized imaging units; clinical services highly differentiated by function; teaching activities; and size ranging from 300 to 1,500 beds.[62] In sum, the big-five hospitals in Korea refer to five particularly well-known “superior general hospitals,” and it can be said that these five hospitals stand on the top of the medical delivery system in Korea.

A patient visits a local clinic to consult with a doctor. If the local doctor recommends that the patient go to a “bigger hospital,”[63] the doctor will send the patient with his or her referral to a general or a superior general hospital in the patient’s residential district. Yet this protocol is theoretical; it is common to see patients sitting in a waiting room of a tertiary hospital having skipped the initial step. Even when a patient directly visits a doctor in a tertiary hospital without a local doctor’s note, medical care is available, though the service may not be covered by the National Health Insurance. Due to this relatively low hurdle of receiving care in tertiary hospitals, the well-known hospitals are always crowded with patients who come from all across the nation. Among the hospitals and clinics in Korea, the big-five hospitals accounted for 6.23%

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[61] Beyond this two-layered category of institutions, community health centers, nursing hospitals, nursing homes, and hospices belong to health care institutions. See Medical Service Act Article 3-3.4.
http://www.law.go.kr/LSW/eng/engLsSc.do?menuId=2&section=lawNm&query=medical+service&x=0&y=0#liBgcolor0
http://www.law.go.kr/LSW/lsInfoP.do?lsiSeq=204193&efYd=20181115#0000

[62] https://www.who.int/management/facility/ReferralDefinitions.pdf

[63] This is an idiom that refers to a general hospital or a superior general hospital.

of the total medical expenditures in 2018.[64] As a result, the concentration of visits to these hospitals creates an overload for their staff. The Korean Medical Association has insisted that the fundamental cause of this unsupportable concentration is a failure of the medical delivery system and the failure of the low-fees-for-medical-services policy by the Korean government.[65]

Although scholars and professionals alike have criticized this concentration as a pathological phenomenon and a failure of the medical system, the problems of the health care delivery system are not entirely to blame. This is because patients strongly prefer not just a tertiary hospital, but a tertiary hospital in *Seoul*. Sociologists assess the political-economic growth of South Korea as “compressed modernization” (Chang Kyung-Sup 1998), which means that a modernization has unfolded over a very short period of time, compared to the Euro-American countries, and it has been led by the government. Because the government, which monopolized the authority to distribute resources, has concentrated capital investment on the capital, Seoul, and only a few other big cities, this country now suffers from the severe imbalance between the capital and non-capital regions, in all respects—population size, the gap in property values, wages, the cultural infrastructure, and the health care infrastructure. The medical infrastructure in Seoul overwhelms that of non-capital regions, with regard to the number of medical institutions, the number of doctors, and investment in advanced equipment and research and development.

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[64] The total medical expenditures in 2017 were 70.8 trillion KRW, and the medical expenditures of the big-five hospitals were 408 billion KRW (approximately 3.45 billion US dollars). This proportion has continuously increased up to the present. “Last year, the medical expenses of the Big 5 Hospital surpassed 4 trillion KRW,” *Financial News*, 2019. 9. 20. http://www.fnnews.com/news/201809200850151423; ; “Concentration of patient gets worse,” *Medi:Gate News*, 2019. 4. 18. http://www.medigatenews.com/news/717919472

[65] ″Doctors at large hospitals are overworked while doctors at small clinics are on the verge of death,” *Cheongnyeon Uisa*. 2019. 3. 14. http://www.docdocdoc.co.kr/news/articleView.html?idxno=1066220

Desperate patients view the tertiary hospitals—in particular the big-five hospitals in the capital—as places that they can trust because these medical complexes must be equipped with the state-of-the art medical technologies and the most outstanding doctors.[66] One often hears people give the advice "You must go to a big hospital in Seoul" when talking about a person's symptoms, and "a big hospital in Seoul" typically refers to these five hospitals.

In the cases of cancer, this preference for big hospitals in Seoul is even more prominent. Although the five-year survival rate of cancer patients has improved, cancer is still classified as a life-threatening disease. Once cancer is diagnosed, a patient and her relatives overwhelmingly prefer to receive treatment from well-known hospitals in Seoul.[67] Physicians point out that enrolling in hospitals within the vicinity of the patient's home is of benefit to patients because doctors would apply different treatment regimens depending upon the commuting distance between the patient's place and the hospital, but the preference to attend big hospitals in Seoul remains robust.[68]

If a person who resides in the provinces is to think over whether to receive treatment in adjacent hospitals or in hospitals in Seoul, she would likely get the following advice: "Major hospitals are more competent and experienced." "Big hospitals in Seoul are good at managing emergency situations in which patients need critical care." "The gap in the quality of medicine between Seoul and the provinces is significant, and your life can depend on even a very tiny

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[66] The "big-five hospitals" are aligned with the top five medical schools.

[67] "One in ten cancer patients use four or more hospitals," *Seoul Shinmum*. 2017. 9. 20. https://www.seoul.co.kr/news/newsView.php?id=20170921002003

[68] "What is the problem with the concentration of cancer patients to Seoul?" *Kyungsang Ilbo*. 2019. 3. 20. http://www.ksilbo.co.kr/news/articleView.html?idxno=686904

difference.” “Well-known hospitals can give you more opportunities to take part in trials.” “Well-known hospitals in Seoul have a much better system.”[69]

The remarks of those who have experienced both hospitals in Seoul and in the provinces are often the deciding factor: “When my parent had been diagnosed with cancer, a doctor in the province said that there was no available option and foresaw a couple of months of life expectancy for my parent. But my parent lived years more after receiving treatment in Seoul.” All of the advice eventually converges on: “You’d better try everything possible if you want to survive from cancer.” A patient’s wife told me:

> My husband used to be a police officer. On his way home, he fell down and complained of pain in his legs. Local doctors could not uncover the cause of the pain, and we went to C University Hospital. A doctor at that hospital identified the disease as cancer. I wanted to do everything for him, so we came to S Hospital.

C University Hospital is a general hospital in Gyeonggi-Do (a province adjacent to Seoul) attached to a university medical school. Yet, even though the couple had the disease identified there, the wife transferred her husband to S Hospital. She defined her action as doing everything for the patient. She was so determined to help her husband recover that she endured many personal inconveniences, such as moving to Seoul (from their home in a southern province), being placed on a long wait-list, and being charged high costs. To the couple, coming to S Hospital thus signified emergency, crisis, desperateness, and the best effort they could make; they were willing to mobilize all the economic and social capital they could in order to fight against this disease.

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[69] I gathered these quotes from the on-line community of patients with cancer.

Some of the patients in the terminal-cancer ward came directly—via a doctor's referral—from one of S Hospital's outpatient departments, but this is not very common because of the chronic shortage of beds in all wards in S Hospital. Rather, the more common route was from the ER to the terminal-cancer ward. When a patient suffers from an acute symptom—such as fever, eating problem, and bleeding, which can be a side effect of an anti-cancer regimen, another symptom of cancer, or a new disease (e.g., pneumonia)—the patient with cancer cannot afford to make an appointment with a doctor and then wait for days or weeks, when she could be carried into the ER. While receiving necessary treatment and waiting in the ER for up to 72 hours, she will be moved to the terminal-cancer ward. That is, the ER functions as a shortcut to S Hospital admittance that bypasses the long wait-list.

After hospitalization, many of the patients in the terminal-cancer ward can have the acute symptoms that brought them there attended to and/or they can complete anti-cancer treatments and return home. However, for some of the inpatients, the doctors will find them to be in the terminal stage, which signifies that these patients now are no longer treatable and need to prepare for their death, as discussed in Chapter Four. At this point, they are supposed to leave this ward and to move another place, where the "preparation" will be realized.

Why Patients Cannot Stay in the Ward until the End: An Acute Care Hospital

Before tracking the paths of dying followed by patients after they leave the terminal-cancer ward, it is important to ask why these patients must leave this ward. Why could they not stay and just die here? This question urges us to look into both the internal structure of S Hospital and its relation to the national health care system, which together compel this relocation. The ways in which the medical staff working in S Hospital perceived the hospital was very different from that of patients and families, who came to S Hospital in order to do everything they could. For the staff, the most important and distinguishing feature of S Hospital was that it was *an acute care hospital*. They address acute symptoms and then transfer patients to other facilities, such as homes, secondary hospitals, nursing homes, and the like. That is, to treat and move patients out as quickly as possible was the fundamental function and imperative of tertiary hospitals, including S Hospital.

Early scholarship on institutional aspects of hospitals paid attention to the pressure to "move things along" (Kaufman 2005; Rhodes 1996), which Mizrahi (1986) named the "Get-Rid-of-Patients perspective." Throughout their training and careers, physicians and nurses learn and embody the value of and diverse strategies for dispatching patients as quickly as possible (Mizrahi 1986). Tertiary hospitals in Korea, as with such hospitals in other countries, suffer from a chronic shortage of resources and excessive demand.

I felt the excessive demand when I observed Doctor Park's outpatient clinic in S Hospital. On that day, I met 58 patients over a period of four hours, and Doctor Park said that it was just an ordinary day. For four hours, Doctor Park never left his room. In spite of his restless, intensive work, the long wait line outside did not seem to move very fast, and in situations in which the patients had put up with long delays past their appointment time, Doctor Park could spend, at best, only five minutes with each patient, and this short consultation appeared insufficient to both Doctor Park and his patients.[70] For the medical staff working in tertiary hospitals, whether or not they can “process” patients as quickly as possible becomes a critical quality to prove their competence because one member’s delayed processing would cause a knock-on delay to the next staff member, and, further, to other staff—for instance, the nurses would be faced with many complaints about the long wait.

Fundamentally, in S Hospital, the idea of moving things along (Kaufman 2005) was rooted in how limited medical resources were allocated. Both the number of medical staff and the number of beds were not infinite, whereas the needs of patients were much greater than S Hospital was able to accommodate. Considering this lack of space, it is not surprising that S Hospital was not equipped with a hospice ward. A decade ago, they had had a hospice ward: in the late 1990s, some of the medical staff of S Hospital had formed a group to study hospice and palliative care, even though the hospice movement had not yet been popularized in South Korea. This study group had succeeded in persuading the head of the hospital to run a hospice ward. Their justification for this request had been very reasonable: high demand. Given that a good number of critically ill patients with cancer had come to this hospital and many of them had needed palliative and hospice care, the decision to run the hospice ward had been appropriate to meet the needs of patients with humane care. Resonating with their efforts, S Hospital had started to run a hospice ward.

However, a couple of years later, S Hospital eventually decided to close the hospice

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[70] Doctor Park was well-known among the medical staff in S Hospital as a doctor who took a (relatively) long time to see a patient. In other words, other doctors spent less than five minutes per a patient.

ward, and the hospice ward had been switched to a general ward, but a ward specifically, but implicitly, for terminal-stage cancer. When I asked why the hospice ward had been abolished, Nurse Roh answered, “S Hospital should not run even a hospice ward, because we are a tertiary hospital. If we [such a gigantic hospital armed with advanced technologies and personnel] run a hospice ward, other institutions would feel that we deprive them of a chance to invite terminal patients. Our job is to send the patients to hospices outside of the hospital.” In her explanation, S Hospital occupied a specific place in the national health care delivery system, a place that linked this large-scale hospital to various other types of institutions. It was true that there was still high demand for hospice care for critically ill patients in S Hospital, but, S Hospital did not need to monopolize every health care service in a situation where patients from across the nation were concentrated. This political-geographical inequity embedded in the national health care delivery system justified the internal geographical marginalization and distribution of palliative and hospice care. Moreover, the economic feasibility of a tertiary hospital comes from a high bed turnover rate, a demand which a hospice ward could not meet. In short, from the S Hospital’s point of view, there was no justification for or practical benefits from running a hospice ward.

Establishing a palliative care team would be a desperate attempt to compromise with reality since this type of palliative care service—which is called consultation-based hospice—does not need a separate dedicated space. Among the big-five hospitals, three hospitals were running this team-approach to palliative and hospice care service. Instead of a hospice ward, S Hospital reserved one private room for the dying—which was called an *imjongbang*—in the terminal-cancer ward.

The structural order for discharging patients as quickly as possible was also related to an incentive payment program of this hospital. According to the National Assembly Budget Office, S Hospital has implemented a performance-related pay system for its doctors since 2003. The more contributions to profit, the higher bed-turnover rate, the more new patients, the more hospitalized patients, and the fewer long-stay patients, the more incentives the doctors of S Hospital receive. The National Assembly Budget Office reported that 1.45 billion KRW (approximately 1.26 million US dollars)[71] was paid to 516 doctors of S Hospital in 2014.

This economic pressure to increase the bed turnover rate was embedded in the care plan for patients. From the moment a patient arrived at the hospital, doctors were supposed to establish a plan for when, where, and how the patient would be moved. In a staff meeting, Doctor Park made this point clearly to a newly recruited faculty member, Doctor Kwon Jaein:

> Once a patient comes, you should have at least a rough plan for the patient. Most patients come to this hospital through an ER due to acute problems. If the acute problems are solved, they can go home in a week. If not, they will eventually be transferred to ICUs. There will be a big difference whether or not you think about how to discharge a patient from the beginning. One problem is that some [attending] doctors are unwilling to discharge their patients because the doctors don't want the ER people to keep tossing their patients to us. The patients do not want to be discharged, so if the doctors do not push the patients to go home, then the patients think, "Hang in here for three weeks no matter what." Then, the ER will be in chaos. This week we got a lot of new patients, which is a good sign [of bed turnover rate].

Doctor Park's instruction indicated the intertwined relationship of time and space in the hospital. Patients assigned to the palliative care team are moving along on a virtual conveyor belt, which starts from the ER, moves to the wards, and then moves to the ICU or the outside world. The

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[71] All exchange rates in this dissertation are based on the applicable values in early 2020.

influx of new patients from the ER will be endless. If the ward staff is not cooperative with the internal rule of moving things along, it will create a bottleneck, which causes the ER to overflow, because patients will not voluntarily go home. Physicians in the terminal-cancer ward must manage traffic control so that patients do not linger in the ward as long as possible. An index that shows how well the traffic control works is the length of the hospital stay.

A type of document that was circulated to the palliative care staff in the staff meetings symbolizes the system's pressure to quickly remove inpatients and the workers' concerns with the pressure. This staff meeting document was a list of patients staying in the ward that contained the disease history, the history of treatment, age, gender, caregivers, etc.—that is, all the relevant information needed to take care of patients. It was noticeable that the total length of stays of the entire ward and each patient's length of stay were noted in the document so that the staff could easily notice who had stayed too long or not. Doctor Park, the director of the terminal-cancer ward, was the one who was most concerned with the numbers in that he often addressed the issue of hospital stays in the staff meeting as follows:

> Doctor Park: (talking about a patient) Ms. Oh Changhee has not been discharged yet? How is she still here?
>
> Resident: (briefing her status)
>
> Nurse Kim: (looking to the list of patients) Now the total length of hospital stays have decreased by one week after Mr. Cho Bongsu was discharged. Ms. Oh Changhee, she has been here for 100 days.
>
> Resident: I just do taping for her. I was told to be careful of ommaya [reservoir][72] because she had an event during surgery.

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[72] An Ommaya reservoir is an intraventricular catheter system that can be used for the aspiration of cerebrospinal fluid or for the delivery of drugs (e.g., chemotherapy) into the cerebrospinal fluid. It consists of a catheter in one

Doctor Park: But she should go anyway. How long will she stay here?

Mr. Cho and Ms. Oh both were patients whose hospital lengths of stay had exceeded 100 days. Because the relatives of the patients did not want to move patients with bad conditions somewhere else, the resident could not push them to go home, but it was clear that their long stays definitely irritated the staff. They felt that this kind of extended stay should be prevented. Doctor Park often warned the residents rotating into the ward not to provide an opportunity for their patients to linger in the ward.

> Resident: (reporting a patient's case—the patient had come to the ER due to fever after receiving chemotherapy. He was diagnosed with pneumonia and received antibiotics) I am thinking about discharging him once his pneumonia improves, but he can't eat. If the eating problem is fixed, he can go home. But I guess his relative bears in mind that the second chemotherapy is coming and wants him to be discharged after the second therapy.
>
> Doctor Park: (suspiciously) Hmm, won't he stay even after the second therapy?
>
> All: (laughed)
>
> Resident: I will discharge him as soon as possible once the second therapy is over.
>
> Doctor Park: I think that his long-term prognosis will not be good. Maybe we can't get him the chemo in time.

The resident counted solving both pneumonia and the eating problem as prerequisites of the patient's discharge. Yet, according to the patient's care plan, his second round of chemotherapy was coming, and the resident had in his mind that the patient's family members would not want to discharge the patient until the second round of chemotherapy had been completed. In contrast, while Doctor Park agreed with the resident's idea that the second chemotherapy should be the

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lateral ventricle attached to a reservoir implanted under the scalp.

Maginot line of this patient’s stay, he warned the resident that his care plan would likely not go as planned due to the patient’s poor prognosis. The resident might need to establish a back-up plan for the patient’s discharge.

As with all kinds of human plans, plans for discharge often do not to go as well as hoped, even though the medical staff tries their best to control the patient traffic.

> Doctor Park: Phew, this patient (Mr. Choi Hyeongdong) is a problem. He does not want to go home. He lives in Jinhae (a southern province), but the grandmother (the patient’s wife) feels anxious about taking him home and hangs in here. The patient’s son is a dentist and the son wants to transfer the patient to a hospital that is able to handle his ENT problems. The grandmother said that they will book a hotel around this hospital and come to our ENT clinic every day.
>
> Resident: I was told that their second son lives in Daejeon and they are looking for a hospital located in Daejeon.
>
> Doctor Park: The sons never show up. You need to assign a role to each family member to prevent potential family disputes. The medical staff warned them too darkly that a sudden death could occur, so the grandmother is too scared to discharge the patient now. We can’t proceed with further chemo for him anymore…. You’d better consult with them on hospice. But the grandmother keeps talking nonsense.
>
> Nurse Kim: I think C University Hospital or M Hospital in Daejeon is better at caring for his ENT problem.
>
> Doctor Park: I have told him since he stayed in the 9 ward (one of the general wards) that he would be discharged once the anti-cancer treatment was completed. I kept talking to everyone that this patient should be discharged soon, but no one listened to me. His son knows a staff member in this hospital who is senior to me, and complaints from this patient come to me.

In the face of Mr. Choi’s case, Doctor Park had some difficulties. Even though he made a range of efforts to discharge him on time, Mr. Choi came up to the terminal-cancer ward and refused to be discharged. And since Mr. Choi’s son had exerted pressure on Doctor Park, he could not push this patient out either. In fact, his prognosis was bad, and a resident had warned Mr. Park's wife about the bad prognosis, which caused the plan to backfire. Mr. Park's wife became too scared to agree to the staff's proposal to discharge her husband.

It was not true that the hospital and the government just sat on their hands regarding the allocation of resources problem. Both the hospital and the government resorted to alternative means. For example, the government had initiated a policy concerning ERs for the purpose of preventing overcrowding. According to the policy, every ER was assessed by the length of patients' stays and, if the limit was exceeded, the hospital would suffer some penalties, such as subsidy cuts. The original purpose of this policy aimed to control and maintain the number of patients staying in ER and thus to take a big load off the ER departments, but this policy increased the pressure on the ER staff members to send their patients wherever possible. In the case of S Hospital, a new type of ward, which was called an Emergency Ward, functioned as a way station where patients stayed up to 72 hours until general wards created a slot.

In the case of the terminal-cancer ward, in order to prevent patients from staying too long in multi-bed rooms, S Hospital had created a "three-week policy." A multi-bed room of a tertiary hospital[73] was a sought-after resource. Patients and their families overwhelmingly preferred to stay in a multi-bed room because the national health insurance covered only multi-bed rooms. If a patient was hospitalized in a multi-bed room, a patient paid 12,559 KRW (10.67 US dollars) a day, whereas using a private room or two-bed room cost 103,000 to 417,000 KRW

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[73] The capacity of a multi-bed room depends on each ward and each hospital. In the case of the terminal-cancer ward, five patients were accommodated in a multi-bed room.

(87.14 US dollars to 352.79 US dollars) a day. Due to the high demand for multi-bed rooms, S Hospital restricted a patient's stay in a multi-bed room to three weeks, at the most. After three weeks, the patient would have to move to a private or double-bed room.

The purpose of the rule was to fairly distribute the hospital rooms with a lower price to everyone and prevent the monopolization of multi-bed rooms by a small number of patients. However, this rule sometimes gave the wrong impression to patients that they were able to stay in the ward maximally for three weeks. As Doctor Park put it, "Patients tend to believe that they have a right to stay here for three weeks because multi-bed rooms let them stay for three weeks. Patients want to go home as soon as possible when they have to stay in a double-bed room, but they say, 'I want to stay in the hospital until my problem is fixed' once they come to a quintuple room."

In sum, the influx of critically ill patients who wanted to receive care and treatment in S Hospital never stopped while the attempts to distribute temporal, spatial, and personnel resources evenly were not very effective. In the hospital system, palliative and hospice care service was marginalized not only in terms of budget but also of space to the extent that S Hospital yielded the palliative care team the ward to accommodate the terminal-stage patients. For these reasons, a "patient" was reclassified as "a patient who needed to leave as soon as possible" once the patient was determined to be in the terminal stage.

Hierarchized Places for Dying

The health professionals of the palliative care team were the sole staff members in S Hospital who resisted medicalized death. The role of the team was different from that of other hospital staff in that the members talked to patients and their families about death as an important event through which patients could ultimately make their lives meaningful. The palliative care team members—who joined the team voluntarily with a sense of vocation that all people deserved a good death—conceptualized the terminal stage of diseases (especially cancer) as a time to prepare for dying; and, for them, dying well meant being provided with the chance to (re)affirm love, forgiveness, and gratitude between the dying and their family. Nurse Heo's remark expressed the essence of the meaning of good dying that the team members all shared:

> I sometimes imagine a scene of my dying. The place I meet my ending is not a hospital, but my home. It is not a room, but a living room with full-height glass looking through a yard. My grandchildren are frolicking in the yard. I have a strong wish that my two daughters are with me at that moment. I am lying in a bed or a rocking chair under a quilt. My daughters are sharing old stories, and I reply with a smile, "Yes, we did." I wish for my patients to also meet this kind of death. If not in their homes, it should be a comfortable place, and they should think, "Yes, I have been loved. These people (their families) will know and remember that I lived my days with sincerity." I wish that they may die in peace with this feeling.

Nurse Kim in the team added:

> [A good dying would be] being in the least amount of pain as possible. It is most important to make both your body and mind comfortable. When I highlight to my patients and their families that the patient should be in less pain if it [the dying process] is irreversible, no one disagrees…. In addition to this, it would be better if you can complete your own life in a meaningful way. I wish that my patients will have time to forgive and express gratitude to their significant others.

While Nurse Heo highlighted the relational and emotional aspects of completing one's life, Nurse Kim addressed the basic factor of good dying—no pain. The factors that they counted as the conditions for a good death—(1) with family, (2) with love, and (3) without pain—are in accordance with previous studies on health professionals' understanding of what constitutes a good death (Good et al. 2004; Johnson et al. 2000). In addition to their explicit remarks on good dying, the palliative care team members also shared what a desirable death would be in implicit ways. For example, through daily conversations the team members exchanged accounts of some desirable cases of people who had accepted their unavoidable death, had left their affairs in perfect order, and had left with words of love and gratitude. These conversations ended with praise and admiration for the patient.

The factors that constituted a good death in the staff's thinking were intimately related to places. Each place was assessed in relation to its ability to provide the elements of a good death—whether or not a place could let a patient spend the last time with her family in a warm atmosphere, and without pain. The team members ranked places of death: hospices and homes (if pain control was possible) were at the top, while ICUs were at the bottom, and a ward in the tertiary hospitals was in between. Nurse Kim said:

> S Hospital does not have a setting for a good death. If you want to complete your life in a meaningful way, you are going to a hospice. Some patients have no choice but to die here, and what we can do for them is just to lessen their troubles. This hospital is not suitable for a good death because all of the staff here are busy and nervous, and we have just one single room for the dying.

Her remark made clear that the palliative team members did not consider dying in S Hospital to be the ideal. This was due to the fact that, in a tertiary hospital, a patient and her family would not receive enough attention and care from the medical staff. This medical facility would be good at controlling pain and managing the dead body in an appropriate way, but it was very likely that the patient could not be guaranteed an independent place to complete her life with the family. As Nurse Kim said, this one single room for dying, the *imjongbang*, was not enough to accommodate all those dying in this big hospital. Given that most patients were hospitalized in multi-bed rooms due to medical expenses, a dying patient was likely to meet her demise in the multi-bed room unless the *imjongbang* happened to be vacant at that time. In contrast, a hospice was a place, the primary goal of which was to fulfill the conditions of good dying with the assistance of experts.

The worst death would be dying in an ICU while connected to machines and lines. Nurse Lee had worked in an ICU before joining the palliative care team. He explained why he had moved to this team as follows:

> For the first couple of years [in the ICU], I had approached dying patients in a mechanical way. When a patient passed away, I thought about what procedures and paperwork needed to be done. After I got accustomed to my job, I realized how sad this was, how sad the family members felt, and how bad a place the ICU was for dying…. I learned of the job opening on this team, and I applied.

What frustrated Nurse Lee was the dehumanized and bureaucratic nature of the way that the ICU handled death. When a person died, there were reports to file and procedures to follow, instead of condolences and prayers. The determination that the ICU is the worst place for dying is related to the environmental factors of an ICU. Due to the intensive care needed, admission to an ICU exposes patients to serious stressors, such as respiratory distress, pain, having tubes in their nose and/or mouth, loss of control, sleep deprivation, physical restraint, and not being able to communicate (Biancofiore et al. 2005; Novaes et al. 1999; Skalski, DiGerolamo, and Gigliotti 2006), and it is reported that one fifth of ICU survivors experience post-traumatic stress disorder

(PTSD) (Ratzer et al. 2014).

These traumas would be worthwhile if the aggressive measures saved people from acute diseases in the end, but, at least in the case of those who were expected to die within months, weeks, or days, the medical staff thought these intense treatments were not only futile but also harmful because these treatments contributed only to prolonging the time of dying while damaging the quality of life during its final days. Even if a patient overcame this event, she would likely soon face yet another event. Most of all, the palliative care team assessed dying in the ICU with life-sustaining treatment as the worst death because it deprived a patient and their family of a chance to say their last words. The ICUs had a policy that limited family visits to only twice a day, each only thirty minutes, and the patients often spent their last days alone under the pale fluorescent lights of the ICU. This place, as Ariès criticized (2016[1974]: 285), is not a place where the dying are respected as beings with reason. Rather, the dying are observed as clinical objects, are isolated as undesirable cases, and are not treated as full-fledged persons.

Accordingly, one of the important missions of the palliative care team was to move a patient to a better place while simultaneously saving them from the worst place. Obviously, this mission, in part, responded to the administrative framework of the tertiary hospital—in which spatial resources were chronically in short supply and financial pressures were ever present—but it also came in part from their belief that some places made for good dying. Where the patients were moved would alter the physical and emotional landscape of dying. Despite the palliative care staff’s valiant efforts, however, the transfer often did not go smoothly for several reasons. In the following sections, I trace the routes followed to different end points and investigate the micro-regulations that intervened in the paths taken by the dying.

