

Death, Dignity, and the Significance of Home Hospice Care*¹

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Introduction

The human being have the ability to meet their end, as well as to provide end-of-life care for others, and it is the role of home hospice care to support persons in these situations. Those are the author's beliefs acquired during 20 years of home hospice care.

In the decades since the end of World War II, it has been constantly pointed out that Japanese people have a tendency to avoid facing death (e.g., to attend a dying person). However, the disasters, crimes, and accidents that have taken the lives of many, such as the case of *Aum Shinrikyo* (a Japanese cult that committed a sarin attack on Tokyo Metropolitan area in 1995), the Great Hanshin-Awaji Earthquake, also in 1995, and the 2011 Great East Japan Earthquake and the subsequent nuclear accident of Fukushima, have demonstrated the inevitable reality that a human life consists not only of living but also of dying and death.

Major changes in the world of medicine also have occurred during these years. Demographic changes, such as the aging of Japanese society; low birth rates; an increase in nuclear families; and structural changes in disease from acute illness and infectious diseases to chronic illness and lifestyle-related diseases, have greatly influenced the life and death of each person. Macrosocioeconomic changes, such as the disparities among countries induced by globalization and expanding inequality inside the country, are affecting people's lifestyles, too.

We could say that "a society in which people

have a free choice" is a truly affluent society. A person makes various choices when he or she encounters different life events, such as choosing a school, a place to work, or a place to live. Perhaps not only the width of available options, but also the profoundness in one's decision, is one of the indicators of an affluent society.

In Japan, the vast majority of the people die in hospital; about 90% of cancer patients reportedly die there. This figure, unusually high compared to other developed countries, indicates that in Japan, people cannot choose the place where they will meet their end of lives. Although Japan may appear rich superficially and economically, we cannot really say that Japan is truly an affluent society.

End-of-life Care

Let us think about what is perhaps life's major event—its end. The end of life, i.e., death, is the final event in a person's life. However, one cannot be aware of it, just as one cannot be aware of one's birth. The fact that the one passing away is not aware of the moment of his or her death may create some meaning for the people who are providing deathbed care, and for those who are involved in the person's life.

Taku Shinmura (2001) discusses the "culture of end-of-life care" in Chapter 1 of his work, *Era of At-home Death*. He points out that the awareness of death has become diluted in modern times, and he states that this dilution brings certain kind of poverty in life because longer average life expectancies and the busy daily life

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push the memory of the deceased away. This tendency seems to be enhanced by the general beliefs that the death is the end of everything. He further wrote that pondering about death condenses life, and that the reinstatement of the right to die is necessary in that sense.¹

Let us examine the end of life from the viewpoint of a medical practitioner. Currently, a physician verifies a death by announcing, “He/she has passed away,” and reports the death to the authorities. In Japan, this practice began after the promulgation of the 1874 law codifying the practice of medicine and public health. People’s reliance on medical care and physicians, as well as the subsequent development of medicine primarily based on the Western model, led physicians to play increasingly greater roles in end-of-life care.

At the same time, as medicine advanced, the belief that a physician should never lose hope as long as a patient is alive and should make every effort to extend his/her life, has become increasingly stronger. As a result, it became more common for people to accept medical care until their last breath and to die in hospital. People came to increasingly believe that dying at home is ominous and that it is an evidence that family members failed to provide proper care for the deceased. This has resulted in the current situation that approximately 80% of Japanese die in hospital.

However, doubts about death in hospital grew among people. Could it be that seeking to preserve life until the end and clinging to my life is actually making me lose my humanity as well as my human dignity? Maybe to be hooked up with many tubes and surrounded by various machines is no way to meet my end as a human being.

Dignity

What is human dignity? It is not something special; it is said to be an essential element that every person inherently possesses as they grow as a human being. However, this description lacks specificity. What does “human dignity” actually mean?

Allow me to introduce the case of Girl S. She was a 10-month-old child who was brought into this world with a congenital disease caused by a genetic abnormality. The mother was informed of the baby’s diagnosis during pregnancy, but her

decision to carry the baby to term was firm. She received genetic counseling and other support and prepared for the delivery and child rearing. The baby spent her first 8 months in hospital. When the baby’s pulmonary hypertension progressed and her chance of recovery faded, she was brought home as it was considered her last chance to spend any time there. Surprisingly, her stay in home was filled with tranquility, but the baby developed pneumonia after about 2 weeks and was re-hospitalized. Despite every effort in treatment, her condition further deteriorated, and her parents were told that she had a day or two left to live.

