



Thinking about End-of-life Care for the Elderly

Chapter 2: From the perspective of medical ethics

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1. Landscape of end-of-life care for the elderly



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One of major issues concerning end-of-life care for severely frail elderly is what to do when they can no longer eat even with assistance.

The major trend in Japan in the 1990s was the use of feeding tubes when severely frail elderly could no longer eat. For example, there was a hospital that created a policy of “choosing natural death when severely frail, bed-bound elderly with advanced dementia can no longer eat.” The hospital came in for some harsh criticism, saying that the hospital was practicing a policy of “passive euthanasia” by withholding tube-feeding that could enable elderly people to continue to live.

Today, nearly twenty years later, there have been an increasing number of media reports in recent years claiming quite the opposite of what newspapers argued in the 1990s. These reports present skeptical views about the utilization of artificial feeding, such as the gastrostomy, in elderly people living the final phase of their lives, saying that although such treatments could enable the elderly to continue to live for some more time in some cases, they could undermine their dignity as human beings.

In particular, PEG tube-feeding has advantages over other types of artificial hydration and nutrition (AHN), and a dramatically increasing number of people have been using this treatment. It is said that from 2008 to 2010, Japan had more patients receiving PEG



treatment than any other country in the world.

This had a lot to do with what doctors knew very well. There are many different reasons for the introduction of AHN to severely frail elderly people in Japan, such as social consensus regarding natural death, legal issues, the family's wishes and claims by distant relatives. In fact, however, the most significant factor was the doctor's recognition that withholding AHN from elderly people almost equated to starving them to death.

Is withholding AHN from severely frail elderly people really almost the same as starving them to death? The truth is that withholding AHN from patients at the final stage of lives is far from making them starve to death; it is a form of palliative care. This is because a reduction in respiratory tract secretions leads to a reduction in the risk of respiratory obstruction, which results in a reduction in the number of aspirations.

In addition, the resultant increase in β -endorphins and Ketone bodies has analgesic and sedative effects naturally, without an injection of morphine.

Currently, nearly 80% of Japanese people spend the final days of their lives in hospital. Hospital staff often provide these people with peripheral intravenous drips. Of course, this is a medical act, and medical acts must involve medical demands. However, these peripheral intravenous drips for the final days of patients are more about reducing the mental burden on the family and medical and nursing care personnel than about medical demand. When an intravenous drip bottle is hung at the bedside, it soothes the emotions of the family and medical and nursing care personnel, who want to believe that they are doing "something" for the patient.

This is a familiar scene for family attending the deathbeds of elderly people in Japan, but now is the time to reconsider whether or not it is beneficial for the patients themselves. These elderly people have needles in their arms. The needle of an intravenous drip needs to be stuck into the arm of a patient many times. We often see elderly patients whose arms have turned brownish as a result of multiple injections of intravenous drips.

Why do medical staff do this? I recommend that medical service providers stop giving peripheral intravenous drips at the end-of-life merely to care for the emotions of the family and medical and nursing care personnel. Instead, medical professionals should educate people that such drip infusion goes counter to palliative care.

2. Guidelines in other countries

Medical literature say that AHN is unsuitable for facilitating pain-free final days in the lives of patients. Withholding and withdrawing AHN is appropriate in terms of both medicine and ethics. Until some time ago, this approach was only seen in Western countries, but we



also began to see the same approach in Japan around 2000, started by a very small number of doctors.

Many Western medical organizations including some governments formulated guidelines on end-of-life care years ago. For example, “Guidelines for a Palliative Approach in Residential Aged Care,” which was approved by the National Health and Medical Research Council of the Australian government in 2005, recommends that intravenous drips and tube feeding not be used for severely frail elderly with advanced Alzheimer’s disease.

In accordance with these examples in Western countries, the Japanese Society of Neurology (JSN) drew up guidelines on treatment for patients with advanced dementia in 2010 and announced its basic policy of primarily promoting oral intake instead of using feeding tubes or intravenous drip infusion for patients with advanced dementia.

The American Geriatrics Society recommends in its guidelines that proper oral care is very important for end-stage patients. For providing a bit of water, it is preferable to give tiny ice cubes to patients, and it is not good to provide AHN to patients in most cases. It is said that patients whose final days are drawing near feel neither hungry nor thirsty.

3. From “terminal care” to “end-of-life care”

A very difficult question in the field of geriatrics in terms of medical ethics arises when it is medically possible to prolong life by the use of AHN and other medical technologies, although it is clear that he or she is in the final stage of life narratives. For example, it is possible to imagine a situation in which, although AHN appears to be effective for prolonging the life of a patient by a unit of one year, it will give the patient a harder time and make him or her different from the way he or she is, undermining their dignity.