On the Way to a Hospice

One day, I visited Ms. Yim Heesun to see if she wanted to do a footbath, which she had enjoyed previously. Ms. Yim was talking with Nurse Heo, and I was able to join their conversation. Ms. Yoon was a “wonderful person” in Nurse Heo’s words. She was one of a few people who was able to enjoy their terminal stage because of her positive attitude. She did not despair but traveled back and forth with her family members, and showed us some pictures she had taken during these trips. Since she wanted to stay in a hospice where a clean and quiet room was offered, Nurse Heo had been trying to get her a bed in a hospice. Nurse Heo conveyed to her good news that one bed had become available in N Hospital.[74]

According to the N Hospital staff member, who called Nurse Heo, Ms. Yim could get a double room if she could come today but she would get a middle bed of a three-bed room if she got transferred there tomorrow: there was little difference in cost between the double room and the three-bed room. Ms. Yim’s preference, of course, was the double room. She was so eager not to lose this bed that she called her daughter and son to come and take her to N Hospital.

They had to hurry to deal with the discharge process. Ms. Yim was supposed to bring a couple of required documents with her to the hospice, such as the attending doctor’s note, CD of

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[74] As a public general hospital, N Hospital was equipped with a hospice ward, where three palliative care physicians worked.

her X-rays and CTs, and her medical record. Nurse Heo instructed the patient what documents she needed to be issued and where she could get them. Their conversation ended with Ms. Yim's thank you, "You did a great job for me. You were very kind. I wish you health and happiness."

Ms. Yim's case was one of the ideal referrals to a hospice: (1) The patient understood why she had to go there both for herself and for the hospital's administrative reasons; (2) her health status was good enough to be moved to another place; (3) she was not only able to get a bed in a hospice where she wanted to stay, but she was also able to choose between two room options. Nevertheless, still, Ms. Yim had had to put herself on the waiting list of several hospices and wait until a slot became available, and she had had to hurry to secure the slot. The referral process required paperwork to prove her eligibility for the hospice and to make the transition from a tertiary hospital to a hospice possible. Her path of dying involved booking, waiting, and documenting.

Unlike Ms. Yim's case, to make patients understand the reason why they needed to go to a hospice was the first, yet the biggest, hurdle for the nurses. The logic and process of patient referral would be the same as with the other departments, but the inclusion of hospice as the endpoint of the referral entirely changed the meaning of the transfer. Just as the ways in which patients and their relatives perceived S Hospital were very different from that of the medical staff, so too the patients and the palliative care team had quite different views of hospice. Many patients and family members felt frustrated when the medical staff tried to transfer them to other institutions. They tended to accept this arrangement as a death sentence because there would be no treatment option if such a big tertiary hospital had failed to cure the disease. In particular, many patients showed strong emotional resistance to bringing up a transfer to a hospice, which to them meant that death was just around the corner. The palliative care team members were well aware that their patients associated being transferred with being abandoned by S Hospital. The referral staff member, Ms. Yun, remarked:

> Most of the patients whom we are in charge of are in the terminal stage, and they have been treated by S Hospital for a long time [both at outpatient clinics and in the wards]. They are moved to other hospitals and hospices when they are declared to be in the terminal stage, so it [the arrangement of transfer] is a bit different from that of other wards. General patients have acute symptoms, are treated, are moved to secondary hospitals to finish their treatments, and then go home. To my patients, the last destination would not be their home, but nursing homes or such. It takes a long time for a patient's family to accept that fact…. In many cases the patient is unconscious [due to having entered the dying process]. The family members of the patient do not want to transfer the unconscious patient to other institutions but want to let the patient pass away here.

Administrator Yun's remark articulated the reason why a referral to a hospice was, and had to be, cautiously done. At the terminal stage, moving somewhere else meant more than a referral. Being asked for a referral signified to the patients a declaration of giving up treatment and a request to prepare for their own death. To them, this was like a double denial. Consequentially, a hospice represented to the patients and their families a place of *death* per se, not a place of *end-of-life care*. As a wife who had lost her husband stated in a bereaved family gathering, "You can get out of there only after you die." The following conversation I had with a patient's sister helped me to understand the ways in which the patients and their families viewed going to hospices:

> [Scene: Conversation with a Patient's Sister]
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> Ms. Hahn Taerim was a lovely woman in her thirties. She used to teach children

> how to draw, but after being diagnosed with breast cancer, she quit the job she loved. Her tumor had metastasized to her brain, which caused a cerebral infarction. In April, she was carried to the ER of S Hospital due to sepsis. Her attending doctor assessed Ms. Hahn as entering a terminal stage and requested her transfer through the referral center.
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> Because Ms. Hahn liked it when the volunteers massaged her extremely swollen arms and legs, I often visited her, and we enjoyed small talk while I massaged her. As her condition got worse, she was often asleep when I visited her room, and, on days like those, I talked with her mother and elder sister, who never left Ms. Hahn's side. Her elder sister said:
>
> This hospital wants us to go out quickly but there is no place for us to go. They said that no more supportive care is possible here…. We are just lay people. We are ignorant of hospice. We just came up with "It is a scary place. If you go, you die there." But I was told that, in some hospices, you can take anti-cancer drugs while receiving palliative care. They provide a good service, and some of patients can survive for two years or so. You can get out of there if you improve. The thing is, I was told, that you need to carefully persuade a patient. If you take a patient there without a good explanation, the patient can suffer from depression, saying "Why did you put me here?" I think I need to delicately persuade my sister…. The reason why Doctor Yang Jinyeong declared stoppage of the anti-cancer treatment was that my sister looked "too sick" for the next chemotherapy for now, and the doctor does not want to bother the patient. The doctor said that anti-cancer treatment can be renewed at any time if my sister's condition gets better…. There are many hospices, and I am going to visit every single institution. What you hear from people and what you see are not the same…. Doctors in the ER told us that she was going to die and that we needed to be prepared. But she has overcome! She has a strong will to fight against cancer. Thus, a hospice does not fit her. She is too young and wants to get anti-cancer treatment. If you are too young and have a strong will to continue anti-cancer treatment, you don't fit in a hospice. She survived a cerebral infarction so I believe she will survive this time too.

As the elder sister acknowledged, Ms. Hahn's attending doctor had decided to stop her anti-cancer regimen. The doctor's declaration meant "no further care plan" and "time to prepare," but the euphemism the doctor used, "Let's stop it because the patient looked so exhausted," was interpreted by the patient's family to mean that the treatment regimen could restart whenever the patient's condition improved. They did not understand (or refused to understand) that the doctor indicated that improvement would not happen.

The misunderstanding of the doctor’s euphemism and the misunderstanding of the goal of hospice created the confusion between “You can come back home if you get better” and “You can get out of there only if you die.” The elder sister’s definition of hospice as a scary place where people go to die represents the popular vision of hospice among lay people. Hospitalization in a hospice meant the end, which echoed with the wife’s remark above. Yet at the same time, she maintained a faint hope that her sister could return home from a hospice if the patient got better.

In order to protect patients and their relatives’ feelings, the palliative care team approached their patients very carefully. For example, the volunteers were informed whether a patient was willing to receive care service or refused the volunteer’s visit. To “make a patient open her mind,” the volunteers made efforts to develop useful strategies in approaching patients, such as offering a cup of tea and initiating small talk. This contributed to an unusual asymmetrical relationship between the palliative care team members and their patients. The relationship between caregiver and care receiver, in general, is regarded as asymmetrical because of the dependency of the care receiver. Yet the palliative care team of S Hospital reversed this aspect of the relationship. The care receiver very often declined to receive care and did not welcome the caregivers. The volunteers often encountered those who refused their visits; and the medical staff—in particular the nurses and social workers—encountered those who did not want to talk with them. Doctor Lee Jiwon, a pediatrician in palliative medicine, said half in jest, half in earnest, “It seems like the parents [of the young patients] think of me as the messenger of the underworld when the medical staff recommends they consult me. Often I am told by the parents that they were very upset when their attending doctors told them to see me."

Once the patient finally agreed to go to a hospice, the palliative care nurses and the referral staff member, Ms. Yun Yeongran, searched for available hospices and made a list of them so that the patient and her family members could select one of them. To make this list, the nurses and Ms. Yun took various conditions into consideration: the hospice must be located near the rest of the family so that the caregivers could visit the patient every day; if the patient was associated with a religion, the staff looked for a hospice that was run by the same religious institution; the economic capacity of the patient was also an important factor in selecting a hospice. Most of all, the preferred hospice must have a slot for the patient. According to a report published by the Ministry of Health and Welfare, there were eighty-three hospices with 1,318 beds in 2018.[75] Given that the recommended number of hospice beds is calculated as fifty beds per million population (Kyung Min-Ho et al. 2010), a population of fifty million people in South Korea should have approximately 2,500 beds. Due to the shortage of hospice beds and institutions, which is partly caused by a lack of governmental support, patients often wait for an available bed for days and weeks, and it is not uncommon that the patient eventually dies in S Hospital while waiting for a call from a hospice.

There were other barriers on the route to a hospice, too. One of the barriers to moving

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[75] "Current Status and Prospects on Hospice and Palliative Service," *Health Insurance Review and Assessment Service*." http://naver.me/GqUw8w8o

patients to hospices was the patient’s “condition,” both the physical condition the dying body produces and the technological intervention the dying body requires. When entering the terminal stage, dying bodies require a variety of medical interventions that, in turn, require special after-care by experts; and some bodies may already manifest some corporeal signs that indicate that their condition may worsen rapidly. Their body conditions sometimes call for more technological interventions than before, and due to this, it is not possible to refer some patients to hospices. For example, a patient, like Ms. Oh Changhee, who had received an ommaya reservoir (for the purpose of controlling brain pressure), would be declined by all hospices because the medical staff working in hospices did not, or could not, take special care of the device. It was also quite common that a patient had contracted a resistant bacterial infection, like VRE.[76] Once VRE is found, a patient should be isolated in a private room, and those who enter the room should wear protective gear (e.g., gloves, gowns, and masks) and use only disposable equipment. Most hospices could not afford to maintain such conditions, and any infected patient could not be moved anywhere.

Finally, late or delayed attempts to refer a patient to hospice frustrated many patients’ ability to transfer. As seen in Chapter Four, the oncologists tended to wait until the last treatment option failed, and consequently the referral to a hospice was delayed, too. Moreover, hospice staff did not welcome patients whose death was imminent, and often they declined to admit such a patient

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[76] Vancomycin-resistant Enterococcus, or vancomycin-resistant enterococci, are bacterial strains of the genus Enterococcus that are resistant to the antibiotic vancomycin.

> [Scene: A Delayed Referral to a Hospice]
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> In a staff meeting, the participants discussed Mr. Jeong Seonkyu's referral. Mr. Jeong suffered from tongue cancer. Being desperate with his dysmorphic and stinky tumor, he wished his ending to come as soon as possible. Ms. Yun, the referral staff working with the palliative care team, tried to arrange his referral to K Hospice in Suwon, but the contacted hospice refused to take Mr. Jeong as their patient. Ms. Yun reported it to Doctor Park.
>
> "They declined after meticulously hearing about the patient's condition. It seemed that they got some cases where a patient passed away right after hospitalization."
>
> Doctor Park, at first glance, appeared to understand this refusal on medical grounds, but it soon turned out that his guess came from an economic factor. He assumed the reason why hospices did not welcome a patient whose death was so imminent was that the hospice would be reimbursed less than in the case of those who stayed longer in the hospice. Ms. Yun corrected his assumption.
>
> "Hospice workers work hard to establish rapport and provide end-of-life care based upon this rapport with the patients and their families. If we 'toss' a patient whose death is imminent, the hospice people would make a strong protest that hospices do not exist for disposing of dead bodies. And we would face a lot of complaints from the relatives of the deceased."
>
> Doctor Park asked again.
>
> "Hmm, I think of one week as enough of a period to build rapport. It [the case of a patient dying shortly] is actually not the hospice's fault but the previous hospital's, isn't it? Why do the relatives of the dead blame the hospice workers?"
>
> Ms. Yun explained, "I heard that some relatives even blamed the hospice staff for accepting this patient because the patient would have lived longer in the hospital."

Doctor Park probably discounted this astonishing story as one of the common but irrational and preposterous complaints from lay people that Doctor Park himself often encountered in his outpatient clinic. Doctors and nurses tend to think that non-medical professionals are prone to blame medical professionals regardless of the legitimacy of the medical intervention. However, Ms. Yun was paying attention to the subtext of the lay people's complaints. Later, Ms. Yun elaborated as follows:

> In cases like that, the relatives of the dead would think that the patient could have lived longer if she stayed in S Hospital, and they often project their anger and sadness on the hospice where the patient passed away. No one would want to complain to the medical staff who had looked after the patient for a long time. It is easier to express your anger there and just walk away because the nurses and doctors in the hospice would be strangers. I think this situation is really inappropriate.

As I noted in the first part of this chapter, the patients and their family members tended to consider being referred to a hospice as “going there to die” and “the doctor’s giving up,” in contrast to the implication of coming to S Hospital as “doing our best.” If a patient passed away in a hospice right after transfer to the institution, it was very likely due to the late referral. Yet, in dealing with the guilty feeling of not having done their best, some relatives would blame the hospice staff. For them, it was much easier to make a scapegoat out of the hospice staff—whom they had never met before and would never meet again—rather than to argue with the staff in the original institution (or blame themselves for delaying the transfer). Late referrals to hospices made hospices into places where people merely awaited death, and where dead bodies were disposed of. This was all in direct contradiction with the true hospice spirit. In a place of “instant death,” no one could be happy, neither the dying and their relatives nor the doctors and nurses working in the hospice. As a result, late referrals were declined by the hospice institutions.

Beside these different viewpoints on the nature and purpose of hospice care, some spatial characteristics raise a question, “Is dying in a hospice really the best option for the patients?” One day, I shadowed Nurse Heo’s consultation with a patient who wanted to go to a hospice that had a garden so as to stroll with the assistance of a caregiver. After the consultation ended, Nurse Heo told me:

> Actually, there are few hospices that are equipped with a garden. S Hospital, too, does not have a garden, just has a nice view, right? I can name only A Hospital, B Hospital, N Hospital, and H Hospital' hospice wards…. It looks like we are just saying a hospice. I sometimes feel that we kick out our patients because there is no bed for them in this hospital. Because we can't bear to say "get out" to our patients, we provide a place for them to go. I think it's natural that the patients and their families feel as if they're being kicked out. They can't stay for a long time even after moving to hospices. At best, two weeks?

A study on the architectural design elements of hospices (Hong Impyo 2017) supports Nurse Heo's observation. The author analyzed the ways in which six hospices laid out their floor plans, and only two hospices had space for a garden. To the palliative care nurses, good dying needed time to "prepare" for the ending. The dying should be able to process financial affairs, write some letters, have conversations with their families and friends, and recall their past with good memories. The fact that only a few hospices were equipped with a space for walking meant that most facilities did not consider hospice patients to be mobile patients: most transferred patients were unconscious and/or bedridden. Nurse Heo's faith in hospices as the best place for dying entailed a vision of the hospice patient as one who actively and peacefully enjoyed their final days with beloved others. If a patient was referred to a hospice, then lost consciousness for a week, and died, the prevailing fear of hospice as a "place to die" was not just a fear but a reality.

Further, due to the shortage of hospice institutions, almost every hospice had a policy to restrict a patient's length of stay to 60 days total. Most inpatients died ranging from 13.82 days (Kim Hyoung Suk, Kyung Ja June, and Young Sun Son 2016) to 22.7 days (Kim Chang Gon 2017), which was far earlier than their 60th day in hospices. Nevertheless, if a patient lived longer than the allowed time period, the patient was supposed to be discharged or transferred to another institution and could be re-admitted to the hospice when a slot became available again. Compared with this, the average length of stay for hospice patients in the United States was 77.9 days during 2018.[77] Examining the care work in independent hospice wards is beyond the scope of this dissertation, but it is at least evident that a chasm surely existed between the palliative care team members' belief in hospice as a best place for dying and the reality of how the hospice operated. Perhaps the idea that hospice was the best option meant that a hospice was the best option the palliative care staff could make at this point in time.

On the Way Home

Some people were discharged and returned to their homes, where they met their demise. In the palliative care staff's ranking, homes were another best option and comparable to referral to a hospice. Despite the prevailing romanticization of the idea of home death in comparison with hospital death, however, the number of patients who returned home was actually not much bigger than that of patients going to hospices. According to a report of the palliative care team, among the patients who had enrolled in the consultation-based hospice, 45% died at home while 42% were referred to hospices.

Why does home death not outnumber hospice death, if people pointed to homes as the ideal place of death and the palliative care staff set a high value on home death? One reason relates to changes in health status. Healthy people can imagine the scene of dying at home in

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[77] https://hospicenews.com/2019/11/25/average-hospice-length-of-stay-rose-during-2018/

abstract ways, but patients with life-threatening diseases can be more concerned with medical assistance in order to feel more secure (Yoon Hyun Kouk et al. 2001). As seen above, the corporeal conditions and technical interventions that the critically ill body requires make the patient and their families hesitate to choose the path to home. In particular, the technological equipment that is already hooked up to the dying body can cause anxiety for the patient's family caregivers, not to mention the patient, when they consider taking responsibility for caring for the patient. In the hospice consultations, the major concern family caregivers expressed was whether or not they would able to deal with various medical devices and the biological changes concomitant with the dying process.

Even though family members of a patient decide to take care of the patient at home until the end, when the end actually arrives, they are easily bewildered and eventually call 119. If the patient is carried into the ER, she is very likely to receive invasive treatment, such as a tracheostomy, and consequently life-sustaining treatment in the ICU. The ER was another place that the palliative care team avoided sending their patients. When patients and their relatives wished to return home at the end of life, Nurse Kim would carefully direct the patient's relatives not to bring the patient back to the ER when their last moment in the world came, saying, "You take your courage to take your father home now. You are not going to take him to the hospital when he reaches a critical condition. You need to prepare to send him off in peace at home. You need to be brave. If you bring him back and forth, the patient will be anxious." To the palliative care team members, returning to the ER was the equivalent of bringing the patient back to a bad place for dying. Even if the family members knew the patient's wishes, it was not easy for lay people to say no to the doctor in the ER when the doctor tried CPR or tracheostomy.

Home-based hospice care can be an alternative to reconcile the wish to let a patient die in a familiar place and the family's problem of technical and psychological incompetence when it comes to handling the dying body and emergency situations. However, a complicated web of regulations makes the home-based hospice care far from an answer, especially in terms of pain management issues. Because 90% of patients with cancer suffer from pain (Pargeon and Hailey 1999), pain management is the most important part of care for cancer patients. According to the National Comprehensive Cancer Network's guideline, above level 4 pain intensity, the use of an opioid—such as morphine, codeine, oxycodone, fentanyl—is strongly recommended. The patients' caregivers were also educated about issues related to pain management.

Although opioid analgesics are indispensable in the care of patients with cancer, nevertheless, in order to monitor the traffic in opioid analgesics, the Narcotics Control Act strictly prohibits the use of fluid opioids outside medical institutions. Only orally-administered and patch-type analgesics are permitted for patients who receive care at home, but these forms of analgesic are limited in their efficacy to control cancer pain. Inevitably, home-based hospice care is limited to the management of tubes and administration of fluids (injection). Under these circumstances, even when a patient fully understands her limited time and wants to spend the rest of her time at her own home, the palliative care staff cannot help grant this wish if the patient needs strong pain control.

Some patients might want to go home just to die in peace when they were already perilously close to dying but were not able to survive the journey home. In this case, too, the route home was not easy. One day, I observed that Nurse Kim had a hospice consultation with an elderly woman. Her husband was in his eighties, had been receiving intensive care for ten days, and now had been sedated to mitigate his pain. All the family members understood that his last moment was coming, and the wife of the patient asked his attending doctor to let him die at home. The patient's intention was also clear: he tried to extract the tube that connected his body to the mechanical ventilator whenever he gained consciousness. Thus, the necessity of treatment withdrawal was shared by all involved parties—the patient, the patient's wife, and the doctor. However, although the goal of this family, including the patient, was to go back home, the attending doctor considered letting him die in the *imjongbang* as the best option for now.

The attending doctor prognosticated that the patient would die within several minutes after the extraction of the tube, given his grave condition. For the patient's wife, letting him die anywhere in the hospital was as meaningless as continuing the life-sustaining treatment: her ultimate aim was letting him die in his hometown, Seosan—which was a two-hour-long drive from S Hospital—being surrounded by the other relatives. Whether or not the patient would be alive at the moment, the last physical encounter mattered to her.

One possible technical solution would be to maintain his breath by ambu-bagging, as the intern in the Boramae Hospital Case did. Yet, Doctor Jin, on the one hand, had a sense that it was not right to mobilize interns, i.e., an important medical personnel resource, in that way. In addition, she was worried that this process would cause great pain to the patient. Even if it did not matter to the patient and his wife, there was another concern. Assuming that the attending doctor succeeded in turning off the treatment and putting the patient in an ambulance with an intern, there was a possibility that the patient would die *before* the ambulance crossed the threshold of S Hospital. If this hypothetical event occurred, the intern would have to return the ambulance to the hospital and carry the dead body to the ER to attempt resuscitation. Whether or not the ambulance crossed the threshold of the hospital mattered because, if one dies within hospital property, the hospital is in charge of the death, and the staff must take responsibility for "saving" the life. Under such circumstances, given the determined attitude of the wife, she would likely insist that the intern not turn the ambulance around, but rather go ahead home. Doctor Jin, in agreeing with Nurse Kim's concern, said, "We medical practitioners have an obligation to declare a death. I am not sure it would be right for us to delay the death declaration in such a situation.

As Foucault keenly observed (2012[1978]), death takes up a big part of biopolitics today. For the purpose of managing death, a regulation stipulates a process for issuing a death certificate and for handling the after-matter of a death. For example, one tertiary hospital provides an instruction on the after-death process as follow:[78]

> (1) In the case of hospital death: request an attending doctor to issue seven copies of the death certificate and to move the dead body to the funeral hall of the hospital
>
> (2) In the case of home death: move the dead body to the ER for death declaration, request the doctor to issue seven copies of the postmortem examination, and move the dead body to the funeral hall of the hospital.

Regardless of the place of death, the dead body must be checked out by a doctor in a hospital and the death should be confirmed by a death certificate, which is necessary in order to proceed with

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[78] http://funeral.amc.seoul.kr/asan/depts/funeral/K/content.do?menuId=3850

the next administrative processes, such as having a funeral and registering the death. This procedural inconvenience restrains the patients and their families from choosing to die at home unless the patient shows a strong will to die at home.

The End-of-Life Care Documents as Ingress and Egress

The Act facilitated the patients' path to good dying whilst it prevented them from going to the worst place for dying. The kernels of the Act—an AD and a POLST—were more than simply administrative procedures to make clear what a patient wanted. As seen in Chapter Four, an attending doctor's order for a resident to obtain an AD or a POLST from a patient made official the irreversibility of cancer progression and gave a heads-up to patients and their relatives. In explaining the importance of signing end-of-life care documents, the doctor's and nurses' value-laden judgments were revealed regarding better and worse places for dying. One wife of a patient said to Nurse Kim:

> For a long time, the professor and the resident have told me multiple times that my husband would eventually go down [to the ICU], and that he would not be able to see the family there and would only go through hardship, so we never let him go there. So, I have prepared myself. I signed the document, too, when the professor suggested I do so—the document on what we would do and would not do. I am so sad now, but I am prepared because it is something that will eventually happen. I signed it because we are not supposed to run about in confusion when the time comes.

In the doctor's justification for obtaining the end-of-life care documents, ICUs were represented as a place where only suffering would await the patient and where familial unity could not be realized. In particular, the "confusion" the doctor had mentioned to the wife is important because making the patient and her family members foresee future events and giving them heads-up were one of the end-of-life care document's missions. Patients entering a terminal stage were exposed to the potential risk of emergent events, such as respiratory failure (which mostly came from pneumonia), sepsis, or sudden bleeding after procedures. If an emergent event occurred during a patient's hospitalization, it was mandatory for the medical staff to intervene and save the patient, and the patient was thus more likely to be moved to an ICU. This was the very situation that the palliative care team members aspired to prevent. In order to prevent this situation, the palliative care team sensitively and continuously gave warnings to patients and their families that a sudden event could occur and that they needed to think about what they would do in advance.

Unlike physicians and nurses, lay people might not comprehend when and how fast a patient's condition could worsen. If a patient's relatives did not understand that the patient had entered a terminal stage and had thus not prepared for this scenario, no one would agree to withhold a patient's intensive care. However, once in intensive care, it became much more difficult for both the medical staff and the patient's family members to stop the ongoing treatment. The doctors would likely fear a potential lawsuit, which they had seen happen in the Boramae Hospital Case (see Chapter Two), and the family members often would feel too guilty to withdraw the life-sustaining treatment, as it made them feel as though they were letting the patient die.

If, for any reason, a patient and her relatives missed a chance to write her AD or POLST and the patient was eventually admitted to an ICU, signing a POLST was the only way to stop the treatment and to escape from the ICU. If a patient had been hospitalized in an ICU already, the palliative care team tried to empower the family members to make a good decision:

> [Scene: Escaping from an ICU]
>
> Mr. Jin was a 67-year-old man. His two feet were badly swollen with dropsy, a sign of dying. He was lying unconsciously in the ICU on a mechanical ventilator. His wife, stroking his arms, said, "Sweetheart, stay comfortable, stay comfortable."
>
> His son said, "Dad, Daddy, please open your eyes."
>
> His wife asked Mr. Jin, "What are we supposed to do? Shall we stay here just a bit longer? Shall we? Just a few more days?"
>
> "No, Mom, let's stop it. This is too hard for Dad," the son said.
>
> Nurse Kim said, "It would be more helpful to think about what the patient would want rather than what you want."
>
> The son talked to his mother. "Dad, of course, wants to stop it. My personality and his are exactly the same."
>
> "But, wouldn't it be right to follow the doctor's opinion? The doctor suggested that we give him a couple of days. Let's stay here a couple of days."
>
> "I would do it if he could get better in a couple of days, but it won't happen."
>
> Nurse Kim gave them time to discuss the matter with each other. After talking to Mr. Jin's resident, the nurse approached them.
>
> "We have made the decision. We want to stop it. It prolongs his life just one day or so," the son said.
>
> "Ok. Then do you want to talk with the doctor together?" The wife cried. The nurse consoled her saying, "Please don't cry. He will go to a good place. This is ok and that is ok too. We made a choice between two good options."
>
> Nurse Kim told the resident in the ICU how to fill out a POLST and how to move the patient to the *imjongbang*. The resident filled out the document, and the wife signed it. As Mr. Jin was leaving the ICU, an ICU nurse followed and consoled the wife.
>
> A staff member transferred him on a bed to the terminal-cancer ward where the only room for the dying in the hospital was located. Mr. Jin's older sister, the

> wife's sister, the grandchild of the patient, his son, and his daughter-in-law gathered. Other relatives were coming. The older sister wailed, "Don't go, please. Don't go." Nurse Kim told them that the loud crying and those kinds of words would bother the patient. She also let his wife, who was shoved to the back by the sister, come close to the patient. A wife should be the one who stands by a dying man, Nurse Kim thought. The Catholic priest whom she had called arrived and all started praying together. Nurse Kim also gave some instructions to the nurse who was in charge of the room. Mr. Jin passed away in the *imjongbang* surrounded by his relatives.

Reading this scene, one might think that the nurse's role was very small, for only a few sentences belonged to Nurse Kim. However, every single intervention and all the care that the palliative care staff carried out were always nuanced, as in this scene. Nurse Kim, despite her own strong belief, did not make her opinion evident. The suggestion to think about what the patient would want over what the wife herself wanted was probably the strongest opinion she expressed. Why did she not try to persuade the wife by addressing the patient's pain or the futility of the treatment? I found the answer in her consolation that represented both options—continuing or withdrawing the life-prolonging treatment—as good ones. In the conflict of opinion between the wife and the son, none of them were on the wrong side: the wife just wanted to cling to her hope for Mr. Jin's recovery and wanted to be with her husband as the two living bodies, whilst the son wanted to end his father's suffering. Neither position was wrong or bad. By assessing the wife's wish to be a good option, Nurse Kim expressed her sympathy for the wife's grief. By signing the POLST, their decision made official and the patient was able to be discharged from the ICU. The POLST symbolized permission for a course of non-intervention in Mr. Jin's death.