The parents decided to care for her on her deathbed at home, and requested home care for the last time. On the day of discharge, they were told that their child might not live to see another day, but the baby spent a week at home. She was surrounded by such apparatuses as an oxygen concentrator, an oxygen cylinder, and an aspirator, but she was able to live at home with her parents and older brother (age 4). Physicians and nurses from the hospital visited her. She was also bathed, which she liked very much, with the help of a visiting nurse and my hospital’s nurse. Although she was never able to express her own will, her parents spoke on her behalf during home care.

“What if her life was shortened because we took her home?” The mother still asks this question, even now. This question troubles her, because she seriously considered how Girl S’s life should be and she made decisions on S’s behalf. She suffers from anguish because she actively tried to protect S’s dignity as a human being. It is said that dignity is an essential element that every person inherently possesses as a human being. Nevertheless, maybe one’s dignity is something that is realized through relationships and the efforts of parents, other family members, schools, communities, and other players in one’s life, just as education and other involvement in life shapes a human being. The case of Girl S demonstrated to us what I have believed: that dignity cannot be maintained without such continuous involvement and efforts of family members and health professionals.

Home Hospice: Supporting the End-of-life and Dignity

The following are the factors that the author

Table 1 Comprehensive palliative care and selective palliative care

	Comprehensive palliative care	Selective palliative care
Disease/stage	All (cancer, intractable neurological disease, dementia, child with severe disability, organ failure, etc.)	Terminally ill patients with cancer or AIDS
Persons in charge (team)	Medical team, life support team, and others	An integrated team of physician(s) and nurses
Relationships within the team	Equal (i.e., no hierarchy)	A physician or skilled nurse provides guidance (i.e., vertical hierarchy)
Approach	Narrative approach	Evidence-based medicine (EBM)
Relationship with welfare workers or long-term care insurance service workers	Strong, and constantly in contact	Weak, and occasionally in contact
Prospect (mental horizon)	Community and diversity	Each team is independent from one another
Involvement with a primary care physician	Closely involved	Not very involved

believes constitute the “requirements for good death,” based on his experience in home hospice care:

- (1) One’s way of life;
- (2) One’s relationship with family members (and others);
- (3) The dying person receives optimal care; and
- (4) Death is peaceful.

Fortunately, a patient who requests home care and a family that accepts such a decision already meet the conditions 1 and 2 mentioned above, meaning that the patient has lived a full life and that the family accepts his or her way of life. Many of these people have much to teach us in that sense. Our support plays a significant role in the conditions 3 and 4, but the involvement of the family (i.e., as caregivers) also is important.

Patient K, a 70-year-old male, suffered from pancreatic cancer and cervical spondylosis with paralysis of both lower limbs as a complication. He had been repeatedly admitted for chemotherapy for his cancer, but the paralysis of his lower limbs gradually progressed, to the point that he needed to use a lift for bathing at home. He became completely bedridden and barely able to ingest food when his condition further deteriorated, but he chose to stay at home. Our home hospice team (physicians and nurses from my clinic; visiting nurses from a home nursing station; a care manager; helpers; and visiting

rehabilitation specialists, among others) supported his wife and son, who were providing care. Although K could not walk on his own, he was able to spend his remaining time at home and meet the end of his life there as he wished because we were successful in controlling abdominal pain and in providing home care support. So, in a sense, we supported the family by providing end-of-life care and the patient by helping him to live—and meet his end—with dignity.

As was seen in case Girl S, home hospice is not always limited to cancer patients; in fact, it can be for any kind of disease. Palliative care for cancer is one of the most urgent needs, given that of the 1.2 million annual total deaths in Japan, 30% are due to cancer. However, it is also time to expand the target of palliative care to other diseases by adapting its history and the experience that we have accumulated (**Table 1**). In the USA and Europe, palliative care for cancer patients already has been expanded; palliative care for patients with intractable neurological disease, the elderly, or dementia patients, as well as children’s hospice care, have become the current leading discussion topics.

The social critic Kei Yonezawa (2009) considers that the human life has two phases; the time for “life” and the time for “death,” and that life is a round-trip consisting of going and returning.² Medicine and its practice have traditionally focused on the “living” part, but Yonezawa pro-

poses medical practice that supports the “death” side as well as supporting life until its end. His argument extends beyond medicine and its practice to encompass a view of how society, as well as people’s values and behavior, should change (Yamazaki et al. 2012).³

For us physicians and other medical workers,

it is the nature of our work to become involved in someone’s death as well as life. We therefore need to take a step beyond our areas of expertise and master humility, so that we can provide end-of-life care not only as professionals but also as human beings.

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