Years ago, the mainstream way of thinking was that if you have any means to prolong the biological life of a patient, you should do so; if you do not do so, then it is disregard for life. However, in this contemporary age with advanced technologies, I believe that it is more important to place a strong emphasis on helping patients to live their final stage of life in a way that is more suitable for them than on the effect of prolonging their period of survival. That is, a stronger focus should be placed on thinking in terms of the life narratives of patients.

I suggest that you should shift your mindset from “terminal care” to “end-of-life care,” that is, “medical treatment and care for the final stage of life narratives.” The Ministry of Health, Labour and Welfare has recently used the latter term. Terminal care is a medical term, and thus, doctors make a primary judgment on it. Placing a stronger focus on the



doctor's standpoint makes it difficult to think in terms of the life narratives of patients. Instead, I suggest that you should use the term *end-of-life care* and shift your mindset to thinking together with patients about care at the final stage of their life narratives.

4. Facilitate patients living the final stage of their life narratives in a way that is more suitable for them

How should we help patients to achieve their own way of living during the final stage of life narratives? It is about providing well-balanced medicine — neither too little nor too much — in terms of what is important for the life narratives of patients, their own ways of thinking, their wishes about how to live during the final stage of life narratives and quality of life (QOL) with a focus on the way patients live, their values and their views of life and death. That is, it is vital to acknowledge that different people have different approaches.

What should you do if you do not know the wishes of patients? In such a case, it is necessary to find out what choice is the best for patients in the process of communication between family and medical staff.

The Japan Geriatrics Society claims in its guidelines issued in 2012 that end-of-life should focus on “satisfaction and contentment on the part of patients.” The society also announces that every patient has “his or her right to receive the best medical services and care,” and that if there is a possibility of increasing the pain caused to patients and undermining their dignity, withholding and withdrawal of treatment should be possible options.

5. Ethical validity and judiciary issues

Thinking together about what choice is best for patients in the process of communication among the patient, the family and medical staff will help secure the ethical validity of determination.

If multiple medical service providers, patients and patients' families discuss what choice is the best for patients and reach agreements in a clinical setting, it will hardly create legal problems. This is the core concept behind the “Guidelines on the Decision-Making Process of Medical Treatment at the End of Life” compiled by the Ministry of Health, Labour and Welfare in 2007.

The following are the three focal points of these guidelines formulated by the Ministry of Health, Labour and Welfare:

- (1) Treating patients through the total efforts of a medical and care service team, not



the singlehanded efforts of doctors alone

- (2) Ensuring that decisions are made based on agreements between the patient, the family and the medical and care service team with a focus on the wishes of the patient
- (3) Promoting palliative care

These are the first and only national-level guidelines on end-of-life care.

Currently, members of the parliament are making bipartisan efforts to formulate a death with dignity bill. The following are the focal points:

- (1) Documented manifestation of the will of the patient
- (2) More than one doctor diagnoses the patient as “having no chance of recovery and approaching the moment of his or her death.”
- (3) In this case, the doctor bears no legal responsibility for the termination of life-prolonging treatments.

Against the background of this kind of legalization efforts are precedents under which doctors were held to have legal responsibility, such as the Tokai University Hospital case. In such cases, doctors were convicted of murder for injecting patients lethal drug. Although no doctor has been prosecuted in cases in which patients died after doctors terminated life-prolonging treatments that were unnecessary for the patients, mass media made them front-page headlines in the wake of police investigation, impressing the public including the great majority of doctors that terminating life-sustaining treatments would not be allowed socially.

At the time when such unprosecuted cases occurred in early 2000s, these issues were in a transitional stage in Japanese society. In order to put an end to such turmoil, the Ministry of Health, Labour and Welfare in 2007 issued the end-of-life care guidelines mentioned above, which was followed by a number of medical societies' end-of-life care guidelines.

If doctors make it a rule to make end-of-life decisions based on such guidelines from now on, it is hard to believe that it will result in the creation of legal problems.

The guidelines formulated by the Ministry of Health, Labour and Welfare are compatible with Advance Care Planning (ACP), which is attracting global attention. ACP recommends that the patient, family and medical service providers should undertake appropriate communications when making medical decisions. ACP includes Advance Directives (AD), such as the living will and POLST (physician orders for life-sustaining treatment), but the documents need to be revised accordingly through the process of discussions and dialogues. This is based on the idea that both patients and

medical service providers should share medical information and information about patients' life narratives in order to deepen mutual understanding and proceed with treatment plans together.

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