Yet, end-of-life documents were not always effective since, in reality, more than signing the POLST was required. First, the Act stipulated two doctors—a doctor in charge of the patient and a specialist—needed to verify that the patient had entered the dying process and the patient's intention. This was necessary in order to prevent any misuse of the Act and also to guard against a chance of misdiagnosis of the dying process. Second, in order for a patient to write an AD, the medical institution was supposed to assign a trained health professional to assist with writing the document. Last, only medical institutions that had an ethics committee could access the computer network of the National Agency for Management of Life-Sustaining Treatment so as to confirm the patient's AD, in the case of a patient who had previously written their AD in another institution.

Large tertiary hospitals, like S Hospital, which were equipped with a good number of doctors and economic resources to install the ethics committee, had no trouble in implementing the withdrawal of life-sustaining treatment. However, small-scale hospitals and nursing hospitals, which constituted the great proportion of dying places in Korea, could not easily meet these conditions. This disparity between these two groups frustrated the smooth transfer to a good place for dying. The following case showed this problem.

[Case: Back from a Nursing Hospital]

> A patient with terminal-stage lung cancer, in her late seventies, had received her anti-cancer treatment in the outpatient clinic of S Hospital while being hospitalized in a nursing hospital. She had an understanding of her sickness and prognosis, and she had filled out her AD in S Hospital. One night, her condition rapidly got worse. A doctor in the nursing hospital applied CPR to her, intubated into her trachea, and sent her to the ER of S Hospital. She then stayed in the ICU of S Hospital for three weeks on the ventilator, before passing away there. The professors in the ER, oncology department, and the ICU of the S Hospital were upset by the fact that, regardless of her written AD, the patient had been eventually sent back to S Hospital and had received life-sustaining treatment that had obviously been against the patient's will.

This patient's AD came to be meaningless because the nursing hospital had no authority to access the National Agency for Management of Life-Sustaining Treatment's computer network because it lacked an ethics committee. According to the Ministry of Health and Welfare, compared to 100% of tertiary hospitals, only 38.5% of other medical institutions, including general hospitals and nursing hospitals, had installed an ethics committee by February 2019. From the point of view of the doctor in the nursing hospital, the Act did not allow her to respect the patient's wishes. There was no way for her to read the patient's AD. Also, there was no second doctor available to verify the dying phase of the patient or to make any decision with her.

Many health professionals have pointed out that the Act was designed only for large-scale hospitals while not taking into consideration the general situation faced by small hospitals and other medical institutions. A great majority of the hospitals where Koreans die do not meet the requirements that the Act prescribes for a dying place. Most of all, one of the blind spots of the Act was that it presupposed a patient would die in the same place where they had been treated. However, as I have outlined, dying patients were moved along various routes that were determined by internal and external pressures—guided primarily by spatial limitations and financial incentives—to move the patients out of one institution into another, or back home.

Conclusion

In this chapter, I described some possible routes through the dying process that were set up for the patients in the terminal-cancer ward. They came to this ward mainly via an ER and then were asked to decide whether to move on to a hospice or to return home. These routes into and out of the terminal-cancer ward emerged in a web where the political-geographic inequity of the health care infrastructure, the marginalization of palliative and hospice care, and the profit-seeking nature of hospitals were tightly interwoven. The palliative care staff, like those in S Hospital, understood how the health care delivery system worked, assessed each possible place for dying along with their criteria for good dying—painlessness, family presence, and love—and struggled to arrange their patients' destinations while taking into consideration a variety of material, geographical, and relational conditions. In part, their endeavor came from the administrative imperative to perform their role as hospital nurses, but, ultimately, they also tried to act in accordance with the values of palliative and hospice care. Despite their best efforts, the routes to good dying often involved rather bumpy rides due to the shortage of available beds, the complexity of the technological interventions, and the difficulties complying with some of the state regulations concerning the management of death. Ultimately, how to realize good dying was affected by a place of the death: each place allowed, forced, or restricted the range of the technological possibilities, and all places were dominated by the various regulations required by the hospital and the larger national health care system. These contingent associations either facilitated or, more often, frustrated the ability of family members to be with the dying during the end-of-life process.

So, what happened to the patients who would eventually meet their end in this terminal-cancer ward? In the next chapter, I will explore the palliative care staff's struggle to make this ward a good enough place for dying and the way that care is deeply entangled with time, space, and social relationships.

Chapter Six

Family Caregivers as *Bohoja*s and Relational-Generative Care Practices

Introduction: The Core of End-of-Life Care

In this chapter, I investigate the essence of the care that is provided to patients in the terminal-cancer ward. First, I examine how patient's family members are invited to become caregivers in the name of the patient's protector (*bohoja*). The scenes whereby a relative takes care of another sick relative seem so natural that it prevents us from problematizing this scene. Yet, by taking a step back from this seemingly natural scene and asking who is likely to be the *bohoja* of a patient, I explore how moral obligation, politico-economic structure, the health care system, and gendered norms naturalize the presence of the family caregivers and their intensive care labor. Second, I look into the details of the care that is conducted by patients' *bohoja*s with the assistance of the palliative care staff, including "capillary care work" and communication with the medical staff. In the circumstance where a *bohoja* is expected to speak to the medical staff as the patient's representative, the *bohoja* is likely to make decisions on all aspects regarding the patient, and decisions regarding life-sustaining treatment are routinely part of the chain of decision-making, communication, and care. The Act, in contrast, approaches decision-making regarding life-sustaining treatment as an independent event that occurs only between the doctor and the patient, and, consequently, it at times does not square with this entanglement of care and communication. In the final section of this chapter, I argue that end-of-life care produces, recovers, and reinforces social relations in this place where the relationship between the living and the dying expires. To grasp this effect of care, I propose a concept of 'relational-generative care,' which links the dying and her family members and connects them to the volunteers, nurses, and a local community.

A Patient's *Bohoja*

A person is critically sick, then enters a terminal stage, and ultimately dies: this series of events requires a person's family members to become moral subjects. The family members are expected to perform certain acts with moral ramifications that are imposed upon both kin and conjugal relations. The required actions range from caring for the sick and taking care of the medical expenses, to being with the dying and the bereaved. In this intimate socioeconomic unit, *hwanja bohoja*s or "patient protectors " are placed on the frontline of the care practices.

What I have called family members, relatives, and kin in this dissertation are commonly called "patient protectors " (환자 보호자, *hwanja bohoja*)[79] within Korean clinical settings, including the terminal-cancer ward. It should be noted that this term, is *not* a legal term that entails an eligibility and corresponding duty. Korean law defines a guardian only for the disabled, minors, elderly people, and prisoners. Thus, this term, *bohoja* of patient, is one that has been historically formed and has been customarily adopted in hospitals to point to certain social

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[79] Given a morphological analysis of *hwanja bohoja* (*hwanja*: patient, *boho*: protection, *ja*: a suffix to a person), it would be more correct to translate this word as a "protector" of the patient than a guardian of a patient. Moreover, a guardian of a patient is used as a legal terminology in the U.S., whereas a *hwanja bohoja* in Korea is not. This crucial difference between a patient's guardian and a *hwanja bohoja* could confuse readers.

relations who are expected to take care of a patient. In general, the presence of protector(s) is not always required unless the patient is a minor or an elderly person whose communicative competence has deteriorated. If a patient is going to undergo surgery, some hospitals require a family member(s) to sign the surgery consent form, but which family members are considered qualified may vary depending on the hospital's policy because this is not a legal requirement.[80]

Although this term does not imply a direct lineal or conjugal relationship, "patient protector(s)" implicitly means family members of the patient. As Lessard et al. (2016: 2) has stated, the practice of referring to family members who care for a loved one as "family caregivers" has only developed within a specific context in recent decades in Canada. Similarly, the expression "a *bohoja* of a patient" in Korea also contains a set of assumptions regarding social responses to a medical crisis. First, this word and its taken-for-granted usage imply that the primary social response to a medical predicament is imposed upon a family in a powerful way. This responsibility is naturalized to such an extent that, despite the long history of this word,[81] not a single paper has addressed—from the perspective either of the law or of kinship studies—fundamental questions such as what a patient's *bohoja* means and who can be the *bohoja.* In the

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[80] For example, some hospitals let a sister of a patient sign the consent form, while some hospitals only approve a spouse, a parent, or an adult child's signature.One report found that an adult woman's mother was not allowed to sign a consent form, and the staff required her husband or her parents-in-law to come and sign it, which shows strong patrilineal bias. See "Only husbands or parents can sign it," *Ilda*, 2016. 9. 16. (http://www.ildaro.com/7595)

[81] The term "*bohoja*" first appeared in newspapers in the 1920s. At that time, *bohoja* was mainly used to refer to a political subject, such as a "a *bohoja* of peace" (in international relations) and "a *bohoja* of people," while it was also used to imply a guardian of a child (e.g., *The Dong-A Ilbo,* 1920. 10. 9.). The term *bohoja* was first used to imply a protector of a patient in a news article in the *Dong-A Ilbo* on 1936. 2. 7. This article reported that a patient who had been hospitalized escaped from the hospital for some unidentified reason and died in a train station. This article referred to the patient's wife as "the wife, Ms. Kwon Seongnye, the *bohoja* of the patient." According to *Naver*, the most popular search engine in Korea, the usage of *hwanja bohoja* increased in the mid-1970s and exploded in the 1990s.

absence of an agreed-upon definition of the term *hwanja bohoja*, it has been used as if it is synonymous with a family member; however, which family member can or cannot be a *hwanja bohoja* remains contested.

A power relation between the sick and the *bohoja* is evident in the fact that this term indicates that one protects another. To protect someone is also another form of care, but those who are protected inevitably cede a part of their autonomy and depend upon those who offer the protection. Moreover, as the example of a “child protector” (*adong bohoja*) suggests, at times, protection assumes one’s incompetency to keep oneself safe. One’s being sick bestows (or, is expected to bestow) a new position and role of protector upon the rest of one’s family members.

The Way that the Medical System Organizes Care

In general situations, the presence of *hwanja bohoja*s is not mandatory. However, in the terminal-cancer ward, whether or not a patient was accompanied by a *good bohoja*(s) was crucial to the patient’s well-being, and the obligation to serve as a protector did not come only from a tacit moral imperative; it also came from the ways in which the Korean medical system classifies, organizes, and assigns caring work in hospitals. Unlike in some countries, such as Germany, nurses in Korea are not in charge of bathing, feeding, or other ways of caring for a patient’s personal hygiene. Rather, they carry out a doctor’s orders, such as injections, blood-gathering, checking blood pressure, administering medications following doctors’ prescriptions, and checking temperatures. If a relative of a patient asks a nurse to help with changing a bed sheet, the nurse may help them, but this action stems only from the nurse's personal goodwill.

However, patients need more than injections and blood pressure checks. Needs would vary depending on the seriousness of the patient's condition, but the patients in the terminal-cancer ward often needed help in using the restroom, eating, moving elsewhere for medical treatments, changing diapers, changing clothes, changing bed sheets, bathing, talking with doctors, and receiving massages. Sometimes they simply needed someone to talk to. All of these activities are so mundane that we barely give them a second thought during our day-to-day lives, yet they are simultaneously so critical that we will fail to keep our dignity and well-being if we are unable to undertake such activities. This kind of care can be compared to capillaries, which permeate our bodies, but are less recognizable than arteries and veins.

The capillary care work[82] is similarly inseparable from a hospital's ability to function well. We cannot imagine a contemporary hospital in which hundreds of patients are lying in beds with clothes contaminated by sweat, blood, and bodily fluids. However, within the Korean medical system, no hospital workers are assigned to this capillary care. DiMoia (2014: 57) investigated how Korean hospitals modernized in relation to international aid projects, and describes some scenes in Korean hospitals in 1950s, when the United States just began to intervene in medical education and hospital reforms through the Minnesota Project:

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[82] This type of care work is called custodial care in the U.S. In contrast to skilled care, which is provided by licensed health professionals, custodial care refers to non-medical assistance with the activities of daily life. Despite the similarities between custodial care in the U.S. and this intensive care labor in South Korea, I have coined the term "capillary care" work in this dissertation. In Korea, there is no vocabulary for indicating the daily care labor of the patient's relatives and the *ganbyeong-in*s. It is one of my purposes, by borrowing the power of analogy, to address how this care labor remains invisible and ineffable outside the health system.

> Among the concerns raised almost immediately were practices governing the routine care of patients, with Korean families permitted to reside on-site temporarily with their ailing family members—providing for basic necessities, including food and laundry—allowing hospital staff members to concentrate their limited resources on meeting the needs of health care.

DiMoia's illustration helps us to infer that family caregiving had a long tradition prior to the 1950s and that this tradition was sustained by underdeveloped modern hospitals partly because it supplemented their lack of resources. Nowadays, unlike the hospitals in the 1950s, hospitals take responsibility for providing food and laundry; however, this division of care labor has persisted.[83]

The hospital system resolved the problem of the lack of staff dedicated to capillary care by outsourcing this type of work. Hospitals made contracts with labor force companies that had a long list of registered paid caregivers, called *ganbyeong-in* (간병인). When a patient needed a caregiver, the hospital provided the patient's family with the company's contact information so that they could hire a caregiver. Thus, the patient and the caregiver could be connected through a secondary agency. In so doing, capillary care remained betwixt and between the hospital system.[84]

This division of labor institutionalized by the medical professions shows how biomedicine and its affiliated system classify and weigh the gravity of a variety of care work.

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[83] In 2016, the Korean government introduced Integrated Nursing Care Services that cover both existing nurses' care and assistance for daily activities, and this service has tended to be extended.

[84] According to Lee Ki-byung (2020), the total number of paid caregivers was estimated at over 300,000 in 2010. Since there was no required qualification to become a caregiver, the entry barriers were low. The overwhelming majority of paid caregivers were not directly employed by either the labor force companies or the hospitals, and thus were excluded from the Labor Standard Act (2019). Due to the low social status, poor wages, and the hard work, Korean-Chinese immigrant workers have taken many of these jobs.

Care work that is related to an individual body as an object of medical intervention is allocated to nurses—medical professionals. The remainder of care work for a patient lies outside the medical system, and individual patients and their families are forced to seek such aid on their own.

In spite of the mediation of the hospital, some patients and their families could not afford to hire paid caregivers, which cost about 80,000 KRW (about 85 US dollars) per day. In addition, many family members of the patients were reluctant to hire the paid caregivers because they believed that the quality of care provided by kin and/or marital relations must be higher than that provided by the *ganbyeong-in* because the former was driven by love while the latter was mediated through money. Consequently, in most cases, all of this care labor fell into the family members' hands, either due to financial stress or the family's preference. For instance, among 35 patients who were staying in the terminal-cancer ward on December 20, 2016, only three patients hired full-time paid caregivers; three patients hired part-time paid caregivers alongside the care of their family members.

The idea that looking after a patient was supposed to be done by family members was also shared by the palliative care team members. Once a new patient was admitted to the ward, the nurses would first check on who the patient's *bohoja* was, and who would nurse the patient in the ward. The volunteers also assessed the family dynamics and family bonds through daily conversation with their patients in order to make sure that the capillary care work was done without difficulty. Even if a family hired a paid caregiver, the palliative care team would check to see if the family members visited and emotionally cared for the patient. Those who were likely not to have a “proper family support network”—such as divorcees, widows/widowers, and young unmarried patients—were given more attention from the palliative care team. The volunteers visited more often to see if there was anything they could do to help, and the therapists persuaded them to have a therapy session.

Gendered Caregivers

Family is an intricate terrain in which gender, generation, and class intersect (Collier and Yanagisako 1987). Within this social unit, which ties heterogeneous members together under the umbrella of family, moral obligations are never evenly and homogeneously allocated to each member. This leads us to ask who is expected to play the role of *hwanja bohoja* and who is exempted from this familial obligation. Just as the term family is gender-neutral, so too is the term *hwanja bohoja*; and cancer a not a gender-specific disease, excepting some genital cancers. However, previous surveys have reported that, in Korea, male patients receive more support from their wives, while female patients receive more support from their children as compared to their husbands. The main caregiver is most likely to be a wife, followed by an adult daughter, sister, mother, and daughter-in-law (Hong Min Joo et al. 2012; Kim Yun Hee et al. 2015; Lee Jee Hye et al. 2016). This demographic feature of family caregiving is in accordance with my observations. With either a female or male patient, the *hwanja bohoja* in the terminal-cancer ward was often the wife, mother, sister, daughter, daughter-in-law, (rarely) aunt, mother-in-law (husband’s mother), and/or sister-in-law.

This gender division of care labor for cancer patients mirrors the gendered division of labor within the larger society and kinship practices. Although both the ratio of women who receive higher education (more than college level)[85] and the ratio of dual-income families in which both the wife and husband participate in economic activity[86] have steeply and continuously increased, it is still a bitter reality that after childbirth a wife tends, either voluntarily and involuntarily, to quit her job and becomes a housewife.[87] I am not devaluating the work of a housewife, but simply pointing to the fact that this job transition occurs in relation to the larger politico-economic structure, including the low rate of men's participation in childrearing, the long working hours, the wage gap between women and men, and poor social resources to care for the child(ren) of "working moms." Many women wish to return to their previous jobs after raising their children to a certain age, but it is very likely that these *kyeongdannyeo*s[88]—which refers to women who quit their jobs due to reproduction—will migrate to jobs that require a low level of skills, pay a low wage, and through which they will end up being irregular workers. In the familial circumstance in which the husband/father works outside the home and the wife/mother devotes herself to housekeeping, it is taken for granted that the wife/mother will have no choice but to take on the burden of care when a family member needs more intensive care. Especially, among adult children, unmarried daughters are much more likely to become a *bohoja* because they are deemed to be free from other caregiving

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[85] The ratio of female university student was 41.5% in 2018. http://www.index.go.kr/potal/intro/enara/enara_intro.do
[86] The ratio of a double income family to newly married couple (within five years of marriage) in 2017 was 42.5%. https://m.post.naver.com/viewer/postView.nhn?volumeNo=19319074&memberNo=20092661&vType=VERTICAL
[87] http://www.index.go.kr/potal/main/EachDtlPageDetail.do?idx_cd=3039
[88] A coinage that combines career (*kyeongryeok*), discontinuity (*danjeol*), and a female suffix (*nyeo*).

duties (as a wife/mother) and the obligation to provide financial support (as a husband/father).[89]

In fact, the same gendered division of labor found in both the economic domain and the domain of family life was also found in the skewed sex ratio of other caregivers in the terminal-cancer ward: the *ganbyeong-in*s (paid caregivers) and the volunteers. A paid caregiver is one of the jobs that women have come to choose because the entry barrier for this job is so low that any healthy adult can do it. According to a report published by the Korean Confederation of Trade Unions (Son Mia et al. 2009), 95.5% of paid caregivers were women, and 44.2% of paid caregivers were heads of household; on average, they were in their 40s or 50s; 94.4% of them had graduated middle or high school; and their average wage was 863,000 KRW/month (or 723 US dollars). In other words, when a woman who has quit her original job and devoted herself to being a housewife tries to reenter the labor market due to a financial crisis, she has very limited job options: one option is to be a paid caregiver as it requires no previous work experience, although it does not provide stability of employment or labor protections such as employer-paid insurance.

In the case of the volunteers on the palliative care team, they were mostly women over 50 who had completed their childrearing and had some time to themselves.[90] When women think about participating in volunteer work, caregiving is a common option because it is already their specialty, one that has been honed through their lifetime while caring for their children and other relatives as wives, mothers, daughters, and/or daughters-in-law. I realized this fact after

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[89] Unmarried daughter's taking responsibility for caring for parents is observed in Japan, too (Jee Eunsuk 2017). Jee Eunsuk points out that the unmarried daughters are likely to fall into poverty while nursing critically ill parents.

[90] There were approximately six to seven male volunteers, all over 50; among the female volunteers, there were no unmarried or childless people.

giving birth and becoming responsible for childcare at the final period of my fieldwork. I still vividly remember the strange feeling that I felt when, for the first time, I washed a grandfather-like patient's face. It was almost my first experience of touching and stroking someone else's face in such a way. It was not surprising that my stroking on that day was very clumsy. And then one day, while meticulously bathing my daughter, I realized that it was the very action that the volunteers of the team had done all their lives as mothers and volunteers.

In sum, if a family member was sick, a woman—a wife, mother, daughter or daughter-in-law—became a caregiver in the name of *hwanja bohoja*; if a woman sought income outside the home, she became a paid *ganbyeong-in* caregiver; if a woman hoped to contribute to a local community, she became a volunteer caregiver. The terminal-cancer ward was a place where women gathered as various forms of caregivers: *hwanja bohoja*, *ganbyeong-in*, and volunteers.

The allocation of women to care labor is not an effect of biological traits but rather a cause and effect of the firm entanglement of the labor market and kinship practices, yet this allocation is so deeply entrenched that gynocentric care labor[91] goes unquestioned and is considered to be a natural fact. In the terminal-cancer ward, everyone generally accepted that female relatives would care for either female or male patients. In contrast, if a male family member assumed care of a (female) patient, the *bohoja* was often praised as a great father/husband/son. Further, the male *bohoja*'s caregiving often elicited the need for special attention from the volunteers, as in the following scene.

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[91] The discussions in a workshop led by Professors Suzanne Gotchang, Goncalo Santos, and Jacob Eyferth inspired this section, "*Gendered Caregiver*." I appreciate all comments and feedbacks from the participants of the workshop.

> [Scene: Naturalization of Male Caregiver's Poor Care]
>
> Nurse Kim: (to the volunteers) In the case of this family, a husband and two sons take care of this patient. Since the caregivers are all males, there is no skilled caregiver. Could you visit this family and see what the patient needs?
>
> Ms. Park Seonja: I visited them last week. The husband said that he had not changed her diapers. It seems like the patient also did not want him to take over the work. While we changed her diapers, the husband didn't know what to do, and was just standing outside the room. He had not changed the diapers for so long that her lower part was messed up… We should visit this family and change the diapers every day.

When Ms. Park Seonja and Ms. Lee Seonghye took care of this patient, I was with them. The patient's genitals were swollen and festered due to the diapers not having been changed in a timely manner. Avoiding the urine drainage port, we wiped her lower part, changed her diaper, and changed her clothes. All of these processes took almost one hour. At the end of the day, Ms. Park and Ms. Lee repeatedly told the other volunteers how severe the patient's body condition was. Even to the veteran volunteers, who had gone through a variety of situations in the ward, what they did on that day to the patient was difficult and traumatic, and they shared their story as a coping strategy to relieve their stress.

Clearly, having volunteers visit the patient on a more frequent basis was not a solution for maintaining her hygiene, as the volunteers only worked for four hours each day, and only during weekdays. Why did the nurses and the volunteers not just teach the husband how to manage his wife's body? Nurse Kim's remark implied that the husband's gender was an excuse—it was not an indictment, but rather a justification—for his poor care as male caregivers were naturalized as un-skilled caregivers. This internalized belief in the clumsiness of male caregivers suggests that the primary responsibility for taking care of a patient was not merely imposed upon a family. Rather, it is more accurate to say that the role of *bohoja* was imposed on the female members of a family.

Capillary Care and the Family Project

In their collaborative research conducted in a neonatal intensive care unit, a research laboratory, and a nursing home in Denmark, Svendsen et al. (2018) define care as practices of substitution. Precarious and vulnerable beings, such as neonates weighing less than one pound and elderly patients with severe dementia are not able to do vital activities, and their caregivers substitute themselves for their charges. The terminal-stage patients, too, gradually, but conspicuously, lose their ability to control their own bodies and to maintain their mundane lives. A patient, who had walked around the ward last week, might be barely able to sit upright on the bed this week, and might just lie on the bed next week. If we, the volunteers, postponed a patient's bath to tomorrow, due to a long queue or busy treatment schedule, the patient's health status might get worse so rapidly that we might never regain the chance to bathe the patient again. Nurse Kim always said, "Our patients cannot promise 'the next time.'"

For those, whose needs increased at every turn, while their competency decreased at every turn, the *hwanja bohojas* and the palliative care team members took over the patients. The patient's *bohoja* was regarded as a primary caregiver. The family members kept a vigil at the patient's bedside day and night at a great sacrifice to their own basic needs of sleep and comfort. Desperately seeking for a sustainable way to nurse a patient, some families created a scheduled timetable of care, and family members were assigned to take turns so that someone would be by the patient at all hours. Alternatively, one member of the family would act as the main caregiver and stay in the ward all the time, except for a few hours during which other members would cover the main caregiver's absence. Despite their efforts to save themselves from physical and emotional burn-out, it was very arduous to conduct the capillary care work as *bohojas* of patients because there was no time or place for caregivers to stay. At night, *bohojas* of patients slept on small, low cots that did not even allow them to turn over. The cots were provided by the hospital, but *bohojas* were expected to bring blankets and pillows for themselves.

The *hwanja bohoja*'s tasks included not only the "basic" care that I have listed earlier, but also observing the patient's condition (e.g., the color and amount of urine and feces), recording the kind and amount of diet, and sterilizing around drainage ports. The *hwanja bohoja*s were supposed to notice every detail of the patient's body and mind and to manage any new situation that the dying body produced.

Given the diversity and importance of the capillary care, how well-trained a caregiver was had direct implications for the patient's quality of life. Yet, many family caregivers were not able to offer a proper level of care to the patients: when a patient was first diagnosed, the family caregivers generally lacked the skills required for administering care; and when a patient had long-struggled with a disease, family members became entirely exhausted. It was the volunteers who assisted these clumsy or tired family caregivers. From their long experience in caring for people as volunteers and family caregivers, the volunteers had acquired the technical know-how necessary to treat patients, and they were willing to pass on their knowledge so that the family caregivers could cope with the work without volunteers' help. The following example concerns one basic task: changing clothes:

> [Scene: Knowledge of Changing Clothes]
>
> Ms. Kim Makrye and Ms. Ahn Keumja were helping a patient to change his clothes. The patient was in his sixties and he was limp, almost without consciousness. It was hard to change his clothes without the patient's spontaneous cooperation, such as lifting his own body. His wife also did not possess the strength necessary to handle her husband's body by herself. Ms. Ahn had me bring a middle-sized bedsheet from the storage room in the ward, and talked to the patient's wife.
>
> "If you lay this small sheet under the patient's body, it will be easier to move and turn his body next time. First, put his right arm into the arm hole of the new clothes. Turn his body halfway, squash the other half of his clothes under his body, and put the half of the small sheet under the right part of his body. Like this. Then turn his body the opposite way and pull out the clothes and sheet from under his body. This way, you don't need to lift his whole body, do you? When we can't help you, you can use this method to save your energy."

Changing clothes with minimal force was what we learned in the volunteers' workshop. The veteran volunteers had accumulated their own trivial, but useful, skills of care while engaging in the ritualized mundane activities of maintaining sick bodies (Aulino 2016), and they shared their know-how during these workshops—including how to move a patient lacking energy from a bed to a wheelchair, how to change clothing without affecting the IV lines, and how to wash hair without causing flooding around the bed. These workshops functioned as an opportunity to exchange individual tips, to improve individual practices, and to teach novice volunteers like me.

Using the medium-sized bed sheet was Ms. Kim Makrye's own personal tip. She herself had experienced taking care of her mother and mother-in-law for a long time, and this skill was what she taught herself during that period. Now she was passing her knowledge to the *bohoja*s of the patients in this ward. Each volunteer always conveyed how to massage a patient with cancer (not kneading but slightly stroking), how to give a foot bath to a patient (using a plastic water bottle to maintain the water temperature), and how to cleanse a patient's hair (using dry powder shampoo).

Although the terminal-cancer ward is a place that compressively shows the intensity of capillary care work, this care labor is needed both inside and outside the hospital from the moment a diagnosis of cancer is made. One *bohoja* commonly assumes full charge of the care work by staying in the ward with the patient; however, the broad range of intensive care work engages all family members in patient care, which makes this work a family project. Indeed, from the beginning of a potentially long and arduous struggle with a malignant disease, not only the patient themselves but also their family members undergo a reorganization of everyday life. In extreme (but not rare) cases, some family members leave the cities where they have lived for a long time to be closer to the patient or quit their job in order to nurse the patient. At the very least, a patient's relatives are not able to escape even minimal changes in their daily life—visiting the patient in the ward, researching information on cancer and cancer treatment, making reservations for renowned doctors, or calling the patients more often than before.

> [Case: Nursing a Patient with Cancer]
>
> Ms. Hahn Eunsuk's father was diagnosed with prostate cancer. The patient did not like to be in a hospital, and the rest of the family respected his wish. The three familial groups—(1) Ms. Hahn's mother and unmarried eldest brother, (2) the second brother's family, (3) and Ms. Hahn's immediate family—divided the labor of care: the sister-in-law who had married the second brother was in charge of bringing the father to S Hospital for doctor's appointments; the mother nursed

> him during the day while the eldest brother undertook night care; Ms. Hahn took care of him during weekends. The family members had also hired a paid caregiver, and she came home and nursed the father outside the hospital. Her professional care skill was of considerable help. As Ms. Hahn's husband was a priest, he presided over prayer. Her husband and sister-in-law also participated in all decision-making, as they contributed significantly to the care of the father.
>
> Nursing Ms. Hahn's father at home was very burdensome. The last two months of his life were particularly tough because the cancer had intruded into the lower half of his body. With paralyzed legs, he could not move at all. The patient became highly strung, while the other relatives were exhausted. The mother and the elder brother, who both lived with the father, had a hard time watching the patient suffer from pain.
>
> After his legs were paralyzed, her father seemed to feel in his bones that his death was imminent, even though no one would openly talk about death. He let the people he wanted to see visit him and conveyed warm words of love to his family members. Her father passed away in peace. When the dying signs appeared, Ms. Hahn was so scared and wanted to bring him to an ER, but the eldest brother, a CPR instructor, said that it would be more important to let him go without suffering any more. She felt sad in the moment, but looking back, she thought they had made the right decision. It was spring when he passed away. They visit her father in the *napgoldang*[92] (columbarium, 납골당) on the anniversary of her father's death, and the presence of flowers on the road consoles them.

Ms. Hahn's story well depicts how a family member with a life-threatening disease calls for a family project of care. A total of three households within Ms. Hahn's extended family took part in caring for her father, and each member was allocated an individual task that accommodated their time, place, and occupational circumstances; each member learned to incorporate the assigned care task into the routine of their daily lives. Through the seven-year long journey, each family member experienced physical and emotional burn-out and learned how to cope with their own distress, as well as how to console each other. Mr. Hahn, the patient, was thus never the only one who experienced a new way of living life with cancer; the entire family

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[92] A public building where urns are stored.

was also entangled with what the disease brought to the patient as they became his caregivers.

Main Interlocutors with the Medical Staff and Decision-Makers

If we consider care as practices of substitution, what is the scope of the substitution? Feeding, changing, and sterilizing a surgery scar easily count as typical care practices that require the caregiver's substitution. What about communication with the medical staff? Can it be a part of care? I have illustrated how (female) family members of patients in the terminal-cancer ward came to be called the *hwanja bohoja* and were expected to take responsibility for various activities necessary for the patient's well-being. This status, *hwanja bohoja,* and its duties were not dictated by any law; however, it had been shaped through a long history and by a specific health care system. Likewise, the expectation that the *bohoja* would communicate with doctors and nurses in the terminal-cancer ward did not come from any code or law, and it was not technically based upon family relationships of consanguinity and marriage either.

When we say "caregiver," we likely envision someone who is an *assistant* to the person in need of help. However, the *bohoja* of a patient is not limited to a shadow care laborer. Rather, a patient's *bohoja* has to be a proactive interlocutor with the medical staff with the tacit consent of the patient. This was salient in the clinical communications among the doctor/nurse, patient, and relatives of the patient in the outpatient clinic and ward. The following is an excerpt from my field notes on a day I shadowed a resident's rounds.

[Scenes: Communication Patterns in Ward Rounds]

> (A patient was lying in his bed, and his paid caregiver was sitting on the cot.)
>
> Resident: Did [you/he] have diarrhea today?
>
> *Ganbyeong-in*: He did. Three times, but they were not too watery. I think his bowel is sensitive when he eats something.
>
> Resident: How was it last time? (Conversation continued for a while) It looks like [you/he] can go home today.
>
> *Ganbyeong-in*: Today? How is it possible?
>
> Resident: I will talk to [your/his] adult children.

One characteristic linguistic feature of Korean is that the subject and the object in a sentence can be omitted. This resident also did not clarify who his interlocutor in this conversation was. If he said, “Did you have diarrhea?” he talked to the patient and the *ganbyeong-in* stepped in. If he said, “Did he have diarrhea?” he ignored the patient and talked to the *ganbyeong-in*. However, he opened the possibility of both the patient and the *ganbyeong-in* being his interlocutor, and the *ganbyeong-in* proactively participated in the conversation while the patient stepped back.

> (Another patient was sitting up in his bed, and his son was standing by the patient.)
>
> Resident: Did [you/he] have breakfast?
>
> Patient’s son: Yes.
>
> Resident: Did it go down the wrong pipe?
>
> Son: No.
>
> Resident: What about the medication?
>
> Son: (pointing to a little can around him) He took this amount [of the medication]… How is the radiation therapy’s schedule?
>
> Resident: We will try a chemo on Monday.

Son: What about a blood test?

Resident: [You/He] doesn't need it for now. (The conversation continued)

Son: He said that he suffers from serious coughs when he lies down. Why is that?

Resident: (answering this question) (the rest omitted)

In this conversation, the son reported some changes in the patient's "condition" and what he ate to the doctor. Further, the son asked about the next treatment schedules and sought out the doctor's explanation of why his father had not recovered. The resident did not stop the son from speaking or try to let the patient speak. At the same time, the patient did not want to participate in the conversation or feel upset by his son's surrogate answers. The three people in the conversation just accepted these communicative aspects of the conversation as if that was how it worked. On that particular day, only two patients among 29 talked to the resident without the *bohoja*'s participation. Mostly, the *bohoja*s reported what they observed about the patients' bodies, asked about the reasons for the pain and uncomfortablefeelings that the patients had mentioned to the *bohoja*s, and asked the resident about the next care plan. Thus, the main pattern of communication in the clinical setting involved the *bohoja* in the role of communicator for the patient.

The *bohoja*'s role of communicator was not only implicitly approved by the medical practitioners and the patients, but was also regarded as a duty of the *bohoja*. One day, Nurse Kim remarked on a patient's husband in a morning briefing:

> Her husband is too introverted. I visited him for a hospice consultation and he ran away, saying 'Talk to my wife.' After having a consultation with the patient, the husband showed up. I did not feel right about this situation and approached him again, and he ran away again. Surely, he loves his wife but he shies away from

> honesty and confrontation. I ended up talking with the patient's daughter, not her husband.

Nurse Kim tried to discuss a patient's end-of-life care plan, but the husband of the patient refused to talk with Nurse Kim. She could not help but talk to the patient's daughter. Nevertheless, Nurse Kim did not "feel right about it." In her thinking, the husband had to be the main interlocutor with her. It was his duty to seek out important information from the doctors and nurses regarding what would happen to his wife and what he should do for her. Avoiding being a main interlocutor made the medical staff doubt if the *bohoja* sincerely performed his care duties.

What Is Required of a Bohoja as a Communicator

Basically, the capillary care work and communicating with the medical practitioners were done by the same person, and in general, the *bohoja* of a patient was a member of the family. However, although, with regard to the capillary care work, it mattered less whether a *bohoja* was a family member or had certain qualities, when it came to communication with the medical staff, the *bohoja* was expected to be an eligible and communicable person because the communication would entail decision-making on treatment and end-of-life care. First, the *bohoja* was supposed to be related to the patient through by kinship or by marriage, and it was best if a spouse or nuclear family member spoke on behalf of the patient. If the *bohoja* was a paid caregiver, a common-law spouse, or a friend of the patient, the doctors and nurses tried to make sure that the *bohoja* discussed the patient's evolving situation with a spouse or other membera of the patient's nuclear family (a parent, a sibling, or an adult child) or made a phone call to them and let them know of any important clinical results or future care plans.

Yet, a relationship on the basis of "blood" or marriage was not everything. In every clinical encounter, the nurses and doctors implicitly observed and assessed the *bohoja*'s personality and the degree of intimacy between the *bohoja* and the patient. For instance, when a husband seemed "indifferent" to what the patient went through, the palliative care team shared this information, paid more attention, and tried to find another eligible *bohoja*. Of course, even if a husband did not seem intimate enough with the patient, there was not much that Doctor Park and Nurse Kim could do about it. At best, the doctor tried to look for an adult daughter or son of the patient or told the husband that the patient needed good quality care. However, the fact that the palliative care staff was concerned with it was important because their concern indicated that the proper *bohoja* was not merely grounded in a kinship relationship, but also grounded in a sincere engagement with the physical and emotional care and attention to the patient's body through their on-site presence.

For communication to go smoothly, especially in discussions of the end-of-life care, the *bohoja* was expected to have an ability to communicate with medical professionals. This capability was not the same, however, as being competent to understand said communication. Rather, to the medical staff, it was important that the family member was able to comprehend the disease progression, care plan, and prognosis as communicated by doctors and nurses. In particular, when a doctor used a euphemism to convey that there was no longer an effective treatment, it was imperative that the *bohoja* understood the underlying meaning. If a family member continued to express hope for full recovery even after the doctor's warning, the family member would be classified as “a *bohoja* with poor understanding” and the medical staff might try to contact another family member.

Decision-making as a Part of Communication

Communication was not merely receiving information from the medical staff and delivering it to the patient. Proactive substituting for a patient meant that the *bohoja* would likely know the prognosis prior to the patient and to make decisions on treatments. Unless there was a special request from the patient, the doctors and nurses never excluded the *bohoja* from any decision-making process. For example, on the day I shadowed the resident’s rounds, a patient, Mr. Kwak Beomhak, refused to receive a scheduled endoscopy.

> Resident: Today we will perform the endoscopy.
>
> Mr. Kwak: (even before the resident finished, the patient shook his head.)
>
> Resident: There is bleeding.
>
> Mr. Kwak: (writing a note that he does not want to receive the exam)
>
> Resident: Because you feel too weak?
>
> Mr. Kwak: (writing “an analgesics” in the note)
>
> Resident: (to the *ganbyeong-in*) Please call the *bohoja*.
>
> (The *ganbyeong-in* called the patient’s daughter and put the resident on.)
>
> Resident: (to the daughter) We are supposed to perform an endoscopy, but your father does not want it. To let him eat something, we should see if the bleeding has stopped. (hanging up the phone and writing “We have to do the exam” in the note)
>
> Mr. Kwak: (again, writing “No” in the note)

Resident: Then, when the *bohoja* comes, we will talk to her.

In the circumstance that he could not vocalize due to his tumor, the patient expressed his strong will not to receive the exam. I do not know why he refused the endoscopy, but it was unforgettable that the patient very firmly expressed what he wanted to do.

Later, the daughter arrived, and they talked with each other on the corridor. The resident explained the necessity of the exam procedure, and, further, he recommended that the patient try one more anti-cancer treatment, not for full-recovery but for a supportive purpose. The daughter said that her father recently did not want any more treatments. She wanted to respect his wish, but, at the same time, was not sure if this was the time to stop. The resident asked her to talk to the patient and let him know their decision on the endoscopy. Later, I was told that Mr. Kwak received the exam on that day. In this conversation, even though the patient expressed what he wanted, the resident invited the daughter into the clinical dialogue. The daughter, while conveying the wishes of both parties, cooperated with the doctor to have the patient receive this treatment. Her presence was inevitable in the dialogue as a conduit of information and as a persuader.

As Mr. Kwak's daughter did, any *bohoja* of a patient would make numerous decisions: whether or not to continue an anti-cancer treatment; whether or not to move the patient to a hospice; where to hold a funeral (at the current resident city or hometown) while also considering the transportation fee and the cemetery fee; the handling of the body (cremation or not); and what kind of burial (a traditional burial, natural burial, or columbarium).

Whether or not to try life-sustaining treatment and when to cease it were among the numerous decisions made by a *bohoja*. In many cases, the family members wanted to be a proactive gatekeeper of bad news unless the patient strongly insisted on directly interacting with the doctor. The example of a gatekeeper of a bad prognosis comes from Ms. Hahn Eunsuk's story, which I revisit below.

> [Case: Ms. Hahn's Strategy to Deal with the Bad Prognosis]
>
> Since receiving the cancer diagnosis, the family members talked about their father's disease in a very roundabout way. "My father was not a strong man," Ms. Hahn said. All of Ms. Hahn's family members knew that if he learned about the prognosis, their father would have "hassled" other family members. They explained to the father, "Everyone has a small number of cancer cells, and you have a little bit more than others." The first, young, doctor strongly opposed the idea that the patient was not informed of all the details of the disease's progress, so the family changed to "a veteran doctor who could understand it." The second doctor said to the patient, "The PSA level (prostate specific antigen level) is slightly higher than before, so take care of yourself." At the moment that the patient and his accompanying family member were leaving the clinic, the doctor called the relative to a halt and asked, "Can I talk to you for a second?" While the patient was waiting in the corridor, the doctor explained the poor prognosis to the relative. Then the family amended and restated the prognosis to the father, "It looks like the number of cancer cells has increased. You will be fine if you are cautious about your diet." The patient thus knew that he "had cancer cells," but his family did not explain it to him in a straightforward manner such as "You are a cancer patient" or "You are now in stage 4."

Many family members adopted a strategy similar to that of Ms. Hahn's family. Typically, prior to the doctor's appointment, they passed a small note to a nurse with the written message, "Please do not talk about bad things to the patient." Then, the doctor conveyed the real prognosis to the *bohoja* after the meeting was over, as the doctor did in Ms. Hahn's story. Ms. Shim had a similar but different version of the story in which the *bohoja*'s strategy failed owing to the doctor's noncooperation.

> [Case: Ms. Shim's Strategy and Doctor's Noncooperation]
>
> My mother-in-law is 73 years old. She felt an uncomfortable feeling in her stomach, so we (Ms. Shim and her husband) admitted her to D University Hospital and had the doctors run some exams on her. The doctor told us that it was stage-4 liver cancer and that surgery was not possible. The doctor also said, "Let's not talk about the stage to the patient so that she can receive treatment with a positive attitude." We wanted to transfer my mother-in-law to a hospital around our place and she was referred here. On the first appointment with a surgical oncologist, once we (Ms. Shim, her husband, and the mother-in-law) sat on the chairs, the professor unexpectedly said, "The cancer started from the pancreas, and this type of cancer is very malignant and spreads rapidly over the body. Did you see this picture [the CT image]? You patient, too, can see it. From here to here, all are black, which are all cancer. The tumors have spread to too many places in your body to do any surgery. This is called stage 4, the terminal stage. We usually foresee 6 months or one year." He said this to the *patient*! Then, he continued, "Receiving treatment is very painful and exhausting. If you don't like pain, you don't need to receive the anti-cancer treatment. You do what you want." He kept talking to *my mother-in-law*. I stepped in and flatly said, "We want to start any treatment." He said, "You may, but it will be very painful."
>
> We were ready to do anything. My mother-in-law had been worried about money, and we had cried and begged her to try anything possible. We had managed to drag her to the hospital and the professor abruptly told the patient everything, even though we shook our heads behind the patient. I understand. He might think that the patient should understand that surgery is impossible in stage 4. However, we came from Masan to receive treatments. I was so upset when the doctor spoke as if all these things were nothing.
>
> Anyhow, after another consultation with the oncologist, we decided to try first-line chemo and we kept saying to her, "Just remember what the oncology professor said." However, as soon as we got home, she called her brother and said that she had only six months more. I was so upset. I cannot help but shed tears because there is nothing we can do for her. It is like the sky is falling. She keeps saying "after six months." We had gone on a trip two months ago. She had kept smiling like a child and never stopped talking. After the day of the appointment, however, she looked much older than before. It was like, "This person will die soon" is written on her face. She even could not walk well. It is like the sky is falling. She did not watch TV anymore and refused to eat anything.

A week later, Ms. Shim looked calmer. She rethought the medical encounter. The patient seemed resilient from the initial shock. Ms. Shim said, "My mother-in-law heard a story of a patient who has lived with cancer for six years in a nursing hospital, and I think this story gave her hope. I can see now the patient is affected by everything, and I learned that the doctor's talk was not a big deal. I think he just did his job. We wanted to give her some time to be ready for the bad news, but now I am not sure if we would really be able to convey it later. It was good for her to hear from the doctor rather than things being hidden."

As seen in Ms. Hahn's and Ms. Shim's cases, the *bohoja*s wanted to control the timing, tone of the talk, and contents of the bad prognosis while considering the patient's personality, health condition, and period of struggling with cancer. They did so to *protect* the patient—they endeavored to protect the patient's feelings, hopes, and the psychological energy needed to maintain daily life. As a *bohoja*, they assumed that this kind of protection was their duty and was an extension of what they had done for the patient.

Thus, the communicative patterns in the end-of-life conversation were heterogeneous: some doctors did not want to let the patient know the terminality, while some doctors contended that the patient should know everything; some doctors did not like the *bohoja*s' idea but cooperated with them. A *bohoja* might convey the bad prognosis in a roundabout way or convey a part of the bad prognosis; a *bohoja* might have decided not to reveal the life expectancy predicted by the doctor, but reverse that decision later; a *bohoja* might want to let the patient know the bad prognosis but be afraid the knowledge would depress the patient. The ways in which patients react to a bad prognosis were also heterogeneous: a patient might want to know everything and be prepared for everything; or a patient might become aware of the terminal stage but just not want to talk about it, which was the most common reaction (Seo Minjeong 2015).

Whatever the actors chose, they did it because they wanted to protect the patient from psychological shock and depression, as Ms. Hahn and Ms. Shim did. But it was precisely the *bohoja*'s and the doctor's aim of protecting the patient that generated problems in the dying process because they had not openly talked about the use of life-sustaining treatment with the patient. As a consequence, the patient was very likely to receive life-prolonging measures since it was a default procedure in the hospital. This was what all people regarded as a bad death, and the Act was designed to prevent this bad death.

The Ways that the Act Intervened

Leaving aside the overall context in which a family member was, as a *bohonja*, required to engage in acts of care and decision-making, the provisions of the Act envisioned decision-making in a different way. First, the Act dealt with decision making about life-sustaining treatment as an event independent of the ways in which the patient, family members, and medical staff altogether participated in end-of-life care in the terminal-cancer ward. Second, the law envisioned the dying process and related practices in a specific way: a doctor discloses the bad news to a patient and explains hypothetical consequences of receiving life-sustaining treatment to help a patient to make a decision; if the patient is convinced that receiving such treatments is not what she wants, the patient signs her POLST or AD and the doctor respects the choice; if the patient loses her ability to make a decision on her own, or to express her wishes before any official documents have been written or signed, her family members testify as to the patient's unofficial wishes, or substitute their decision-making on behalf of the patient. In this scheme, each actor assumes responsibilities as doctor, patient, and family member, respectively. It is as though the order of appearance on the stage is fixed: first, a doctor and a patient appear, and then the patient exits the stage. Next, the family members take their turn. Similarly, each event (disclosure, signature, surrogate decision-making, etc.) is arranged in a set sequence as if A happens first, and then B follows.

Unlike the law's ambitious attempt to establish logical sequences of end-of-life decision-making, the assumptions made in the Act were incongruent with the reality. The law assumes that the flow of information is from a doctor to a patient, but as I have shown, in reality, the information primarily flows from a doctor to the *bohoja* of the patient; and whether the information is delivered to the patient is dependent upon the interaction between the family members and the patient.

However, neither the hospital system nor the actors in the clinical setting were ready to establish a direct line of communication from doctor to patient. In conformity with this reality, the palliative care team tried to persuade the *bohoja*s to have honest conversations with their patients, as long as the patient's condition seemed conducive to discussing end-of-life care, and the existence of the Act buttressed this persuasion. Nurse Kim said, "Now we have a good ground on which to persuade families. We say, 'It is written in the law.'" This inducement definitely worked, especially when the family members recognized the necessity of discussing imminent decisions regarding care with the patient, and perceived that the patient was willing to make such decisions on her own. As a result, in 2018, during the first year of the Act, the ratio of end-of-life documents signed by patients increased to 20-30% of the entire POLST, which was a great achievement. The remaining 70-80% still relied on family's decision-making on behalf of patients because the *bohoja*s were unwilling to inform the patient of the bad prognosis, because the patient refused to talk about the issue, or because the patient rapidly got worse before the end-of-life care discussion began.

In circumstances in which a patient had not signed an AD or POLST in advance, a new problem emerged after the Act. The Act stipulated that the family members testify to the patient's wish or unanimously agree on withdrawal of life-sustaining treatment, and the scope of family was defined as a legally recognized (heterosexual) spouse, lineal ascendants (*jikgye jonsok*, 직계존속: parents, grandparents, great-grandparents...), lineal descendants (*jikgye bisok*, 직계비속: children, grandchildren, great-grandchildren...), and siblings.[93] Only those counted by the Act as family members were the *bohoja*s of a patient eligible to testify as to a patient's unofficial wish or eligible to make a unanimous decision on withholding or withdrawing life-sustaining treatment.

However, as I have explored, the status of *bohoja*s was more than simply a family relationship in the terminal-cancer ward. A *bohoja*(s) should be present beside the patient; if this is not possible, a *bohoja*(s) should at least be able to be reached by the doctors and nurses to

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[93] This scope of family does not correspond with other laws that define what family is. For example, the Civil Act Article 779 defines family members in general as (1) the spouse, lineal blood relatives (직계혈족), and brothers and sisters; (2) spouses of the lineal blood relatives, lineal blood relatives of the spouse, and brothers and sisters of the spouse. The Civil Act Article 1000 and Article 1003 define the scope of inheritors as to (1) a spouse, and lineal descendants of the inheritee; (2) lineal ascendants of the inheritee; (3) brothers and sisters of the inheritee; and (4) collateral blood relatives within the fourth degree of the inheritee. (Refer to http://www.law.go.kr/LSW/eng/engLsSc.do?menuId=2&section=lawNm&query=inheritance&x=0&y=0#liBgcolor23) In other words, there was no previous legal basis to define the eligible family members to participate in the end-of-life care decisions. Further study is needed to investigate the background of these definitions of family.

discuss the care plan. Further, a *bohoja*(s) should understand the patient's health conditions and psychological changes through intensive capillary care work and communication with the medical staff on behalf of the patient. Finally, a *bohoja*(s) should be someone whom both the patient and the medical staff could rely upon. In addition, the doctors and nurses usually contacted one *bohoja* to be a representative of the patient and the family, and in many cases, this *bohoja* was a daughter-in-law, aunt, or common-law spouse.

This discrepancy between the actual *bohoja* and the eligible legal agent came into question especially in the case of families that were not so-called "normal families." Due to divorce and long disconnection, the legal agent specified by the Act might not contribute to any of the care labor. Conversely, the main *bohoja* might not be the legal agent. On April 26, 2017, in a conference in which the feasibility of the Act was discussed, an oncologist at K hospital, in Seoul, Doctor Kwon Junghye, spoke to the absence of the proxy in the Act:

> I am working in K hospital. Those who go to the big-five hospitals are likely to be able to afford expensive treatments; however, many patients in our hospital are economically encumbered. In underprivileged families, a daughter-in-law commonly supports her parents-in-law with her young children after her husband has died. There are so many families who are not covered by lineal ascendants and descendants (*jikgye jonbisok*, 직계존비속). In these cases, the daughters-in-law cannot participate in the decision-making process even though these in-law relations financially support each other.

Given that daughters-in-law often play the role of the main caregiver, it could cause a serious problem in an emergency situation. If a daughter-in-law stays with a patient and an emergency situation that requires the signature of a POLST occurs, she has no right to sign the document on behalf of the patient regardless of her involvement in caring for the patient. In this scenario, the patient is likely to receive CPR until the rest of the family members arrive. What

Doctor Kwon specifically addressed was a correlation between the relationship outside the "normal family"[94] and the economic capacity. An extreme case would be that of a homeless person or a patient without any next-of-kin (*muyeongoja*, 무연고자). Although I did not observe such cases during my fieldwork (probably because of the demographic features of S Hospital's inpatients, as Doctor Kwon noted), the medical staff members who worked in some public hospitals were worried that the Act did not allow any proxy to be designated. This becomes a critical problem for members of vulnerable social groups who are unable to die without unnecessary suffering.

Another problem was how to recognize the *bohoja*. Within the context of care, the presence of the *bohoja* beside the patient, the continuous and representative communication that proved the *bohoja*'s restless observation of and listening to the patient were utilized by the staff to judge if this *bohoja* was a good *bohoja*. In contrast, according to the Act, the only effective way to verify eligibility was through legal documentation, e.g., a family relation certificate or resident registration. Commonly, these official documents can be issued in a community service center or a district office. However, death can occur at any time, regardless of office working hours. To resolve this problem, S Hospital instituted certificate-issuing kiosks. When a patient needed a family member's statement or unanimous agreement for withdrawing life-sustaining treatment, the palliative care team identified eligible family members and asked them to bring the family relation certificate. The nurses often made a joke, saying that "We should always carry

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[94] A "normal family" ideology refers to an idea that supposes a middle-class, nuclear family based on a heterosexual marriage as "normal." From this ideological perspective, divorced families, bereaved families, childless couples, homosexual couples, and single people are not regarded as "normal families." See Kim Heekyeong (2017).

the family-relation certificate with us and renew it every three months to avoid futile prolonging of life."

This proof of the eligibility via documentation caused not only some inconvenience but also meaningless life-sustaining treatment. Here, I would like to revisit Mr. Hahn Dongcheol's case, which I presented in Chapter Five. This patient with bladder cancer had two sons, and, after having recently recovered his relationship with his father, one son wanted to try everything he could. Mr. Hahn's attending doctor had a hard time convincing the son that his father was in the end-of-life process, which required all family members to sign the POLST. Although the stubborn son at last changed his mind and decided to sign the POLST, in the time it took the family to prepare the family relation documentations, Mr. Hahn experienced a second cardiac arrest and CPR. Many years prior, Mr. Hahn's first son had immigrated to Canada, where he had his own son, and had thus lost his Korean citizenship. There was no way for the son and grandson to get another certificate to verify their relationship to Mr. Hahn outside of visiting the related ministry in person, which thus caused Mr. Hahn to stay in the ICU for twenty hours.

Mr. Hahn's story well demonstrates that what the state prioritized when it intervened in the governance of death. The most urgent interest of the state was not the suffering of a patient or the farewell ritual of a family but the proof of the eligibility to become decision-makers. There was no doubt that this person had accompanied the patient to this hospital for months as a son, and this very person guaranteed the two men as his brother and nephew, but these guarantees were invalid. The attending doctor was not willing to take any risk as long as the Act stipulated the regulations and punishments for their violation.

In this section, I have argued that family caregiving includes a broad range of care labor, which shapes a unique communicative pattern in the terminal-cancer ward. In this pattern of communication—where the doctor and the *bohoja* mainly speak—the patient's *bohoja*s were supposed to adjust the way of conveying bad news to the patient. Decisions were never bound to a moment, to a place, or to a single or even a few individuals, and decision-making was construed as a part of care (Navne and Svendsen 2018). Obviously, the increase of POLST written by patients themselves from 0% to 30% was a great achievement of the Act. Yet, the remaining 70% of POLST written by family members suggests that the Act was missing something. I will come back to this issue in the conclusion of this chapter.

Relational-Generative Care

Care for the dying was coproduced by the *bohojas* and the palliative care team members in the terminal-cancer ward. While the family members were struggling to substitute for the dying, the palliative care staff at times assisted, at times re-substituted for, and at times taught the family caregivers care techniques. Obviously, all of this support was necessary to make the dying patient comfortable. However, is there any implication beyond the practical purpose of the end-of-life care? In seeking an answer to the question of the palliative care team's ultimate raison d'être, I argue that the end-of-life care that the palliative care staff provided in the terminal-cancer ward centered on a relationship: through their subtle and seemingly trivial care practices, the palliative care staff generated and reinforced social relations. The following scene depicts how the nurses shaped the dying process as a family event that embedded some values, such as participation, nuclear family solidarity, and choice.

> [Scene: Waiting for the Family Members to Come]
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> Mr. Kang Jungmun, a man in his fifties, had been diagnosed with cancer only three months earlier. At that time, the cancer had already spread to his spine. He had a strong will to fight against his disease, so he was transferred from a local hospital in Ulsan to S Hospital in the capital of Korea. In S Hospital, Mr. Kang and his wife learned that the cancer had also metastasized to his brain. One day, an emergent event suddenly occurred and he was moved from the terminal-cancer ward to an ICU to be placed on an artificial respirator and vasopressor.
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> The couple had a daughter and two sons; the eldest daughter was preparing for her college entrance exam, and the two sons were middle school students. This couple had not yet told the children about his disease. Mr. Kang's elderly parents and other relatives were hurrying to S Hospital from Ulsan, a five-hour drive. The eldest daughter still had no idea what was happening. Nurse Kim met Mr. Kang's wife to consult with her.[95]
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> Wife: I want to let him go in peace. I don't want to use any type of life-prolonging treatment with him. (Silence.) If we use them, how long can he hang in there?
>
> Nurse Kim: Not so long. Now we are giving him vasopressor. Vasopressor squeezes all of the vessels and pumps the blood to the heart. If you use it for a long time, the limbs will become necrotized. It is not something that you can use long term.
>
> Wife: Then, please just let him go in peace. (Sigh.) My parents-in-law and sons are on their way here. I would like to do everything we can until they arrive. Once they arrive, I want to stop using the vasopressor. But I don't want to wean him from the artificial respirator. We should let him breathe, shouldn't we? The kids have not had any idea at all. I don't know how to tell this to them.
>
> Nurse Kim: When they arrive, you sit your children in a quiet place and tell them, "We have been in this situation, and this happened before we were able to tell you. I am so sorry." I am a nurse, but the circumstance of the ICU is terrifying even to me. So, tell them that "once you go into the ICU, it will be terrifying. Doctors are everywhere, and all of the patients are connected to machines. If you are too terrified to go to the ICU, I fully understand. It is ok. If you take your

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[95] I regret that I am only able to present this conversation through (translated) text. Nurse Kim's tone, voice, facial expressions, and body language conveyed her deep consolation and comfort.

> courage and decide to go to the ICU, I will be with you. Father can't answer you, but he can hear you. You can hold his hands. Tell him the things you are grateful for, tell him you love him, and tell him you are sorry if you have some things you feel sorry for." If the children can't digest the situation, you stop and reassure them. The adult relatives might come and cry, "You should get up," but this disturbs the patient. We are no longer in those stages. You cry here, calm yourself, and then make the patient comfortable. When he passes away, the nurses will pull out all of the tubes that are connected to him now. Then you may hug him and tell him that you love him.
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> Wife: How about the eldest daughter? What would you do if you were me?
>
> Nurse Kim: I have had a conversation with my kids regarding a hypothetical situation like this. They were upset that we would not tell them that their Mom or Dad was dying. You have three options: You can tell her after the college entrance exam, you can tell her now and let her come tomorrow, or you can let her attend the funeral.
>
> Wife: The eldest daughter is a sensitive kid.
>
> Nurse Kim: If I were you, I would call and tell her, "This is the situation where we are. I am so sorry not to tell you in advance. What would you like to do? You can stay there and attend the funeral, or you can come here." I would give her options to choose from.
>
> Wife: (Silent) I am ok, but I am worried about my children and my parents-in-law.
>
> Nurse Kim: No, a spouse is the one who has the hardest time. Children have their own lives. Children are resilient enough to accept the reality. But the spouses have always looked only to each other.

In terms of the use of life-sustaining treatment, Mr. Kang's wife had a determined position; she wanted to minimize her husband's suffering and prioritized a final family union by the conditional use of a vasopressor. What Mr. Kang's wife was not sure about was how to disclose Mr. Kang's dying to their sons and daughter while also minimizing their shock, and how to care for her children before and after their father's death. Mr. Kang and his wife had not told their children about Mr. Kang's illness and grave prognosis for several months, as many parents did in the previous scenes I have illustrated (e.g., p. 123). In particular, Mr. Kang's wife was worried about their eldest daughter, who had prepared for the university entrance exam: whether or not to tell the daughter her father's death?

Nurse Kim had expressed to Mr. Kang's wife that she had three options for how to approach the subject with her children and, by sharing an anecdote from her own life, she implied that telling the truth and letting the children make their own decisions would be for the best. Nurse Kim's advice was not forceful or straightforward, but rather subtle, as always. When a *bohoja* of a patient could not decide whether or not to reveal the bad news (bad prognosis, the terminal stage, and death) to the patient or other family members, Nurse Kim always recommended that the *bohoja* share the important news with the family members. Dying should not be hidden and untold; rather, dying should be discussed by all family members so that they can prepare for the death together. Even though each member could react to the farewell in different and unexpected ways, they should have a chance to make a decision on how to spend this time.

Through this participatory event, all family members—even the young children—were to gather for a final moment of physical contact and farewell, with verbal expressions of the completion of their relationship. Mr. Kang seemed like he also took part in this family ritual by enduring prolonged suffering. It was his wife who decided to use the vasopressor conditionally, but, if Mr. Kang was able to express his intention, he would have made the same decision as their father, husband, and son. While waiting for the last family reunion to be held, Mr. Kang, the dying, also fulfilled his familial duty and responsibility and struggled to show his love and affection to his wife and children.

Also, in Nurse Kim's advice, the dos and don'ts are noteworthy. The crying out that Nurse Kim counted as a don't was not an uncommon response in Korea. At traditional funerals, the wailing of relatives was one of the ritual elements which indicated a close relationship between the living and the dead, how much the living loved the dead, and how much grief the living now experienced. Thus, when Nurse Kim advised Mr. Kang's wife on what the family members should do, she actually gave direction to a new way to bid farewell that consisted of words of love, holding hands, hugs, and not emotional bursts. By sharing this moment, Mr. Kang and his family members could part from one another on their own terms; their relationship was now going to enter a new phase, and the alteration of this relationship had to follow a proper ritual (Van Gennep 2013[1960]).

At times, I encountered a scene in which elderly people (e.g., patient's older sisters or parents) cried out around the bedside of the dying patient while his wife was standing behind them. In this case, Nurse Kim quietly said to the relative, "If you cry out, the patient feels anxiety." Then, she handed cotton pads to the wife and directed her to cleanse the patient's face and hands. By doing so, Nurse Kim let the spouse be the patient's main caregiver and let the dying patient, the spouse, and their children lead the farewell ritual. That is, through her consultations, Nurse Kim rendered one's dying as a nuclear-family-centered event in which all members of the family shared their grief, supported each other, and participated.

The nature of care that fostered closerelations between the dying and the family was especially prominent in cases where the palliative care team succeeded in renewing the family relations before death occurred.

> [Case: Rural Police Found Long-Lost Daughter]
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> While a mother was admitted to the ICU on life-sustaining treatment, one of the patient's daughters, who had long been out of contact with the rest of the family, presented a problem. In order to withdraw the patient's life-sustaining treatment, the daughter's consent was necessary. But how could they find the daughter? In a desperate attempt, Nurse Kim asked the police if they could find the daughter's whereabouts. The police replied that the strict policy of privacy protection did not allow for this. However, this impasse was solved in an unexpected way. The patient's hometown was in the countryside, and, after Nurse Kim's inquiry, the rural police station seemed more willing to bend the "privacy rules." To coin a phrase Nurse Kim used, the rural police station "had a heart in contrast to the urban police." The police eventually found the daughter and got her connected to the family members.
>
> It turned out that the daughter had divorced her husband after his business had collapsed, and she and her two children had suffered from financial difficulties. She did not want her family members to know of her difficulty and thus chose to distance herself from them. When she received the police call, the daughter was shocked and immediately came to the hospital at daybreak. The mother and daughter had one last moment to say goodbye to each other, and the daughter expressed her gratitude toward the palliative care team.

This case well illustrates how palliative nurses endeavored to make a death good within the given structure. The Article of the Act required all lineal ascendants and descendants to sign the POLST. In order to get a signature from the patient's daughter, Nurse Kim even contacted the police in two regions, and she managed to reach the daughter. Given the disjuncture between the legal requirements and the contingency of the daughter's absence, the palliative care staff felt morally compelled to investigate the daughter's whereabouts and bring her back into the relation with her dying mother. The palliative care team achieved both goals, namely, stopping the life-sustaining treatment and letting the family members say goodbye to each other. Thus, they realized their ultimate aim of making the death good.

Generating Social Relations

The term "relational care" highlights the dependency of life. The relationality of care refers to the fact that we are relational beings throughout our lives and that the quality of people's lives depends hugely on the quality of the social relations in which they live, and on how people treat one another (Sayer 2011; Barnes 2016). By relational-generative care, I argue that acts of care eventually generate a new relation and, further, that this relatedness in itself can serve the aim of care.

One day, Nurse Kim defined what she did as "making families here." She said:

> Some people feel so lonely and isolated in the hospital and they want a family they can rely on and have a small chat with: someone who would welcome them when they come here again. We are supposed to become a family to them.

By "family," what did Nurse Kim mean? Would it be possible to establish a kin-like relation in this ward, where people stayed for days and weeks and then would not come back? Some of them would be admitted to this ward again; however, from the patient's perspective, this readmission would not be what they hoped for. What did we produce here? Some ethnographic scenes answer this question.

> [Scene: Helping Shampooing]
>
> Ms. Park Seonja, one of the veteran volunteers, and I visited Mr. Kim Chunbae. He was already almost unconscious. His wife, Ms. Kim Jeongha, was waiting for our arrival. Since the patient was unconscious, we had a difficult time moving his bed and his body, but it was overall a routine job. Mr. Kim's wife said, "It has been so long since his hair has been washed. He must feel so good now." When we finished washing Mr. Kim's hair, Ms. Kim hugged me and Ms. Park, respectively. I thought that Ms. Kim showed her gratitude, and I just gave back a light hug to her, with a bright smile. Yet Ms. Park sobbingly said, "Thank you." At that moment, I realized that what this

> moment meant was very different to Ms. Kim and me. Ms. Park seemed to know the meaning of the hug. Ms. Park stroked Ms. Kim's back tenderly, saying, "You two have had so many great days though? You can work through this by thinking about those days?" Ms. Kim nodded.

As a representative apparatus of surveillance (Foucault 2012), this place required all people to hide their unique personality and to follow the temporal, social, and spatial rules of the hospital. Although the patients and their *bohoja*s tried to develop some small strategies to make the place around their bed a comfortable, home-like place (Kellehear, Pugh, and Atter 2009), these strategies were not enough to fulfill their purpose. When people were decontextualized from their everydaylives, each day dragged by. People could not find something to do or someone to interact with. Mr. Kim's wife always slept curled up in a small and narrow cot beside the patient's bed and had only a few minutes to grab food while devoting herself to caring for her husband. The deprivation of time to take care of herself exhausted Mr. Kim's wife. Psychologically, she felt powerless in that she could not even turn Mr. Kim's body to other side on her own. In addition, she felt lonely. She could not share all these feelings with her husband, who was already unconscious. It was a time that Mr. Kim and his wife both, yet respectively, endured.

Mr. Kim's wife always shed tears when the volunteers visited the room. The care services that we provided lightened her burden of care for her critically ill husband as Ms. Park filled the care vacancy caused by Mr. Kim's wife's exhaustion. Most of all, Ms. Park's hug and stroking were more than perfunctory gestures. The stroking was a part of non-verbal communication which showed Ms. Park's sympathy and companionship as a human who shared the fate of mortality. This hug was one of the very few moments of physical contact that Mr.

Kim's wife experienced while serving here as a *bohoja*, which connected her emotionally and physically to others. Also, through her last remark, Ms. Park redefined this time of sadness and suffering as a time of fruition of the life that Ms. Kim and Mr. Kim had shared. Ms. Park empowered Mr. Kim's wife by recalling their intimate relationship.

I learned from Ms. Ryu, who was losing her only-daughter (p. 133), that this solidarity was not merely limited to acts between the two individuals. Ms. Ryu said to me at the end of our conversation.

> Anyhow, owing to you and your team, now I feel relieved. I believe that if a country retains a great number of volunteers, that country is a developed country.... You volunteers give me great psychological comfort and I appreciate it. I won't forget it. One of the spiritual brothers in my church, too, came here and prayed for us. I received a lot of consolation. When I am having a difficult time you come to me and console me. Thank you very much. I will look for a way to contribute to the society. I will.

Her appreciation was not given to *me*. She said that she would look for a way to contribute to *society*. When she was in the most pain, Ms. Ryu ruminated on the support she received from others. She was losing her daughter—this was a fact that no one could change, and no one could remove her pain. However, she could see that, through the practices of caregiving and care-receiving, she was connected to her religious community and the local community that consisted of those who were willing to help her. As Ms. Kim and Ms. Ryu did, the patients and their family members could realize that they were not abandoned and alone at this sorrowful time.

What Ms. Park did was to redirect the *bohoja* to the relationship with her husband as well as to create a humanitarian solidarity with the patient's wife through physical and emotional contact and words. In the case of Mr. Hong Seungbu and his wife, the nurses and a group of volunteers did similar work for the patient and the *bohoja* by filling a dreary space with religious songs and their presences.

> [Scene: A Small Concert Held in a Ward Room]
>
> Ms. Hahm Seon-A and Mr. Hong Chanki were a young couple. While Mr. Hong was admitted to the ward, Ms. Hahm could not hide her sadness, and the palliative care team cared deeply for this young family. It was the day a small concert was held, and Nurse Kim visited Mr. Hong's room to suggest attending the concert. Ms. Hahm was pleased with this suggestion, and they tried to put Mr. Hong in a wheelchair. However, his condition, at a glance, was quite poor. He had lost so much weight that his head had become smaller, like a baseball. His face had turned yellow and he could not utter anything other than monosyllabic vowels. Nurse Kim, Ms. Hahm, and I together carefully moved the drooping IV lines that were connected to him and laid some blankets on the wheelchair so that the patient with scrawny hips sat on the wheelchair without pain—but all of the process was difficult and the patient looked quite exhausted. Nurse Kim and Ms. Hahm decided not to bring him to the concert. Nurse Kim and I laid the patient back on the bed and left the room. Nurse Kim whispered to me, "His death seems imminent."
>
> Nurse Kim asked the quartet to sing a song in Mr. Hong's room, and the volunteers willingly agreed. After the concert was over, the four singers of the chorus, two accompanists, three Catholic volunteers of the palliative care team, and two nurses visited Mr. Hong's room. When the chorus started singing, Ms. Hahm, tightly holding Mr. Hong's hand, shed endless tears. All of us in the room were unable to hold back our tears. After the songs ended, the volunteer belonging to both the quartet and the palliative care team held the patient's hands and said, "Hello, Mr. Hong. I am a Christian. You are Catholic, aren't you? May I pray for you, though?" Mr. Hong looked pleased with this whole event. A couple of days later, his wife moved Mr. Hong to a suite room—an expensive room—of the Cancer Hospital since the *imjongbang* was occupied by another dying patient. A couple of days after that, he passed away.

It was through such actions that the palliative care team tried to make the dying's bed a place worthy of the patient's dignity. Mr. Hong's room was an isolated island where the couple handled and endured the painful time. When we failed to sit Mr. Hong on the wheelchair, Ms. Hahm was devastated because this immobility signaled the patient's worsened condition. With the visit of several people and the beautiful hymn, however, Mr. Hong's room was filled with the warmth of human beings, their song, and the sound of musical instruments. Even though it lasted only for a short time, the young couple appreciated the music, holding hands, just like they used to. Since the palliative care team members could not move Mr. Hong to a better place before his ending came, they mobilized their limited resources and transformed the room into an unorthodox place, where four men singing in tailcoats, a piano and the player, a steel-framed bed, and an IV pole together were encircled by the white walls.

Also, the room was filled with a dozen of people. If the couple just turned on the radio and listened to the music in the room, the meaning of the moment would be different from the time we created together. It was crucial that there were some people who shed tears, expressed grief over Mr. Hong's leaving this world, and showed sympathy for the young wife. In the place at the moment, Mr. Hong and Ms. Hahn were not alone but were connected to others who shared their sadness.

Meanwhile, the palliative care team created a new bond by linking the *bohoja*s to each other through bereaved family gatherings, which Nurse Roh Hyojeong was in charge of. When a patient passed away, Nurse Roh would meet with the patient's family members. She consoled them and gave them strategies for coping with the onslaught of emotions following a loved one's death. She registered the family caregivers on the list of bereaved family, and routinely sent letters and made phone calls to ensure the caregivers were okay. A bereaved family gathering was held three or four times a year.

[Scene: A Bereaved Family Gathering]

Several people arrived at the palliative care team's office prior to six o'clock, which was the time that had been communicated to all participants. They exchanged greetings and began to share how they had been doing. With six o'clock approaching, the group was moved to a restaurant in the S Hospital where Nurse Roh had made a reservation. In a big room, almost thirty people had gathered around and started dinner. Nurse Roh stood up and delivered her speech: "Thank you for coming today despite this bad weather. We know that you might hate the sight of this hospital." One of the participants responded, "Yes, that's why I was reluctant to come today."

In a quiet mood, after all had half-finished the dinner, Nurse Roh opened the time for sharing. One by one, she let the gathered members tell their story. To ease the beginning, she asked some people who had participated in this gathering before to start. A woman in her sixties stood up and began her speech.

"At first there was nothing I could do but cry. Then my friends dragged me to a hobby farm owned by one of my friends, which was good for me. I enjoyed talking to nuts and sesame. I said, 'Dear nuts, there are so many cancer masses surrounding you. I will get rid of them all.' Talking to someone else about cancer can seem inappropriate, but weeds do not care what you are talking about. Having meals with someone else [the food] does not taste good, but at the farm, it tastes good even if I eat a bowl of rice with only kimchi.[96] One day, one of my friends said to me, 'It will be hard to remarry after six months of bereavement. I will introduce someone to you. I would like you to see him.' I did not say anything to her, but upon returning home, I cried. I thought that she looked down upon me and would never have spoken to me like that if I had a husband.' For a long time, I could not put on colorful clothing because I blamed myself for being a widow. My friends could not stand it anymore and they bought me bright clothing."

Another woman in her forties said, "My husband had lung cancer. We went to B hospital first and I think we lingered too long there. The doctor in the hospital diagnosed stage three or four of renal cancer and an early stage of lung cancer. We should have visited a couple of hospitals for a second opinion, but at that time my husband insisted we not do so. When we moved to this hospital, the anti-cancer treatment schedule was delayed due to the doctor's conference attendance. But we were not told of the terminal stage. We could not even ask about life expectancy because the doctor always spoke so harshly. It was in a consultation following the anti-cancer treatment that we were told that 'the remaining time

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[96] An idiom that expresses poor meal.

> would be short, and now let nature take its course.' I felt like I was standing on the edge of cliff—a dark cliff. My husband and I were best friends. We enjoyed our life. I could not throw out a piece of Kleenex he had used and instead put it beside my bed. My friend saw it and she said that I was crazy and begged me to move on. One day, I found mold in his shoes, and I realized, 'Oh, this man is really no longer a person in this world.'"
>
> As with these two women, the participants talked about how their family struggled with the disease, what made them sad (mostly doctors and other family members), and how they had embraced the bereavement stage. Most participants cried while they were speaking and as they heard one another speak.

Some might not understand the emotions and actions the attendants vocalized in their stories. For example, I could not see a reason why the first speaker was so upset by her friend's suggestion to meet someone else. However, I could see that her sentiment regarding the anecdote gained sympathy from all at the table. One of the attendants said on that day, "I never cry when I am with somebody because I heard someone in my church said, 'Ugh! She is sobbing again! It's boring!' Instead, I climb up a mountain every day. There, I hug a tree and cry out so that no one can hear it and judge me." A safe place to talk about their grief and to cry, and being together with people who had the same experience were probably the most important factors in incorporating the bereavement into their daily lives. By organizing this self-help gathering, the palliative care team gave them a chance to be connected to each other as they tried to move on. After the gathering was over, the attendants exchanged their contacts, created some groups chats on Kakao Talk (a messenger application like WhatsApp). The members of this small group had a lunch, went to a columbarium together, and went on a picnic.

This "posthumous care" was not merely perfunctory. The case of Mr. Lee Sangcheol, who had long been a member of the palliative care team, is particularly noteworthy. Mr. Lee, a sincere Catholic believer in his seventies, was one of the team's veteran volunteers. He rarely got involved in bodily care, such as bathing—likely due to his age. His main job was to pray with the Catholic patients when requested. In the initial period of my research, one of the volunteers asked about my original hometown while at the lunch table. I answered that I came from Daejeon, a large city in Chungcheong Do (province). Mr. Lee interjected, saying, “Chungcheong Do? You came from Meongcheong Do!” Meongcheong means “idiot” and “stupid” in Korean, and “Meongcheong Do” was a demeaning expression referring to Chungcheong Do’s people. It is said that people in Chungcheong Do talk slowly and act slowly, and some (particularly the elderly) refer to this province as Meongcheong Do. At the time I was not offended because I merely considered that those at his age could be insensitive.

Later, we had a chance to speak privately and Mr. Lee told me about his wife: “My wife, too, came from Chungcheong Do, the Meongcheong Do. She was too stupid to ever complain when she felt badly. When she first addressed pain in her abdomen, it was already too late to do something. No. 3 bed in Room No. 16 was our place.”

It was striking that Mr. Lee’s wife had been one of the patients in the terminal-cancer ward, and thus Mr. Lee was one of the *bohoja*s of patients. As his wife had experienced a belated diagnosis, I realized that his remark on Meongcheong Province came from his own sadness, self-reproach, yearning, and sorrow.

Months later, I heard the story of how Mr. Lee had joined the palliative care team through a conversation with Ms. Park, another veteran volunteer. After Mr. Lee eventually lost his wife, Nurse Kim paid extra attention to Mr. Lee. She was sincerely concerned as to whether or not he was doing okay. She often made phone calls to Mr. Lee to say hello. When Mr. Lee did not answer or return her calls for days, Nurse Kim was so concerned that she and Ms. Park visited Mr. Lee's place, and they found that he was not okay. Nurse Kim persuaded him to take part in volunteering, and Mr. Lee accepted her offer. By getting involved in the social activity, Mr. Lee was able to restore his spirits while learning to sublimate his grief. When he lost the connection to his wife, Nurse Kim and Ms. Park connected Mr. Lee to a new social relationship with the palliative care team. Owing to the palliative care staff's effort to create a new solidarity with him, I, too, could be connected to Mr. Lee during my fieldwork. When I suffered from pregnancy complications, Mr. Lee always called me to check out our well-being and wished us good luck, which I deeply appreciated.

Conclusion

In this chapter, I have discussed two issues related to the relationality of care. The first half of this chapter dealt with family caregiving in the terminal-cancer ward. A family member's caregiving for an ill person seems to be almost a universal phenomenon in the world, but the particular shape of family caregiving in this context is a joint production of culturally constructed moral duty, the health care system, and gendered kinship practice. In the absence of institutional assistance, the scope of the care labor of the *bohoja* involves substituting for the dying 24/7 with respect to communication with the doctors. The appropriateness of the *bohoja* is assessed not only by the family relationship but also by the companionship, capillary care labor, and intimacy with the patient.

By placing end-of-life care decisions within the broader context of care, I have provided a new way to understand decision-making by family, which goes beyond looking at who signs the document. Some previous studies have pointed to familism, Confucianism, and individualism to explain the cross-cultural differences in end-of-life care discussions. These grand concepts may or may not provide the fundamental reasons for the different patterns of decision-making. However, speaking in the abstract without empirical evidence of what actually happens on the ground—and of whether different cultural ideologies lead to different practices—cannot help us to find the right way to improve the decision-making context in the clinical setting. Drawing upon the ethnographic data, I have argued that in the clinical setting in South Korea, the family members are expected to be the main interlocutors with medical staff, and, within this communicative pattern, convey news of a bad prognosis and end-of-life decision-making also fall into the category of what the *bohoja* is supposed to do.

Second, my approach, which analyzes decision-making with regard to care practice, may offer suggestions for how the Act needs to be supplemented in the future. Not all the actors in the terminal-cancer ward knew how to talk about death without hurting each other. If we recognize that a conversation about death is a speech genre, the shared fear and concern among the patient, the patient's family, and the medical staff indicate that this speech genre is not common in Korea. In order to increase the proportion of POLST written by patients, the introduction of a person to facilitate end-of-life conversations is necessary.

In the second half of this chapter, I have rethought the relationality of care. In the whole dissertation, relationality has been fundamental tothe practices of making death a good death.

Has a proper relation taken care of the dying? Has the dying person found a good place to be with people she cherished? And has the dying person found good meanings from her social relations? These questions propelled all the caregivers in the terminal-cancer ward to do or not to do certain things. In particular, the palliative care team members—those who had not had a pre-existing relationship with the dying—ultimately aimed to strengthen family relationships, create solidarity between the *bohoja*s and the palliative care staff, and link the isolated *bohoja*s to other *bohoja*s, to the local community, and to others. In the hospice consultation, in bathing the dying, in stroking, in singing together, and in chatting, in all these moments the palliative care team's actions generated new social relations *here*, in the place where people are dying.

Chapter Seven

Conclusion

End of Life, End of My Story

Throughout this dissertation, I have explored what constitutes the present landscape of hospital dying in Korea, particularly in the contexts of the rapid rise in hospital death since the 1990s. The deaths described in Chapter Two precipitated public discussions on how to improve the quality of death in Korea. People from diverse backgrounds have sought ways to promote more desirable forms of death, and legislation was one of the collective endeavors that sought answers to the question, “How can we die well?”

Because my fieldwork was conducted in a terminal-cancer ward from 2016 to 2018, I was able to observe and participate in these discussions as they were unfolding among the medical and palliative care staff. In the context of a tertiary hospital in Seoul—where the highest levels of medical knowledge and technology were assembled to “save” people from life-threatening diseases—I asked how the hospital system shaped particular cultural technologies of dying, how the structure of the hospital system is supported and reproduced, and what agency we, as mortal beings dreaming of immortality, have within the medical bureaucracy.

The ethnographic data that I collected in S Hospital demonstrates that a variety of issues are intimately entangled in the process of hospital dying. In 2016 when I started fieldwork, the spectre of the Boramae Hospital Case was still haunting the medical practitioners causing them to treat their patients in defensive ways, and consequently the mutual distrust between the medical professionals and lay people was widespread (Chapter Two). S Hospital organized the time, place, and roles of people in accordance with its own goals: efficiency (to treat as many patients as quickly, with the least amount of personnel as possible), prestige (to attract more patients from across the nation), profit (to earn as much as possible with as little investment as necessary), and hierarchy (as a top-down institution). In this organizational logic , the palliative and hospice care were marginalized within the hospital (Chapter Three).

The idea of a care plan—which embodies biomedicine's central philosophy—renders the terminal stage as a time of irreversibility and activates end-of-life care when there is no other available option to suggest to a patient. Yet, the activation of the terminal stage was not only often done too late, but its timing also did not square with the ways in which the patients and their families understood the terminal stage of cancer (Chapter Four). Upon being declared to have entered the terminal-stage, patients should be referred to another institution, but the palliative care staff's attempts to move terminal-stage patients to a better place for dying were often hampered and frustrated by the conditions that the dying body produces and by various regulations relating to death (Chapter Five). Through this long journey of struggling with cancer, a patient's family member was interpellated (Althusser 1970)—that is, became a new subject—as a *bohoja* in the terminal-cancer ward who took responsibility for the intensive capillary care labor including communicating on behalf of the patient with her doctors. This communicative pattern complicated the end-of-life care discussion (Chapter Six).

The values and conditions that the palliative care staff pursued for realizing good dying could not be formulated by using a monolithic scheme or a single principle. The palliative care team members tried to ensure that their patients had enough time—not too much yet not too little—to bid farewell to their relatives. Pain must be controlled. The place for dying was supposed to be a quiet and private one so that the dying and their family members could gather without interruption. The aggressive treatments should be stopped without appearing to abandon the patient. The terminal period should be a family event in which all (nuclear) family members interact and share their feelings together. The patients and their family members were supposed to untie the "knots" in their relationships so that they could move on and find some meanings from their lives. Decision-making by the patient was an important value for good dying; however, it did not override other conditions. Thus, the landscape of dying in the hospital consisted of various structures both inside and outside the hospital as well as heterogeneous values that emerged in contingent situations. And various actors—the doctors, nurses, social workers, administrative staff, volunteers, the patients and their family members—cooperated with one another to make a death good within the given medical bureaucracy.

In this closing chapter, I would like to answer two final questions: "How can we improve the quality of dying?" and "Ultimately, what does good dying mean?" The first question seeks more practical answers, whereas the second question explores a more fundamental nature of care, relationality, and death.

On the Future Direction of the Act

The Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and

Palliative Care or at the End of Life was an attempt to fix a part of this entanglement—that is, the meaningless suffering caused by heroic medical measures. Toward this goal, the Act officially legalized withdrawal of life-sustaining treatment if a patient had signed an AD or POLST, or, if the family members of the patient agreed. From the beginning of the demonstration projects, this Act received so much attention that the palliative care team was inundated with inquiries, which reflected the high demand for "death with dignity." According to the Ministry of Health and Welfare and KoNIBP, the number of people who signed the end-of-life care documents has constantly increased: a total of 430,457 people had signed their ADs and 31,661 people had signed their POLST by October 2019. In the period between April 2018 and February 2019, a total of 36,224 people withheld or withdrew their life-prolonging treatments and died. Among them, 32.3% decided on their own via POLST and AD, whereas 35.9% made this decision by unanimous agreement from the whole family, and 31.8% by statements of two or more family members.

Also, the Ministry of Health and Welfare and KoNIBP have received feedback from the medical practitioners and have tried to respond to their suggestions via diverse channels, including public hearings and reports from the demonstration projects. As a result, the Act was amended, and the amended Act has been in place since March 2019. In this revised version, the range of life-sustaining treatments has been extended to include extracorporeal life support (ECLS), transfusion, and vasopressor; the range of diseases has been extended; and the scope of family members who must participate in the unanimous agreement for stopping a patient's life-sustaining treatment has been reduced.

Table 1. The Revised Act

	The Original Act	**The Revised Act**
The scope of life-sustaining treatment (Article 2-4)	-Cardiopulmonary resuscitation -Hemodialysis -Anticancer drugs -Mechanical ventilation	-Extracorporeal life support (ECLS), transfusion, and vasopressor were added to the original four treatments.
The range of disease (Article 2-3)	-Cancer -Acquired immune deficiency syndrome (AIDS) -Chronic obstructive respiratory disease -Chronic liver cirrhosis -Any other disease prescribed by Ordinance of the Ministry of Health and Welfare	The Article 2-3 was deleted.
The scope of family member (Article 18)	-A spouse -Lineal descendants (children, grandchildren, ...) -Lineal ascendants (parents, grandparents, ...) -Siblings	-A spouse -Children -Parents -Siblings

Overall, I expect this revised Act will contribute to covering more patients and to reducing the number of relatives required to make end-of-life decisions.

Nevertheless, I would like to put forward some suggestions for the future direction of the Act. In the Introduction, I suggested that people let anthropologists intrude in and observe their daily lives because they also expect something from the anthropologists' stay. The doctors and nurses I worked with in S Hospital expected my work to contribute to improving hospital dying in Korea, and I am certain that one of their expectations was about the Act.

As I argued in Chapter Four, and as the practitioners who implement this Act in the clinical settings have also argued, the division between the terminal stage and the end-of-life stage in the Act is not effective. For example, Doctor Koh Yunsuk—who was involved in the legislation and had served as a chair of the ethics committee of one of the "big-five hospitals"—asserted that a patient oscillates between the terminal stage and the end-of-life process. In addition, he maintained, the assessment of the end-of-life process depends on who diagnoses in what hospital: if the patient is admitted in a large hospital, which has a capacity to provide the patient with intensive care, then the patient is not in the end-of-life process. Even, in the same case, different doctors can differently assess whether or not a patient has entered the end-of-life process.[97]

I would like to extend the appeal of the doctors and nurses regarding the ineffective division between the terminal stage and end-of-life process to an argument that the division between AD and POLST is not effective. As I have discussed, in the clinical setting, the two documents plus a DNR form are used in supplementary ways as the case may evolve. Fundamentally, the three documents all have only one aim: to express what a person would want to do in his final time in this world. Whether the person is healthy or sick at the moment of signing the paper, and whether a doctor or a patient signs it—these are only peripheral to the ultimate aim of the documents, and the separation of the three forms does not contribute to enhancing the quality of death. I cannot find any good reason that we should be confined to the

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[97] On Februrary 26, 2019, in the celebration for the anniversary of the implementation of the Act, the case that Doctor Koh presented was a male patient in his seventies with diabetes and its complications. He had received dialysis treatment. One day, he was admitted to the ER due to pneumonia and sepsis and was put on a mechanical ventilator three times in the ICU. He was in cardiac arrest during dialysis. Doctor Koh said that one third of his colleagues assessed him to be in the terminal stage while two thirds judged him to be in the end-of-life process.

paradigm that requires both an AD and a POLST. I propose to integrate these two forms into one and to let the patient and the doctor update the form when the person becomes critically ill. By doing so, we can concentrate our financial, temporal, and personnel resources on enhancing the quality of death in Korea.

Second, as I suggested in Chapter Six, the relevant national institutions should devise a way to facilitate *conversations* concerning the end of life. In my observation, there were many patients and their relatives who felt the necessity of earnest conversations concerning how to prepare for death and how to spend the last weeks and months. Yet, they did not know how to begin this kind of conversation with each other because this speech genre is not well recognized in Korea. There were also some patients who refused to talk about death and some *bohoja*s who refused to let the patient know a bad prognosis. However, as seen in Ms. Hahn and Ms. Shim's stories, the fundamental reason of the refusal was a fear of hurting each other and causing depression. That is, they refused to talk because they wanted to take emotional care of each other. The doctors were no exceptions. As seen in many previous studies and in my ethnographic scenes, the doctors also feel the burden of initiating an end-of-life care discussion and do not know how to communicate with their patients and their *bohoja*s. From this perspective, what we urgently need is to help the three stakeholders to talk with one another. We can consider ways of educating the three stakeholders and the introduction of communication facilitators in the clinical setting.

Third, the end-of-life care document must clearly express the values that the person wishes to guide her life and death. I recall the day of my fieldwork, during which I attended the monthly workshop for volunteers at which Nurse Lee and the visiting speaker gave lectures on what an AD was, and provided us with the opportunity to fill out an AD. It was an opportune chance to fill in my own AD without the inconvenience of visiting an institution, but I eventually decided not to complete the form.

The volunteers assumed I did not complete the form because I was too young to fill out such a document, but that was not the reason. I was thinking what I would want my family to do for me at my end-of-life time. The first thought I had was that I hate any pain. I am a very timid person to the extent that I ask first and foremost, “Does it hurt?” whenever doctors or nurses try to do something to me in hospitals. I sincerely do not want to go through any aggressive measures. The next thought that struck me was my daughter. In spite of my reluctance to endure any sort of pain, I would endure any suffering in order to be with my, at the time, newly born daughter. Third, nevertheless, if my lying in a hospital bed would be an obstacle (e.g., due to the medical expenses) in my daughter’s life, I would not want to do anything to prolong my life.

The three values I came up with on that day—avoiding pain, being with my daughter, and not being a burden to her—may or may not conflict with one another. Which value must be prioritized depends entirely on the circumstances of the actual event and, according to the circumstances, people around me can evaluate them accordingly. My values, as well as the values that the people who have appeared in my story sought out, were not something that could be reduced to one question, “Do you want to receive life-sustaining treatment?” In the future, the AD and POLST should contain the values a person prioritizes and the priority among the values if they conflict.

Fourth, the Act must allow a person to designate a proxy if the person wants to do so. As seen in Chapter Five, there are many cases in which the actual *bohoja* and the eligible legal agent for decision-making regarding life-sustaining treatment are not congruent. The needs of people to care and be cared for are real, and, as Borneman (2001) points out, this most fundamental need should not be subordinated to the principle of descent and affinity.

Finally, death absolutely belongs to a terrain of uncertainty. Reality is contingent. In addition, it involves (1) various medical institutions, the purpose and capacity of which is heterogeneous; (2) a variety of medical technologies and systems of knowledge, which continue to develop even as I write and you read; and (3) a variety of people belonging to the care network surrounding a person. We have already seen how complicated dying can be in the context of the hospital system (Chapter Three). During a meeting for the demonstration projects, Nurse Kim said, “We cannot live only with law!” Yes, a law cannot take into consideration everything in this entwined complex of people-technology-institutions-and temporal thinking. As Doctor Heo Daeseog has claimed, the Act must not be a law for regulations but a declaratory law. Law should let us remain open to exceptions and idiosyncrasies because death is not something that can be tamed and managed by regulations and rules.

Ultimately, What Constitutes Good Dying and Good End-of-life Care?

What threads through this dissertation is relationality. In order to grasp how proper relationship, familial obligation, and connection center on both care and death, I have proposed a concept of relational-generative care. First, this relational-generative care reflects the fact that the family relationship is essential to good dying. The primary concern of the palliative care staff is to configure the temporal, spatial, and technological conditions that allow patients to be with their family members. In addition to the pragmatic reason that *bohoja*'s care labor directly impacts on the quality of a patient's well-being, the presence of relatives is also crucial because dying and death should be a family event. Family members can strengthen the solidarity of kinship by sharing grief, by expressing love and gratitude, and by untying the "knots" in their relationships. Death is not only an individual opportunity to complete one's life in meaningful ways, but it also is a collective chance to realize familial intimacy. The dying body signifies the fact that we are biological beings with a finite lifetime and corporeal flesh. Nonetheless, the intimate family relationship is a terrain in which the dying person's past is imprinted on family members' lives and the dying person will be remembered in the future within the relatives' remembrance. The biological being can thus be transformed into a historical one that is inscribed within the relationality of one's relatives.

Second, the series of processes through which the patient's family members are positioned as *bohoja*s and carry out capillary care labor leads us to rethink the relation between being kin and doing kin (McKinnon 2016). If we understand being kin as something that is essentially given to us (e.g., by nature or biology) and doing kin as something we create through practice, the ethnographic scenes I have presented suggest a way to understand the dynamics between being kin and doing kin. The palliative care nurses request that *bohoja*(s) take care of the dying patient because they *are* the family members of this patient. In other words, caring for the dying is like a categorical imperative that is assumed to be naturally embedded within the given relationship. From this perspective: you are kin, therefore, you take care of her. However, being kin, in itself, is not sufficient to be a good *bohoja*. Rather, the palliative care team members assess whether a family member of the patient can properly fulfill the role of *bohoja* by observing her care practices, including accompanying, substituting, communicating, and decision-making. From this perspective: you take care of her, therefore you are kin. The processual care labor that the *bohoja*s perform and their relatedness are mutually constructed and mutually prove each other. Care is, on the one hand, an obligation of kinship and, on the other hand, evidence of kinship.

Meanwhile, relational-generative care offers a way of understanding the seemingly trivial care that the palliative care team members carry out. At a conference where I presented a part of my research, a discussant asked, “Nowadays I feel like care, as a theoretical concept, has lost its analytical power and has become an empty concept. Can it be care if the “care-recipient” does not consider it as care or does not want to receive this kind of care?” Her comment haunted me whilst writing this dissertation. She has not yet published any work developing her critique of the validity of care as a conceptual tool, and there is no way for me to understand it until she does. Yet, her comment resonated with me because that was the very problem pestering me during my fieldwork.

Indeed, at times, I wondered what our actions—such as washing a patient’s hair or providing a massage—meant, and to whom. These practices could not dramatically change the circumstances in which the dying patients and their family members were suffering. These acts of care might refresh a patient for a brief time and give her *bohoja* a brief break, but we were unable to unburden them of the bodily pain and the sense of being emotionally overwhelmed that is so much a part of the dying process. Nor could our work fundamentally challenge the nature of hospital dying. Many parts of what the team struggled with—for instance, making a list of potential hospices and making phone calls to secure an available bed for their patients—were subordinated to and benefitted the hospital structure. I never doubted the sincerity of the palliative care staff,[98] but I wondered if these small actions were merely for our self-satisfaction, convincing us that we had helped others, making us good people.

However, as I have argued in this dissertation, these small actions break through the multi-layered limitations of the structures both inside and outside the hospital. This "triviality" encapsulates the essence of care. In a broad sense, my argument pertains to discussions in the social sciences regarding the relation between structure and agency. We articulate and navigate what we hope to achieve within a structure, which is beyond our everyday recognition and awareness. We can exert our power of agency, but the scope of agency is limited by the macro- and micro-structure, as was the case for the palliative care team members. In the end, I argue that it is *care* that emerges when we are intent on finding ways to make a suffering person feel better within a context constrained by unchangeable limitations and restrictions. If the palliative care nurses could change the systemically organized way of hospital dying, it would be a revolution, not care. It was care because the palliative care team members were attentive to the individual

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[98] I assume that some Korean readers of my dissertation will be surprised because the doctors and nurses in my story do not follow the prevailing stereotype of doctors and nurses in Korea. One may wonder whether I have romanticized what the palliative care team staff did by portraying them as heroines and heroes, but I just wrote what I had observed, heard, and felt during my fieldwork.

patients, tried to understand diverse values and goals of the patients and their family members, and tinkered with the conditions by which they were confined as hospital employees and the state-governed medical professionals. From this perspective, care is an embodied action of human agency.

Most of all, the trivial actions of the palliative care team members are generative of new relations. Lingis (1994), in *The Community of Those Who Have Nothing in Common*, contemplates what dying means. To him, the living never understand the dying's words; the living never exchange anything with the dying; the dying is beyond any mutual commitment. Thus, the dying are ultimate Others. The imminent death is an "incomprehendable, unnegatable, unconfrontable, and unpostponable" event (Lingis 1994:174). Death is an event beyond any human capacity to stop and beyond our human languages. Nevertheless, as Lingis argues, we take care of the dying because we all share the fate of death.

In face of this condition, the ultimate mission of our small and trivial actions is to create relatedness (Carsten 2000). As Nurse Kim remarked, "We are supposed to become family to them." The palliative care staff conveys sympathy and companionship as mortal beings through seemingly insignificant acts: giving a hug, asking after the patient and the *bohoja*, listening, singing and praying together, making a phone call, or organizing a self-help group. Through these actions, the dying patients and their family members become connected to the nurses and volunteers, both emotionally and physically; they realize the broader relatedness within the local community and the entire society due to their surroundings during their moment of suffering. In the end, this realization of relatedness takes care of all of us.

Every time a patient passed away, I, and we, grieved for both the dying and their loved ones. When there is no medication or comfort that helps the suffering to escape from the suffering, as Lingis (1994: 179) argues, grieving is the last thing we can do for others. We did what we did for the patients, for the family members of the patients, for ourselves, and for humans. I often think of Nurse Kim's deep warm voice, Nurse Heo's smile, the volunteer Ms. Park's touching, and Mr. Kim's singing. I believe that these trivial gestures and attentions are the last, yet the best, thing a humble person can do for another vulnerable person in facing an existential crisis.

Bibliography

Agamben, Giorgio. 1998. *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford University Press.

Ahn, Eunmi, et al. 2013. "The Impact of Awareness of Terminal Illness on Quality of Death and Care Decision Making: A Prospective Nationwide Survey of Bereaved Family Members of Advanced Cancer Patients." *Psychooncology* 22(12): 2771-2778.

Althusser, Louis. 1971. "Ideology and Ideological State Apparatuses." *Lenin and Philosophy and Other Essays* 1971: 121-176.

Ariès, Philippe 2004[1985]. Images de l'homme devant la mort. Translated by Sunil Koh. Seoul: Saemulgyeol.

Ariès, Philippe. 2016[1974]. *Western Attitudes Towvard Death from the Middle Ages to the Present*. Baltimore: Johns Hopkins Press.

Armstrong, David. 1987. "Silence and Truth in Death and Dying." *Social Science and Medicine* 24(8): 651-657.

Aulino, Felicity. 2016. "Rituals of Care for the Elderly in Northern Thailand: Merit, Morality, and the Everyday of Long-Term Care." *American Ethnologist* 43(1): 91-102.

Bae, Doyong. 2018. "A Study on the Aspects of the Lexical Realization of the Four Attitudes fronting Death in the Sino-Korean (I): Focusing on Our Death and Own Death." *Urimal* 54: 37-64.

Barnes, Marian. 2012. *Care in Everyday Life: An Ethic of Care in Practice*. Bristol: Policy Press.

Beauchamp, Tom L., and James F. Childress. 2001. *Principles of Biomedical Ethics*. Oxford: Oxford University Press.

Biancofiore, Gianni, et al. 2005. "Stress-Inducing Factors in ICUs: What Liver Transplant Recipients Experience and What Caregivers Perceive." *Liver Transplantation* 11(8): 967-972.

Blackhall, Leslie J., et al. 1995. "Ethnicity and Attitudes toward Patient Autonomy." *The Journal of the American Medical Association* 274(10): 820-825.

Blackhall, Leslie J., et al. 2001. "Bioethics in a Different Tongue: The Case of Truth-Telling." *Journal of Urban Health* 78: 59–71.

Blauner, Robert. 1966. "Death and Social Structure." *Psychiatry* 29(4): 378-394.

Bloch, Maurice, and Jonathan Parry. Eds. 1982. *Death and the Regeneration of Life*. New York: Cambridge University Press.

Bloch, Maurice, and Jonathan Parry. 1982. “Introduction: Death and the Regeneration of Life.” In *Death and the Regeneration of Life*. Maurice Bloch, and Jonathan Parry. Eds. Pp. 1-44. New York: Cambridge University Press.

Borneman, John. 2001. “Caring and Being Cared for: Displacing Marriage, Kinship, Gender, and Sexuality.” In *The Ethics of Kinship: Ethnographic Inquiries.* James Faubion. Ed. Pp. 29-46. Lanham: Rowman & Littlefield Publishers.

Brannigan, Michael C. 1999. “Relationality and Consensus in Japan: Implications for Bioethics Policy.” *Health Care Analysis* 7(3): 289-296.

Briggs, Charles L., and Clara Mantini-Briggs. 2016. *Tell Me Why My Children Died: Rabies, Indigenous Knowledge, and Communicative Justice*. Durham: Duke University Press.

Broad, Joanna B., et al. 2013. “Where Do People Die? An International Comparison of the Percentage of Deaths Occurring in Hospital and Residential Aged Care Settings in 45 Populations, Using Published and Available Statistics.” *International Journal of Public Health* 58(2): 257-267.

Bruera, Eduardo, and David Hui. 2010. “Integrating Supportive and Palliative Care in the Trajectory of Cancer: Establishing Goals and Models of Care.” *Journal of Clinical Oncology* 28(25): 4013-4017.

Burns, Jeffrey P., and Robert D. Truog. 2016. “The DNR Order after 40 Years.” *The New England Journal of Medicine* 375(6): 504-506.

Carsten, Janet. 2000. “Introduction: Cultures of Relatedness.” In *Cultures of Relatedness: New Approaches to the Study of Kinship*. Janet Carsten. Ed. Pp. 1-36. Cambridge: Cambridge University Press.

Cátedra, María. 1992[1988]. *This World, Other Worlds: Sickness, Suicide, Death, and the Afterlife among the Vaqueiros de Alzada of Spain*. Translated by William A. Christian Jr. Chicago: University of Chicago Press.

Chambliss, Daniel F. 1996. *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics*. Chicago: University of Chicago Press.

Chang, Kyung-Sup. 1998. “Compressed Modernity and Complex Risk Society.” Comparative Sociology 1998: 371-414.

Chapple, Helen Stanton. 2010. *No Place for Dying: Hospitals and the Ideology of Rescue*. Walnut Creek: Left Coast Press.

Choi, Gilsung. 2010. *한국인의 조상숭배와 효* [*Ancestor Worship and Filial Duty of Koreans*]. Seoul: Minsokwon.

Choi, Kyungsuk. 2016. “Legal and Ethical Issues Regarding End-of-Life Care in Korea.” *Development and Society* 45(1): 151-164.

Christakis, Nicholas A. 1999. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago: The University of Chicago Press.

Clark, David. 2007. “From Margins to Centre: A Review of the History of Palliative Care in Cancer.” *Lancet Oncology* 8(5): 430–38.

Collier, Jane Fishburne, and Sylvia Junko Yanagisako. Eds. 1987. *Gender and kinship: Essays toward a Unified Analysis*. Stanford: Stanford University Press.

Counts, Dorothy Ayers, and David Counts. 2004. “The Good, the Bad, and the Unresolved Death in Kaliai.” *Social Science and Medicine* 58(5): 887-897.

DiMoia, John P. 2014.”Making Death “Modern”: Reevaluating the Patient’s Body, Transforming Medical Practice, and Reforming Public Health at Seoul National University Hospital, 1957-1977.” In *Death, Mourning, and the Afterlife in Korea: Ancient To Contemporary Times*. Charlotte Horlyck, and Michael J. Pettid. Eds. Pp. 57-82. Honolulu: University of Hawaii Press.

Douglas, Mary. 2003[1966]. *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*. New York: Routledge.

Elias, Norbert. 1999. *문명화과정* 1[*Process of Civiliation* 1], Translated by Miae Park. Seoul: Hangilsa.

Engelke, Matthew. 2019. “The Anthropology of Death Revisited.” *Annual Review of Anthropology* 48: 29-44.

Field, David. 1996. “Awareness and Modern Dying.” *Mortality* 1(3): 255-265.

Foucault, Michel. 2007. *Security, Territory, Population: Lectures at the Collège de France, 1977-78*. New York: Springer.

Foucault, Michel. 2012[1978]. *Discipline and Punish: The Birth of the Prison*. New York: Vintage Books.

Frank, Arthur W. 2013. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Franklin, Sarah, and Helena Ragoné. Eds. 1988. *Reproducing Reproduction: Kinship, Power, and Technological Innovation*. Philadelphia: University of Pennsylvania Press.

Frazer, James George. 1990. *The Golden Bough*. London: Palgrave Macmillan.

Glare, Paul, et al. 2003. “A Systematic Review of Physicians’ Survival Predictions in Terminally Ill Cancer Patients.” *BMJ* 327(7408): 195. https://www.bmj.com/content/327/7408/195

Glaser, Barney G., and Anselm Leonard Strauss. 1965. Awareness of Dying. New York: Aldine.

Glaser, Barney G., and Anselm Leonard Strauss. 2007[1968]. *Time for Dying*. Chicago: Aldine.

Good, Mary-Jo DelVecchio, et al. 2004. “Narrative Nuances on Good and Bad Deaths: Internists’ Tales from High-Technology Work Places.” *Social Science and Medicine* 58(5): 939-953.

Goodwin-Hawkins, Bryonny, and Andrew Dawson. 2018. “Life’s End: Ethnographic Perspectives.” *Death Studies* 42(5): 269-274.

Hadders, Hans. 2009. “Enacting Death in the Intensive Care Unit: Medical Technology and the Multiple Ontologies of Death.” *Health* 13(6): 571-587.

Hardwig, John. 1990. “What about the Family?” *Hastings Center Report* 20(2): 5-10.

Hattori, Kenji, and Takao Ito. 2016[2015]. *의료윤리학의 이론과 실제* [*Theory and Practice of Medical Ethics*]. Translated by Dokyung Kim, and Jung Shinhee. Seoul: Rhodos Publishing.

Heo, Dae Seog. 2004. “회생가능성이 불투명한 환자의 치료중단: 보라매병원사건의 확정 판결에 대한 의료인의 입장 [“Treatment Cessation of Irreversible Patient: Perspectives of Medical Community on the Boramae Hospital Case”]. *Korean Hospital Association* 33(9): 14-17.

Hertz, Robert. 1960. *Death and the Right Hand*. Translated by R. Needham, and C. Needham. London: Cohen and West.

Higginson, Irene J., and G. J. A. Sen-Gupta. 2000. “Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences.” *Journal of Palliative Medicine* 3(3): 287-300.

Hirsch, Harold L,. and Richard E. Donovan. 1976. “The Right to Die: Medico-Legal Implications of *in re Quinlan*.” *Rutgers Law Review* 30: 267-303.

Hong, Impyo. 2017. *Study on Architectural Design Elements and Space Hierarchy of Hospice Unit in General Hospital*. MA Thesis. Hanyang University.

Hong, Min Joo, Young Sook Tae, and Mi Young·Noh. 2012. “Relationships between Stress, Ways of Coping and Burnout of Family Caregivers of Cancer Patient.” *Asian Oncology Nursing* 12(1): 92-99.

Hu, Youn Jung. 2013. *Development of a Protocol for Advanced Nursing Practicein Consultation-Based Hospice and Palliative Care*. MA Thesis. Yonsei University.

Jee, Eunsook. 2017. “The Change of Singlehood and the Duties of Unmarried Daughters: A Case Study on Daughters` Taking Care of Parents in Japan.” *Korean Cultural Anthropology* 50(2): 189-235.

Johnson, Nancy, Deborah Cook, Mita Giacomini, and Dennis Willms. 2000. “Towards a ‘Good’

Death: End-of-Life Narratives Constructed in an Intensive Care Unit." *Culture, Medicine and Psychiatry* 24(3): 275-295.

Julier, Alice P. 2013. *Eating Together: Food, Friendship and Inequality*. Champaign: University of Illinois Press.

Jung, Hyo-Sung. 2008. "Current Practices of the Ceasing Medical Treatment for Euthanasia and its Solutions." *Law and Medicine* 9(1): 461-503.

Kang, Hyun-Hee, et al. 2008. "Direction of the law and policy involved in futile medical treatment." *Korean Journal of Medicine and Law* 16(1): 53-76.

Kang, Jiyeon. 2012. "'Natural Pregnancy' in Fertility Clinic: The Rhetoric For Constituting Boundary Between Nature and Culture." *Cross Cultural Studies* 18(2): 53-95.

Kaufman, Sharon R. 2005. *And a Time to Die: How American Hospitals Shape the End of Life*. New York: Simon and Schuster.

Kaufman, Sharon R. 2015. *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Line*. Durham: Duke University Press.

Kaufman, Sharon R., and Lynn M. Morgan. 2005. "The Anthropology of the Beginnings and Ends of Life." *Annual Review of Anthropology* 34: 317-341.

Kellehear, Allan. 2007. *A Social History of Dying*. New York: Cambridge University Press.

Kellehear, Allan, Edwin Pugh, and Lynda Atter. 2009. "Home Away from Home? A Case Study of Bedside Objects in a Hospice." *International Journal of Palliative Nursing* 15(3): 148-152.

Kim, Chang Gon. 2017. "Hospice and Palliative Care Policy in Korea." *The Korean Journal of Hospice and Palliative Care* 20(1): 8-17.

Kim, Do Yeun, et al. 2007. "Do-not-resuscitate Orders for Terminal Patients with Cancer in Teaching Hospitals of Korea." *Journal of Palliative Medicine* 10(5): 1153-1158.

Kim, Heekyeong. 2017. *이상한 정상가족: 자율적 개인과 열린 공동체를 그리며* [*Unusual Normal Family*]. Seoul: East Asia.

Kim, Heekyoung. 2018. "'When I Die': Biopolitics and the Ethics of Dying in the Super–aging Japanese Society." *Korean Cultural Anthropology* 51(2): 59-94.

Kim, Hye-Lim, et al. 2017. "Cancer Care Costs at the End of Life." *The Korean Journal of Health Economics and Policy* 23(1): 123-142.

Kim, Hyoung Suk, Kyung Ja June, and Young Sun Son. 2016. "Home-based Hospice Care Provided by a Free-Standing Hospice Center: Patients' Characteristics and Service Conditions." *The Korean Journal of Hospice and Palliative Care* 19(2): 145-153.

Kim, Jieun. 2016. “Necrosociality: Isolated Death and Unclaimed Cremains in Japan.” *Journal of the Royal Anthropological Institute* 22(4): 843-863.

Kim, Yun Hee, et al. 2015. “Family Caregivers’ Quality of Life, Depression and Anxiety according to Symptom Control in Hospice Patients.” *Korean Journal of Hospice and Palliative Care* 18(4): 314-321.

Kleinman, Arthur, and Sjaak Van Der Geest. 2009. “‘Care’ in Health Care: Remaking the Moral World of Medicine.” *Medische Antropologie* 21(1): 159-168.

Korea National Institute for Bioethics Policy. 2018. *White Paper: Legislation of End-of-Life Decision-Making*. http://www.nibp.kr/xe/act2_1/138754.

Kübler-Ross, E. 1969. *On Death and Dying*. New York: Macmillan.

Kwak, Jung, and William E. Haley. 2005. “Current Research Findings on End-of-Life Decision Making among Racially or Ethnically Diverse Groups.” *The Gerontologist* 45(5): 634-641.

Kwon, Ivo, et al. 2015. “End-of-Life Decisions: A Survey of the Perspectives of People in Korea, China, and Japan.” *Acta Bioethica* 21(2): 173-182.

Kwon, Soonman. 2003. “Payment System Reform for Health Care Providers in Korea.” *Health Policy and Planning* 18(1): 84-92.

Kwon, Soonman. 2009. “Thirty Years of National Health Insurance in South Korea: Lessons for Achieving Universal Health Care Coverage.” *Health Policy and Planning* 24(1): 63-71.

Kyung, Min-Ho, et al. 2010. “Current Status and Activation Plan of Hospice Palliative Care in Korea—Based on Hospice Palliative Care Facilities Survey.” *The Korean Journal of Hospice and Palliative Care* 13(3): 143-152.

Lawton, Julia. 2002. *The Dying Process: Patients’ Experiences of Palliative Care*. London: Routledge.

Lazarus, Ellen S. 1988. “Theoretical Considerations for the Study of the Doctor-Patient Relationship: Implications of a Perinatal Study.” *Medical Anthropology Quarterly* 2(1): 34-58.

Lee, Dojung. 2015. *The Reform of the Space of the Dead, and Its Implication: The Case of the Chiljeon-ri, Uisin- myeon, Jindo-Gun, Jeollanam-do*. MA Thesis. Seoul National University.

Lee, Jee Hye, et al. 2016. “Factors Associated with Care Burden among Family Caregivers of Terminally Ill Cancer Patients.” *Korean Journal of Hospice and Palliative Care* 19(1): 61-69.

Lee, Ki-Byung. 2020. *The Stigmatized Care of Korean-Chinese Caregivers and Biopolitics in a Convalescent Hospital*. MA Thesis. Seoul National University.

Lee, Sang-Yi, et al. 2008. “The National Health Insurance System as One Type of New

Typology: The Case of South Korea and Taiwan." *Health Policy* 85(1): 105-113.

Lee, Seok-bae. 2017. "Issues and Tasks of the sog. Well-Dying Act." *Kookmin Law Review* 29(3): 311-340.

Lessard, Sabrina, Bernard-Simon Leclerc, and Suzanne Mongeau. 2016. "Family Caregivers' Social Representations of Death in a Palliative Care Context." *SAGE Open* 6(1): 1-9.

Lin, Heng-Yi, et al. 2017. "Place of Death for Hospice-Cared Terminal Patients with Cancer: A Nationwide Retrospective Study in Taiwan." *Journal of the Chinese Medical Association* 80(4): 227-232.

Lingis, Alphonso. 1994. *The Community of Those Who Have Nothing in Common*. Bloomington: Indiana University Press.

Livingston, Julie. 2012. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. Durham: Duke University Press.

Lock, Margaret M. 2002. *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.

Long, Susan Orpett. 2013. "Dying in Japan: Into the Hospital and out Again?" In *Death and Dying in Contemporary Japan*. Hikaru Suzuki. Ed. Pp. 49-63. New York: Routledge.

Malinowski, Bronislaw. 1948. *Magic Science and Religion*. London: Faber and West.

Maltoni, Marco, et al. 2005. "Prognostic Factors in Advanced Cancer Patients: Evidence-Based Clinical Recommendations—A Study by the Steering Committee of the European Association for Palliative Care." *Journal of Clinical Oncology* 23(25): 6240-6248.

Manson, Neil C., and Onora O'Neill. 2007. *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press.

Marsh, Frank H., and Allen Staver. 1991. "Physician Authority for Unilateral DNR Orders." *Journal of Legal Medicine* 12(2): 115-165.

Martin, Emily. 1988. "Gender and Ideological Differences in Representations of Life and Death." In *Death Ritual in Late Imperial and Modern China.* Watson, James L., James L. Watson, and Evelyn Sakakida Rawski. Eds. Pp. 164-179. Berkeley: University of California Press.

McKinnon, Susan. 2016. "Doing and Being: Process, Essence, and Hierarchy in Making Kin." In *The Routledge Companion to Contemporary Anthropology.* Simon Coleman, Susan Brin Hyatt, and Ann E. Kingsolver. Eds. Pp. 177-198. New York: Routledge.

McNamara, Beverley. 2004. "Good Enough Death: Autonomy and Choice in Australian Palliative Care." *Social Science and Medicine* 58(5): 929-938.

Min Deulle, and Cho Eunhee. 2017. “Concept Analysis of Good Death in the Korean Community.” *Journal of Korean Gerontology Nursing* 19(1): 28-38.

Mizrahi, Terry. 1985. “Getting Rid of Patients: Contradictions in the Socialisation of Internists to the Doctor-Patient Relationship.” *Sociology of Health and Illness* 7(2): 214-235.

Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice*. New York: Routledge.

Mol, Annemarie, Ingunn Moser, and Jeannette Pols. Eds. 2010. *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Bielefeld: Transcript Verlag.

Moon, Jae Young, et al. “Medical Residents’ Perception and Emotional Stress on Withdrawing Life-Sustaining Therapy.” *Acute and Critical Care* 27(1): 16-23.

Navne, Laura E., and Mette N. Svendsen. 2018. “A Clinical Careography: Steering Life-and-Death Decisions through Care.” *Pediatrics* 142(Supplement 1): S558-S566.

Novaes, M. A., et al. 1999. “Stressors in ICU: Perception of the Patient, Relatives and Health Care Team.” *Intensive Care Medicine* 25(12): 1421-1426.

Olson, Philip R. 2018. “Domesticating Deathcare: The Women of the U.S. Natural Deathcare Movement.” *Journal of Medical Humanities* 39(2): 195-215.

Palgi, Phyllis, and Henry Abramovitch. 1984. “Death: A Cross-cultural Perspective.” *Annual Review of Anthropology* 13(1): 385-417.

Pargeon, Kimberly L., and B. Jo Hailey. 1999. “Barriers to Effective Cancer Pain Management: A Review of the Literature.” *Journal of Pain and Symptom Management* 18(5): 358-368.

Plugge, Herbert. 2017. *아픔에 대하여* [*On Suffering*]. Seoul: DolBegae.

Phua, Jason, et al. 2015. “Withholding and Withdrawal of Life-Sustaining Treatments in Intensive Care Units in Asia.” *The Journal of the American Medical Association Internal Medicine* 175(3): 363-371.

Ratzer, Mette, et al. 2014. “Posttraumatic Stress in Intensive Care Unit Survivors: A Prospective Study.” *Health Psychology and Behavioural Medicine* 2(1): 882-898.

Rhodes, Lorna A. 1991. *Emptying Beds: The Work of an Emergency Psychiatric Unit*. Berkeley: University of California Press.

Robben, Antonius C. G. M. 2004. “Death and Anthropology: An Introduction.” In *Death, Mourning, and Burial: A Cross-Cultural Reader*. Antonius C. G. M. Robben. Ed. Pp. 1-16. Oxford: Wiley Blackwell.

Rosenblatt, Paul C. 2001. “A Social Constructionist Perspective on Cultural Differences in

Grief.” In *Handbook of Bereavement Research: Consequences, Coping, and Care*. M. S. Stroebe, R. O. Hansson, W. Stroebe, and H. Schut. Eds. Pp. 285–300. Washington, D.C.:American Psychological Association.

Rubinstein, Robert L. 1995. “Narratives of Elder Parental Death: A Structural and Cultural Analysis.” *Medical Anthropology Quarterly* 9(2): 257-276.

Sasahara, Tomoyo, et al. 2009. “Development of a Standard for Hospital-Based Palliative Care Consultation Teams Using a Modified Delphi Method.” *Journal of Pain and Symptom Management* 38(4): 496-504.

Saunders, Cicely. 1965. “The Last Stages of Life.” *American Journal of Nursing* 65: 1-3.

Sayer, Andrew. 2011. *Why Things Matter to People: Social Science, Values and Ethical Life*. Cambridge: Cambridge University Press.

Scherz, China. 2017. “Seeking the Wounds of the Gift: Recipient Agency in Catholic Charity and Kiganda Patronage.” In *The Request and the Gift in Religious and Humanitarian Endeavors*. Frederick Klaits. Ed. Pp. 47-64. New York City: Springer.

Seale, Clive, and Sjaak Van der Geest. 2004. “Good and Bad Death: Introduction.” *Social Science and Medicine* 58: 883-885.

Seo, Minjeong. 2015. *An Ethnography of End-of-life Decision Making In Cancer Patients*. PhD dissertation. Yonsei University.

Seymour, Jane, et al. 2007. “Hospice or Home? Expectations of End-of-Life Care Among White and Chinese Older People in the UK.” *Sociology of Health and Illness* 29(6): 872-890.

Shepherd, John R. 2011. “Trends in Mortality and Causes of Death in Japanese Colonial Period Taiwan.” In *Death at the Opposite Ends of the Eurasian Continent: Mortality Trends in Taiwan and the Netherlands 1850-1945*. Theo Engelen, John R. Shepherd, and Yang Wen-shan. Eds. Pp. 45-79. Amsterdam: Amsterdam University Press.

Skalski, Carole Ann, Louisa DiGerolamo, and Eileen Gigliotti. 2006. “Stressors in Five Client Populations: Neuman Systems Model-Based Literature Review.” *Journal of Advanced Nursing* 56(1): 69-78.

Slomka, Jacquelyn. 1992. “The Negotiation of Death: Clinical Decision Making at the End of Life.” *Social Science and Medicine* 35(3): 251-259.

Son, Mia, et al. 2009. *여성노동자의 노동권과 건강권: 간병·요양 노동자를 중심으로]. 민주노총 정책연구원 연구보고서*. [*The Right to Work and the Right to Health of Female Workers: Caregivers’ Cases*]. The Korean Confederation of Trade Unions. [.

Song, Hyeon-Dong. 2005. “Attitudes on Death in Korea: Centering around the Landscapes of

Death." *Cross-Cultural Studies* 11(2): 207-243.

Sepúlveda, Cecilia, et al. 2002. "Palliative Care: The World Health Organization's Global Perspective." *Journal of Pain and Symptom Management* 24(2): 91-96.

Stevens, M. L. Tina. 1996. "The Quinlan Case Revisited: A History of the Cultural Politics of Medicine and the Law." *Journal of Health Politics, Policy and Law* 21(2): 347-366.

Stonington, Scott D. 2012. "On Ethical Locations: The Good Death in Thailand, Where Ethics Sit in Places." *Social Science and Medicine* 75(5): 836-844.

Stirrat, Gordon M., and Robin Gill. 2005. "Autonomy in Medical Ethics after O'Neill." *Journal of Medical Ethics* 31(3): 127-130.

Strathern, Marilyn. 1992. *Reproducing the Future: Essays on Anthropology, Kinship and the New Reproductive Technologies*. Manchester: Manchester University Press.

Street, Alice. 2014. *Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinean Hospital*. Durham: Duke University Press.

Street, Alice, and Simon Coleman. 2012. "Introduction: Real and Imagined Spaces." *Space and* Culture 15(1): 4-17.

Svendsen, Mette N., et al. 2018. "A Life Worth Living: Temporality, Care, and Personhood in the Danish Welfare State." *American Ethnologist* 45(1): 20-33.

Taussig, Michael. 1980. "Reification and the Consciousness of the Patient." *Social Science and Medicine* 14B: 3-13.

Thompson, Charis. 2005. *Making Parents: The Ontological Choreography of Reproductive Technologies*. Cambridge: MIT press.

Ticktin, Miriam I. 2011. *Casualties of Care: Immigration and the Politics of Humanitarianism in France*. Berkeley: University of California Press.

Van Gennep, Arnold. 2013[1960]. *The Rites of Passage*. New York: Routledge.

Walter, Tony. 2003. "Historical and Cultural Variants on the Good Death." *BMJ* 327(7408): 218-220.

Wilson, Godfrey. 1939. "Nyakyusa Conventions of Burial." *Bantu Studies* 13(1): 1-31.

Winance, Myriam. 2010. Care and Disability: Practices of Experimenting, Tinkering with, and Arranging People and Technical Aids. In *Care in Practice: On Tinkering in Clinics, Homes and Farms*. Annemarie Mol, Ingunn Moser, and Jeannette Pols. Eds. Pp. 93-117. Bielefeld: Transcript Verlag.

Yoon, Hyun Kouk, et al. 2001. "Factors Associated with the Place of Death in Korea: a Population Based Study." *Journal of the Korean Academy of Family Medicine* 22(7): 1077-1085.

Yun Young Ho, et al. 2004. "Public Attitudes Toward Dying with Dignity and Hospice·Palliative Care." *The Korean Journal of Hospice and Palliative Care* 7: 17-28.

Zigon, Jarrett. 2011. "*HIV is God's Blessing": Rehabilitating Morality in Neoliberal Russia*. Berkeley: University of California Press.

Zola, Irving Kenneth. 1985. "Structural Constraints in the Doctor-Patient Relationship: The Case of Noncompliance." In *The Relevance of Social Science for Medicine*. Leon Eisenberg, and Arthur Kleinman. Eds. Pp. 241-252. Dordrecht: Reidel Publishing.

Appendix

ACT ON DECISIONS ON LIFE-SUSTAINING TREATMENT FOR PATIENTS IN HOSPICE AND PALLIATIVE CARE OR AT THE END OF LIFE

[Enforcement Date 04. Aug, 2017.] [Act No.14013, 03. Feb, 2016., New Enactment]

보건복지부(생명윤리정책과 - 연명의료결정) 044-202-2942

보건복지부(질병정책과-호스피스 완화의료) 044-202-2517

CHAPTER I GENERAL PROVISIONS

Article 1 (Purpose) The purpose of this Act is to prescribe matters necessary for hospice and palliative care and life-sustaining treatment for patients at the end of life, determination to terminate, etc., such life-sustaining treatment, and the implementation thereof, and thereby to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination.

Article 2 (Definitions) The definitions of terms used in this Act are as follows:

1. The term "end-of-life process" means a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly;
2. The term "patient at the end of life" means a person who has received a medical prognosis under Article 16, from the doctor in charge and one medical specialist in the relevant field that he/she is in the end-of-life process;
3. The term "terminal patient" means a patient who has been diagnosed as expected to die within a

few months from the doctor in charge and one medical specialist in the relevant field in accordance with the procedures and guidelines prescribed by Ordinance of the Ministry of Health and Welfare, because there is no possibility of a fundamental recovery, and the symptoms gradually worsen despite proactive treatment of any of the following diseases:

(a) Cancer;

(b) Acquired immune deficiency syndrome (AIDS);

(c) Chronic obstructive respiratory disease;

(d) Chronic liver cirrhosis;

(e) Any other disease prescribed by Ordinance of the Ministry of Health and Welfare;

4. The term "life-sustaining treatment" means medical treatment by cardiopulmonary resuscitation, hemodialysis, administering anticancer drugs, and mechanical ventilation to a patient at the end of life, which merely extend the duration of the end-of-life process without curative effect;

5. The term "determination to terminate, etc., life-sustaining treatment" means a decision made to withhold life-sustaining treatment, or to terminate it for a patient at the end of life;

6. The term "hospice and palliative care" (hereinafter referred to as "hospice care") means the medical care provided to a terminal patient or patient at the end of life (hereinafter referred to as "terminal patient, etc.") and his/her family for the purpose of comprehensively evaluating and providing treatment in physical, psychosocial and spiritual domains, including pain and symptom relief;

7. The term "doctor in charge" is a doctor under the Medical Service Act who directly treats a terminal patient, etc.;

8. The term "life-sustaining treatment plan" means a written plan prepared by a doctor in charge for the matters concerning the determination to terminate, etc., life-sustaining treatment and hospice care for a patient according to the intention of a terminal patient, etc.;

9. The term "advance statement on life-sustaining treatment" means a written statement prepared by a person aged at least 19 on his/her own determination to terminate, etc., life-sustaining treatment and hospice care.

Article 3 (Basic Principles) (1) All activities concerning hospice care, life-sustaining treatment, and determination to terminate, etc., life-sustaining treatment shall not infringe on the human dignity and value of patients.

(2) Every patient has the right to receive the best treatment and clearly know about the status and prognosis of the injury or disease he/she suffers and the subsequent medical services, and to make decisions for himself/herself thereon.

(3) Each medical person under the Medical Service Act (hereinafter referred to as "medical person") shall provide patients with the best treatment, explain hospice, palliative care, and determination to terminate, etc., life-sustaining treatment, accurately and in detail, and shall respect the patient's decision made based thereon.

Article 4 (Relationship to other Acts) This Act shall take precedence over other Acts with respect to hospice, palliative care, and determination to terminate, etc., life-sustaining treatment, and the implementation thereof.

Article 5 (Obligations of the State and Local Governments) (1) The State and local governments shall strive to establish social and cultural foundations that protect dignity and value of patients as human beings.

(2) The State and local governments shall give priority to formulating policies necessary to establish a foundation for using hospice care to protect patients' best interests.

Article 6 (Designation of Hospice Day) (1) In order to give wider publicity to the meaning and value of life and death, to form a national consensus, to actively use hospice, and to create a social atmosphere that respects the patients' intention regarding life-sustaining treatment, every second Saturday of October shall be declared as "Hospice Day."

(2) The State and local governments shall strive to administer events, education and publicity activities that conform to the purport of Hospice Day.

Article 7 (Implementation and Formulation of Comprehensive Plans) (1) The Minister for Health and Welfare shall formulate and implement a comprehensive plan for hospice, palliative care, and determination to terminate, etc., life-sustaining treatment (hereinafter referred to as "comprehensive plan") every five years, following deliberation by the National Hospice and Palliative Care Committee prescribed in Article 8.

(2) A comprehensive plan shall include the following:

1. Direction-setting and establishing the foundation for institutionally establishing hospice, palliative care, and determination to terminate, etc., life-sustaining treatment;

2. Providing information related to hospice, palliative care, and determination to terminate, etc., life-sustaining treatment, and implementing and supporting education thereon;

3. Providing support necessary for establishing and operating an institutional ethics committee pursuant to Article 14;

4. Developing and disseminating educational programs and guidelines to improve the quality of life of terminal patients, etc. and their families;

5. Fostering institutions specialized in hospice care referred to in Article 25 and training professional personnel;

6. Developing various hospice services;

7. Matters concerning researching and studying hospice, palliative care, and determination to terminate, etc., life-sustaining treatment;

8. Other matters necessary for the institutional establishment of hospice, palliative care, and determination to terminate, etc., life-sustaining treatment.

(3) In formulating comprehensive plan, the Minister of Health and Welfare shall preconsult with the National Bioethics Committee in accordance with Article 7 of the Bioethics and Safety Act regarding matters that may have a serious social impact on bioethics and safety.

(4) The Minister of Health and Welfare shall formulate and implement an annual implementation plan based on a comprehensive plan and evaluate the outcomes of implementing such.

(5) Where the Minister of Health and Welfare formulates a comprehensive plan or amends important matters therein, he/she shall file a report thereon with the National Assembly without delay.

Article 8 (National Hospice and Palliative Care Committee) (1) In order to deliberate on comprehensive plans and implementation plans, the Ministry of Health and Welfare shall establish the National Hospice and Palliative Care Committee (hereinafter referred to as the "Committee") under the jurisdiction of the Minister of Health and Welfare.

(2) The Committee shall be comprised of not more than 15 members, including the chairperson.

(3) Vice Minister of Health and Welfare shall be the chairperson.

(4) Members shall be appointed or commissioned by the Minister of Health and Welfare from among experts from various fields, who have extensive knowledge on and experience in treating terminal patients, hospice care and end-of-life process.

(5) Other matters necessary for organizing and operating the Committee shall be prescribed by Presidential Decree.

CHAPTER II MANAGEMENT SYSTEM FOR DETERMINATION TO TERMINATE, ETC., LIFE-SUSTAINING TREATMENT

Article 9 (National Agency for Management of Life-Sustaining Treatment) (1) In order to manage matters concerning life-sustaining treatment, determination to terminate, etc., life-sustaining treatment, and implementing the same in an appropriate manner, the Minister of Health and Welfare shall establish the National Agency for Management of Life-Sustaining Treatment (hereinafter referred to as the "Managing Agency").

(2) The duties of the Managing Agency shall be as follows:

1. Establishing and managing of a database of plans for life-sustaining treatment registered under Article 10 and advance statements on life-sustaining treatment registered under Article 12;
2. Managing, guiding, and supervising agencies for registration of the advance statements on life-sustaining treatment prescribed in Article 11;
3. Replying to requests for inquiry to confirm plans for life-sustaining treatment and advance statements on life-sustaining treatment pursuant to Article 17 (2);
4. Investigating, researching, and gathering information concerning life-sustaining treatment, determination to terminate, etc., life-sustaining treatment and the implementation thereof; and producing statistics related thereto;
5. Other duties prescribed by Presidential Decree in connection with life-sustaining treatment, determination to terminate, etc., life-sustaining treatment, and the implementation thereof.

(3) Matters necessary for operating, etc., the Managing Agency shall be prescribed by Presidential Decree.

<<Enforcement Date: Feb. 4, 2018>>

Article 10 (Preparation, Registration, etc., of Life-Sustaining Treatment Plans) (1) A doctor in charge may provide a terminal patient, etc. with information on making a determination to terminate, etc., life-sustaining treatment, life-sustaining treatment plan, and hospice care.

(2) A terminal patient, etc. may request the doctor in charge to prepare a life-sustaining treatment plan at a medical institution (referring to a medical clinic, oriental medical clinic, hospital, oriental medical hospital, intermediate care hospital, and general hospital, among medical institutions prescribed in Article 3 of the Medical Service Act; hereinafter the same shall apply).

(3) A doctor in charge in receipt of a request under paragraph (2) shall explain the following matters to the relevant patient before preparing a life-sustaining treatment plan; and shall obtain confirmation from the patient that he/he has understood the details thereof. In such cases, if the relevant patient is a minor, the doctor in charge shall explain such matters to the patient and his/her legal representative:

1. Status of patient's disease and matters concerning the methods of treatment;

2. Matters concerning the methods of providing life-sustaining treatment and matters concerning determination to terminate, etc., life-sustaining treatment;

3. Matters concerning selecting and using hospice care;

4. Matters concerning preparing, registering, keeping, and notifying life-sustaining treatment plans;

5. Matters concerning amending and withdrawing life-sustaining treatment plans, and subsequent measures;

6. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(4) A life-sustaining treatment plan shall include the following matters:

1. Matters concerning patients’ determination to terminate, etc., life-sustaining treatment and matters concerning use of hospice care;

2. Affixation of the patient's signature, name and seal of the patient to indicate that he/she has understood the explanation provided regarding the matters referred to in subparagraphs of

paragraph (3), recording thereof, and confirmation by a method equivalent thereto prescribed by Presidential Decree;

3. Signature and seal of the doctor in charge;

4. Year, month, and date of preparation;

5. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(5) A patient may request to amend or withdraw a life-sustaining treatment plan at any time. In such cases, the doctor in charge shall honor such request.

(6) The head of a medical institution shall register and keep a prepared life-sustaining treatment plan; and where a life-sustaining treatment plan is registered, amended or withdrawn, he/she shall notify the head of the Managing Agency of the outcome thereof.

(7) The form of a life-sustaining treatment plan, and matters necessary for preparing, registering, notifying, etc., a life-sustaining treatment plan, shall be prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 11 (Agency for Registration of Advance Statements on Life-Sustaining Treatment) (1) The Minister of Health and Welfare may designate an agency for registration of advance statements on life-sustaining treatment, from among the following institutions which satisfy the requirements prescribed by Presidential Decree, such as facilities and human resources (hereinafter referred to as "registration agency"):

1. A regional healthcare institution defined in Article 2 of the Regional Public Health Act;

2. A medical institution;

3. A non-profit corporation or non-profit organization (referring to a non-profit, non-governmental

organization registered under Article 4 of the Assistance for Non-Profit Non-Governmental Organizations Act) that provides services concerning advance statements on life-sustaining treatment;

4. A public institution under Article 4 of the Acts on the Management of Public Institutions.

(2) Duties of a registration agency shall be as follows:

1. Affairs related to registering advance statements on life-sustaining treatment;

2. Explaining and assisting in preparing advance statements on life-sustaining treatment;

3. Counselling and providing information on advance statements on life-sustaining treatment, and publicity activities related thereto;

4. Notifying the results of the registration, amending, withdrawing, etc., advance statements on life-sustaining treatment to the Managing Agency;

5. Other duties prescribed by Ordinance of the Ministry of Health and Welfare concerning advance statements on life-sustaining treatment.

(3) The head of a registration agency shall record and keep the outcomes of the duties prescribed in paragraph (2) and report them to the head of the Managing Agency.

(4) The State and local governments may provide administrative and financial support necessary to operate registration agencies and to perform their duties.

(5) The head of a registration agency that closes or suspends operation thereof for not less than one month or resumes its operation, shall report such fact to the Minister of Health and Welfare.

(6) Where a registration agency closes or suspends operation thereof for at least one month, the head of the registration agency shall transfer related records to the head of the Managing Agency as prescribed by Ordinance of the Ministry of Health and Welfare: Provided, That where the head of a registration agency that intends to suspend the operation obtains permission from the head of the Managing Agency by the day before the scheduled date for suspending operation, he/she may

directly keep the related records.

(7) Necessary matters concerning the procedures for designating registration agencies, recording, keeping and reporting the outcomes of duties, and procedures for reporting the closure of business, etc. shall be prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 12 (Preparation, Registration, etc., of Advance Statements on Life-Sustaining Treatment)

(1) A person who intends to prepare an advance statement on life-sustaining treatment (hereinafter referred to as "preparer") shall prepare it directly according to this Article.

(2) A registration agency shall fully explain the following matters to a preparer before he/she prepares an advance statement on life-sustaining treatment, and shall obtain confirmation from the preparer that he/she has understood the details thereof:

1. Matters concerning the methods of implementing life-sustaining treatment and making a determination to terminate, etc., life-sustaining treatment;

2. Matters concerning selecting and using hospice care;

3. Matters concerning the validity and invalidity of advance statements on life-sustaining treatment;

4. Matters concerning preparing, registering, keeping and notifying the advance statement on life-sustaining treatment;

5. Matters concerning amending and withdrawing advance statements on life-sustaining treatment, and subsequent measures;

6. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(3) An advance statement on life-sustaining treatment shall include the following matters:

1. Determination to terminate, etc., life-sustaining treatment;

2. Using hospice care;

3. Date and time for preparation, and methods for keeping such statement;

4. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(4) The head of a registration agency in receipt of an advance statement on life-sustaining treatment shall register and keep it after confirming whether it is prepared by the principal.

(5) The head of a registration agency shall notify the head of the Managing Agency of the result of the registration made pursuant to paragraph (4).

(6) A person who has prepared an advance statement on life-sustaining treatment may amend or withdraw his/her intention at any time. In such cases, the head of the registration agency shall modify or cancel the registration of his/her advance statement on life-sustaining treatment without delay.

(7) Where an advance statement on life-sustaining treatment is amended or withdrawn pursuant to paragraph (6), the head of a registration agency shall notify the result thereof to the head of the Managing Agency.

(8) An advance statement on life-sustaining treatment is invalid in any of the following cases: Provided, That in cases of subparagraph 4, it becomes invalid from that relevant time forward:

1. Where it is not prepared in person by the principal;

2. Where it is not prepared according to the principal's voluntary intention;

3. Where no explanation is provided on each matter prescribed in subparagraphs of paragraph (2) or where no confirmation is obtained from the preparer;

4. Where further advance statement on life-sustaining treatment is prepared after preparing and registering an advance statement on life-sustaining treatment.

(9) The form of an advance statement on life-sustaining treatment, and matters necessary for the preparation, registration, keeping, notification, etc., of an advance statement on life-sustaining

treatment, shall be prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 13 (Revocation of Designation of Registration Agencies) (1) Where a registration agency falls under any of the following cases, the Minister of Health and Welfare may revoke the designation: Provided, That in cases falling under subparagraph 1, such designation shall be revoked:

1. Where it obtains designation by fraudulent or other illegal means;
2. Where it fails to meet any designation criterion prescribed in Article 11 (1);
3. Where it fails to perform any of the duties prescribed in subparagraphs of Article 11 (2) without any good cause;
4. Where it fails to comply with an order or cooperate in an inspection referred to in Article 34 (3) without any good cause.

(2) A registration agency whose designation is revoked under paragraph (1) shall be ineligible to be designated as a registration agency within two years from the date the designation is revoked.

(3) Where the designation is revoked under paragraph (1), the head of the registration agency shall transfer the records kept thereby to the Managing Agency, as prescribed by Presidential Decree.

<<Enforcement Date: Feb. 4, 2018>>

Article 14 (Establishment, Operation, etc., of Institutional Ethics Committee) (1) A medical institution that intends to perform the services concerning determination to terminate, etc., life-sustaining treatment and the implementation thereof shall establish an institutional ethics committee (hereinafter referred to as "ethics committee") as prescribed by Ordinance of the Ministry of Health and Welfare and register it with the Minister of Health and Welfare.

(2) An ethics committee shall perform the following activities:

1. Deliberation on matters requested by a patient at the end of life, his/her family or medical person regarding a determination to terminate, etc., life-sustaining treatment and the implementation thereof;

2. Deliberation on replacing doctors in charge under Article 19 (3);

3. Counseling for a patient and his/her family with respect to determination to terminate, etc., life-sustaining treatment;

4. Education of medical ethics for medical persons of the relevant medical institution;

5. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(3) An ethics committee shall consist of at least five members including one chairperson; it shall not be limited to the persons of the relevant medical institution, but shall include at least two nonmedical persons recommended from the religious community, legal circle, ethics circle, civic organizations, etc.

(4) Members of an ethics committee shall be commissioned by the head of the relevant medical institution, and the chairperson shall be elected by and from among its members.

(5) Notwithstanding paragraph (1), a medical institution which has concluded an agreement with the ethics committee of another medical institution or a shared ethics committee referred to in paragraph (6) to entrust the affairs prescribed in subparagraphs of paragraph (2), as prescribed by Ordinance of the Ministry of Health and Welfare, shall be deemed to have established an ethics committee.

(6) In order to enable medical institutions to entrust the performance of the affairs prescribed in the subparagraphs of paragraph (2), the Minister of Health and Welfare may designate shared ethics committees.

(7) Other necessary matters for comprising, operating, etc., ethics committees and shared ethics committees shall be prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

CHAPTER III IMPLEMENTATION OF DETERMINATION TO TERMINATE, ETC., LIFE-SUSTAINING TREATMENT

Article 15 (Persons subject to Implementation of Determination to Terminate, etc., Life-Sustaining Treatment) A doctor in charge may implement a determination to terminate, etc., life-sustaining treatment, only if his/her patient at the end of life falls under any of the following cases:

1. Where the patient's intention is deemed to make a determination to terminate, etc., life-sustaining treatment, based upon the life-sustaining treatment plan, an advance statement on life-sustaining treatment, or statements of the patient's family under Article 17 and it is not against the intention of the patient at the end of life;
2. Where a determination to terminate, etc., life-sustaining treatment is deemed made pursuant to Article 18.

<<Enforcement Date: Feb. 4, 2018>>

Article 16 (Diagnosing whether Patient Is in End-of-Life Process) Before implementing a determination to terminate, etc., life-sustaining treatment, a doctor in charge shall diagnose, in cooperation with one medical specialist, whether his/her patient is in end-of-life process and shall record the outcome thereof as prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 17 (Verification of Patient's Intention) (1) A doctor of a patient who wishes to make a determination to terminate, etc., life-sustaining treatment shall make verification by any of the

following methods:

1. Where there is a life-sustaining treatment plan prepared at a medical institute, it shall be construed as the patient's intention;

2. Where the doctor in charge verifies the details of an advance statement on life-sustaining treatment from the patient, it shall be construed as the patient's intention. The same shall also apply where the doctor in charge and one medical specialist in the relevant field verify all of the following matters:

   (a) Medical judgement that the patient lacks mental capacity to verify details of the advance statement on life-sustaining treatment;

   (b) The fact that the advance statement on life-sustaining treatment has been prepared within the scope defined in subparagraph 4 of Article 2;

3. In cases not falling under subparagraph 1 or 2, if a patient who is at least 19 years of age is in a medical condition that prevents him/her from expressing his/her intention and if there are two or more identical statements of the members of the patient's family (referring to any of the following persons who are at least 19 years of age; where the patient has only one family member, referring to the state of such family member) regarding the patient’s intention to make a determination to terminate, etc., life-sustaining treatment consistently expressed for a period sufficient to construe it as the patient's intention to make a determination to terminate, etc., life-sustaining treatment, such statements shall be construed as the patient's intention following verification by the doctor in charge and one medical specialist in the relevant field: Provided, That the same shall not apply where any other family member has made a statement of the patient or objective evidence prescribed by Ordinance of the Ministry of Health and Welfare, the details of which are contrary to such statements:

   (a) The spouse;

   (b) A lineal descendant;

   (c) A lineal ascendant;

(d) Where no person falls under any of item (a) through (c), a sibling.

(2) A doctor in charge may inquire about the registration of a life-sustaining treatment plan or an advance statement on life-sustaining treatment to verify it pursuant to paragraph (1) 1 or 2.

(3) A doctor in charge and a medical specialist in the relevant field who have verified the patient's intention pursuant to paragraph (1) 2 or 3 shall record the outcome of the verification as prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 18 (Determining to Terminate, etc., Life-Sustaining Treatment Where It Is Impossible to Verify Patient's Intention) (1) Where it is impossible to verify a patient's intention because the case does not fall under Article 17 and the patient is in a medical condition that prevents him/her from expressing his/her intention, determination to terminate, etc., life-sustaining treatment shall be deemed made on behalf of the relevant patient in any of the following cases: Provided, That this shall not apply if the doctor in charge and one medical specialist in the relevant field verify that the patient did not intend the determination to terminate, etc., life-sustaining treatment:

1. A legal representative (limited to a person of parental authority) of a patient who is a minor has expressed an intention to make a determination to terminate, etc., life-sustaining treatment and the doctor in charge and one medical specialist in the relevant field have verified such intention;

2. Where all members of the patient's family (excluding those who fall under any ground prescribed by Presidential Decree, such as missing persons, etc.) have unanimously expressed an intention to make a determination to terminate, etc., life-sustaining treatment and the doctor in charge and one medical specialist in the relevant field have verified such intention.

(2) A doctor in charge and one medical specialist in the relevant field who have verified determination to terminate, etc., life-sustaining treatment pursuant to paragraph (1) 1 or 2 shall record the outcome of the verification as prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 19 (Implementation, etc., of Determination to Terminate, etc., Life-Sustaining Treatment)

(1) A doctor in charge shall immediately implement determination to terminate, etc., life-sustaining treatment for a patient who falls under any subparagraph of Article 15.

(2) In implementing determination to terminate, etc., life-sustaining treatment, the medical care for relieving pains and simple provision of nutrients, water, and oxygen, shall be provided without ceasing.

(3) When a doctor in charge refuses to implement determination to terminate, etc., life-sustaining treatment, the head of the relevant medical institution shall replace the doctor in charge following deliberation by the ethics committee. In such cases, the head of the medical institution shall not dismiss the doctor in charge or accord any other unfavorable treatment on the grounds of his/her refusal to implement the determination to terminate, etc., life-sustaining treatment.

(4) A doctor in charge who implements determination to terminate, etc., life-sustaining treatment shall record the process and the outcome thereof.

(5) Where determination to terminate, etc., life-sustaining treatment is implemented pursuant to paragraph (1), the head of the medical institution shall report the outcome thereof without delay to the head of the Managing Agency as prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 20 (Preservation of Records) The head of a medical institution shall preserve the following records concerning each determination to terminate, etc., life-sustaining treatment and the implementation thereof for ten years after implementing each determination to terminate, etc., life-sustaining treatment:

1. A life-sustaining treatment plan prepared under Article 10;

2. The outcome of diagnosis made by the doctor in charge and one medical specialist as to whether a patient is in the end-of-life process, which is recorded pursuant to Article 16;

3. The outcome of verification conducted by the doctor in charge and the medical specialist in the relevant field concerning the life-sustaining treatment plan or the advance statement on life-sustaining treatment pursuant to Article 17 (1) 1 or 2;

4. Data and documents concerning the statements of the patient's family under Article 17 (1) 3 and the outcome of verification conducted by the doctor in charge and the medical specialist in the relevant field;

5. Data and documents concerning the expression of intention under Article 18 (1) 1 or 2 and the outcome of verification conducted by the doctor in charge and the medical specialist in the relevant field;

6. The outcome of implementation of the determination to terminate, etc., life-sustaining treatment recorded pursuant to Article 19 (4);

7. Other matters prescribed by Presidential Decree, as important records concerning the determination to terminate, etc., life-sustaining treatment and the implementation thereof.

<<Enforcement Date: Feb. 4, 2018>>

CHAPTER IV HOSPICE AND PALLIATIVE CARE

Article 21 (Hospice Projects) (1) The Minister of Health and Welfare shall implement the following projects for hospice care:

1. Developing and disseminating guidelines for controling symptoms, including appropriate pain management for terminal patients, etc.;

2. Establishing and operating hospital, counsel, and home hospices, and development and dissemination of policies on various other types of hospices;

3. Research and development projects for developing hospice care;

4. Fostering institutions specialized in hospice care under Article 25 and training of human resources specializing in hospice care;

5. Developing and disseminating hospice education programs for terminal patients and their families;

6. Projects supporting medical expenses taking the ability to bear economic burden of patients using hospice care;

7. Projects for registering, managing, and surveying for statistics (hereinafter referred to as "registration statistics projects") by collecting and managing data on the status and management status of terminal patients and hospice care on a continuous and systematic basis;

8. Publicity activities concerning hospice care;

9. Other projects deemed necessary by the Minister of Health and Welfare.

(2) The Minister of Health and Welfare may entrust the projects prescribed in subparagraphs of paragraph (1) to related specialized institutions and organizations, as prescribed by Presidential Decree.

Article 22 (Cooperation, etc. in Provision of Data) Where necessary for registering statistics projects referred to in Article 21 (1) 7, the Minister of Health and Welfare may request related institutions or organizations to submit data, written opinions, etc. In such cases, persons in receipt of a request to submit, etc., data shall comply therewith, except in extenuating circumstances.

Article 23 (Designation of Central Hospice Center) (1) The Minister of Health and Welfare may designate a general hospital referred to in Article 3 (2) 3 (e) of the Medical Service Act (hereinafter referred to as "general hospital") that meets the criteria prescribed by Ordinance of the Ministry of Health and Welfare as the Central Hospice Center (hereinafter referred to as the "Central Center") in order to assign the following duties. In such cases, priority shall be given to a national or public medical institution:

1. Researching the status, diagnosis, treatment, management, etc., of terminal patients;

2. Collecting, analysing, and providing information and statistics on hospice projects;

3. Formulating plans for hospice projects;

4. Development and dissemination of new technologies on hospice care;

5. Provision of hospice care to terminal patients, etc.;

6. Evaluation and utilization of outcomes of hospice projects;

7. Other projects prescribed by Ordinance of the Ministry of Health and Welfare as those necessary for the management of terminal patients.

(2) Where the Central Center fails to perform or inadequately performs a project prescribed in subparagraphs of paragraph (1), the Minister of Health and Welfare may issue a corrective order.

(3) Where the Central Center falls under any of the following cases, the Minister of Health and Welfare may revoke designation:

1. Where it fails to meet any of the designation criteria referred to in paragraph (1);

2. Where it fails to perform or inadequately performs a project prescribed in subparagraphs of paragraph (1) l;

3. Where it fails to comply with a corrective order issued under paragraph (2).

(4) Necessary matters concerning the criteria, methods, and procedures for the designation and

revocation of designation of the Central Center, and the operation thereof under paragraphs (1) and (3) shall be prescribed by Ordinance of the Ministry of Health and Welfare.

Article 24 (Designation, etc., of Regional Hospice Center) (1) The Minister of Health and Welfare may designate a general hospital that meets the criteria prescribed by Ordinance of the Ministry of Health and Welfare as a Regional Hospice Center (hereinafter referred to as "regional center") in order to assign the following affairs. In such cases, priority shall be given to a national or public medical institution:

1. Research on the current state, diagnosis, treatment, management, etc., of terminal patients;
2. Provision of support to hospice projects in the relevant region;
3. Provision of medical support to and evaluation of institutions specialized in hospice care in the relevant region;
4. Provision of hospice care to terminal patients, etc.;
5. Affairs related to education, training and providing support related to hospice projects of the relevant region;
6. Publicity activities concerning hospice care in the relevant region;
7. Collecting, analysing and providing statistics on registration of terminal patients;
8. Other projects prescribed by Ordinance of the Ministry of Health and Welfare as those necessary for managing terminal patients.

(2) Where a regional center fails to implement or inadequately implements the projects prescribed in subparagraphs of paragraph (1), the Minister of Health and Welfare may revoke designation.

(3) Where a regional center falls under any of the following cases, the Minister of Health and Welfare may revoke designation:

1. Where it fails to meet the designation criteria referred to in paragraph (1);

2. Where it fails to perform or inadequately performs the projects prescribed in subparagraphs of paragraph (1);

3. Where it fails to comply with a corrective order issued under paragraph (2).

(4) Necessary matters concerning the criteria, methods, and procedures for the designation and revocation of designation of a regional center, and the operation thereof under paragraphs (1) and (3) shall be prescribed by Ordinance of the Ministry of Health and Welfare.

Article 25 (Designation, etc., of Institutions Specialized in Hospice Care) (1) The Minister of Health and Welfare may designate medical institutions that meet the criteria for facilities, human resources, equipment, etc., prescribed by Ordinance of the Ministry of Health and Welfare as specialized in hospice care, among the medical institutions that intend to establish and operate institutions specialized in hospice care for terminal patients, etc., by classifying them into hospital, council, and home hospices.

(2) A medical institution that intends to be designated under paragraph (1) shall submit an application to the Minister of Health and Welfare as prescribed by Ordinance of the Ministry of Health and Welfare.

(3) The Minister of Health and Welfare may fully or partially subsidize expenses incurred for hospice services of institutions specialized in hospice care designated under paragraph (1) (hereinafter referred to as "institutions specialized in hospice care") differentially, by reflecting the outcome of the evaluation conducted under Article 29.

(4) Except as otherwise expressly provided for in paragraphs (1) and (2), matters necessary for designating institutions specialized in hospice care shall be prescribed by Ordinance of the Ministry of Health and Welfare.

Article 26 (Reporting on Changes, Business Closure, etc.) (1) The head of an institution specialized in hospice care who intends to change important matters prescribed by Ordinance of the Ministry of Health and Welfare, such as human resources, facilities and equipment, shall report the matters to be changed, to the Minister of Health and Welfare.

(2) The head of an institution specialized in hospice care who intends to close or suspend business shall file a pre-report thereon with the Minister of Health and Welfare.

(3) Matters necessary for the reporting procedures, etc., under paragraphs (1) and (2) shall be prescribed by Ordinance of the Ministry of Health and Welfare.

Article 27 (Medical Persons' Duty to Explain) (1) A medical person of an institution specialized in hospice care shall explain to a terminal patient, etc., or his/her family, etc., the selection and procedures for using a hospice.

(2) A doctor or an oriental medical doctor of an institution specialized in hospice care shall explain a treatment plan to a terminal patient, etc., or his/her family, etc., before providing hospice care; and shall explain the status of the disease when a terminal patient or his/her family wishes to know regarding the same.

Article 28 (Application for Hospice Care) (1) Where a terminal patient, etc., intends to use hospice care at an institution specialized in hospice care, he/she shall submit an application to the institution, appending written consent to use hospice care and a doctor's note indicating that the applicant is a terminal patient, etc.

(2) When a terminal patient, etc. lacks decision-making ability, the application may be filed by a pre-designated representative; and where no representative is designated, the application may be filed by a person in the order set forth in items of Article 17 (1) 3.

(3) A terminal patient, etc. may withdraw his/her application for hospice care at any time, in person

or through his/her representative.

(4) Matters necessary for applications, withdrawing, etc., hospice care shall be prescribed by Ordinance of the Ministry of Health and Welfare.

Article 29 (Evaluation of Institutions Specialized in Hospice Care) (1) In order to improve quality of hospice care, the Minister of Health and Welfare may evaluate institutions specialized in hospice care with respect to the following matters:

1. Quality and level of facilities, human resources, equipment, etc.;

2. Current state of the management of quality of hospice care;

3. Other matters prescribed by Ordinance of the Ministry of Health and Welfare.

(2) Matters necessary for the timing to evaluate institutions specialized in hospice care, the scope, methods, procedures, etc., for the evaluation shall be prescribed by Ordinance of the Ministry of Health and Welfare.

(3) The Minister of Health and Welfare may disclose the findings of evaluation performed under paragraph (1) as prescribed by Ordinance of the Ministry of Health and Welfare, and reflect it in providing assistance and supervision.

(4) The Minister of Health and Welfare may outsource duties of evaluation to be performed under paragraph (1), to a related institution or organization, as prescribed by Presidential Decree.

Article 30 (Revocation, etc., of Designation of Institutions Specialized in Hospice Care) (1) Where an institution specialized in hospice care falls under any of the following cases, the Minister of Health and Welfare may revoke the designation or order the hospice to suspend its services: Provided, That the designation shall be revoked in cases falling under subparagraph 1:

1. Where it obtains the designation by fraudulent or other illegal means;

2. Where it fails to meet any of the designation criteria prescribed in Article 25 (1);

3. Where it refuses to undergo evaluation referred to in Article 29 without good cause.

(2) Matters necessary for the criteria for revoking designation, and the methods, procedures and operation thereof under paragraph (1) shall be prescribed by Ordinance of the Ministry of Health and Welfare.

(3) An institution specialized in hospice care, designation of which is revoked under paragraph (1), shall be ineligible to be designated as a registration agency within two years from the date such designation is revoked.

CHAPTER V SUPPLEMENTARY PROVISIONS

Article 31 (Management of Personally Identifiable Information) The Managing Agency, registration agencies and medical institutions may manage the data containing resident registration numbers, if it is essential to perform the affairs related to making decisions on life-sustaining treatment.

<<Enforcement Date: Feb. 4, 2018>>

Article 32 (Prohibition of Disclosure of Information) No person who serves in or has served in the Managing Agency, a registration agency or medical institution shall disclose any information learned in the course of making a determination to terminate, etc., life-sustaining treatment and the implementation thereof, or performing hospice service.

Article 33 (Inspection, etc., of Records) (1) A patient's family member (whose age shall not be limited in this Article) may request the head of the Managing Agency or the head of the relevant medical institution to allow an inspection of the records on making a determination to terminate, etc., life-sustaining treatment or the implementation thereof, as prescribed by Ordinance of the Ministry of Health and Welfare; and in such cases, a person in receipt of such request shall issue a copy of the relevant record or allow him/her to verify the details thereof except in extenuating circumstances.

(2) Necessary matters concerning the scope of and the procedures for the inspection of records under paragraph (1), refusing inspection, and other relevant matters shall be prescribed by Ordinance of the Ministry of Health and Welfare.

<<Enforcement Date: Feb. 4, 2018>>

Article 34 (Report, Inspection, etc.) (1) Where deemed necessary in connection with implementing a determination to terminate, etc., life-sustaining treatment, hospice care, etc., the Minister of Health and Welfare or the head of the Managing Agency may issue an order necessary for such affairs to the head or an employee of a registration agency or medical institution or order such person to submit a report or related documents.

(2) The Minister of Health and Welfare or the head of the Managing Agency may require a related public official to inspect related documents, etc., referred to in paragraph (1). In such cases, a related public official in charge of the inspection shall carry a document verifying his/her authority and show it to relevant persons.

(3) The head or any employee of a registration agency or medical institution shall comply with the order and inspection referred to in paragraphs (1) and (2) except in extenuating circumstances.

Article 35 (Hearings) Where the Minister of Health and Welfare intends to take any of the following dispositions, he/she shall hold a hearing:

1. Revoking designation of a registration agency under Article 13;

2. Revoking designation of an institution specialized in hospice care under Article 30.

Article 36 (Prohibition of Use of Similar Names) No person other than the Managing Agency or a registration agency under this Act shall use the name “National Agency for Management of Life-Sustaining Treatment,” “agency for registering the advance statements on life-sustaining treatment,” or similar name.

<<Enforcement Date: Feb. 4, 2018>>

Article 37 (Prohibition of Disadvantages in Insurance, etc.) No person who died upon a decision on and implementation of terminating, etc., life-sustaining treatment, or a beneficiary of insurance or a recipient of a pension shall be treated unfavorably at the time of payment of the insurance proceeds or pension benefit.

<<Enforcement Date: Feb. 4, 2018>>

Article 38 (Bearing of Expenses Incurred in Making Decisions on Life-Sustaining Treatment, etc.) Expenses for preparing a life-sustaining treatment plan under Article 10, judgment on whether a patient is in end-of-life process under Article 16, and issuance of a doctor's note for application for hospice care and use, etc., of hospice care under Article 28, shall be governed by the National Health Insurance Act: Provided, That expenses not prescribed in the National Health Insurance Act shall be governed by Ordinance of the Ministry of Health and Welfare.

CHAPTER VI PENALTY PROVISIONS

Article 39 (Penalty Provisions) Any of the following persons shall be punished by imprisonment with labor for up to three years or by a fine not exceeding 30 million won:

1. A person who implements a determination to terminate, etc., life-sustaining treatment to a person not subject to the determination to terminate, etc., life-sustaining treatment, in violation of Article 15;
2. A person who makes a false record of any of the matters prescribed in subparagraphs of Article 20;
3. A person who discloses information, in violation of Article 32.

<<Enforcement Date: Feb. 4, 2018>>

Article 40 (Penalty Provisions) (1) Any person who performs any of the affairs related to registering an advance statement on life-sustaining treatment, without being designated by the Minister of Health and Welfare, in violation of Article 11 (1), shall be punished by imprisonment with labor for not more than one year or by a fine not exceeding ten million won:

(2) A person who fails to preserve records of the matters prescribed in subparagraphs of Article 20 shall be punished by a fine not exceeding three million won.

<<Enforcement Date: Feb. 4, 2018>>

Article 41 (Concurrent Imposition of Suspension of Qualification) Where a person who has violated this Act is punished by imprisonment for a limited term, his/her qualification may concurrently be suspended for a period not exceeding seven years.

Article 42 (Joint Penalty Provisions) Where the representative of a corporation, or an agent, employee or other servant of a corporation or individual violates any of Article 39 or 40 with respect to the duties of the corporation or individual, not only shall such violator be punished accordingly, but the corporation or individual also shall be punished by a fine prescribed in the relevant provisions: Provided, That this shall not apply where such corporation or individual has not neglected to take due care concerning and supervised the relevant duties in order to prevent such violation.

Article 43 (Administrative Fines) (1) Any of the following persons shall be subject to imposition of an administrative fine not exceeding five million won:

1. A person who fails to establish an ethics committee, in violation of Article 14 (1);

2. A person who fails to inform the head of the Managing Agency of the outcome of implementing a determination to terminate, etc., life-sustaining treatment, in violation of Article 19 (5).

(2) Any of the following persons shall be subject to imposition of an administrative fine not exceeding three million won:

1. A person who fails to record, keep, or report the outcome of his/her duties, in violation of Article 11 (3);

2. A person who fails to comply with an order issued under Article 34 (3) without any good cause.

(3) Any of the following persons shall be subject to the imposition of an administrative fine not exceeding two million won:

1. A person who fails to report matters changed or to be changed, such as closure or suspension of business, in violation of Article 11 (5) or 26;

2. A person who fails to perform the duty to transfer records pursuant to Article 11 (6) or 13 (3);

3. A person who uses the name “National Agency for Management of Life-Sustaining Treatment,” “agency for registering the advance statements on life-sustaining treatment,” or similar name, in

violation of Article 36.

(4) Administrative fines under paragraphs (1) through (3) shall be imposed and collected by the Minister of Health and Welfare as prescribed by Presidential Decree.

<<Enforcement Date: Feb. 4, 2018>>