

INVITED NOTE

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Reconsideration of medical treatment and care for older adults

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ABSTRACT

The advance care directive is a device for deciding one's own end-of-life care by giving directions on terminal care in advance. A family discussion in the field about these documents is essential to decide the best management measures.

Keywords: ACD, ACP, elderly, medical care, active euthanasia

Abbreviations:

ACD: advance care directive

ACP: advance care planning

ALS: amyotrophic lateral sclerosis

MHLW: Ministry of Health, Labour and Welfare

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MAIN TEXT

Supported by a universal health insurance system, Japan has established a healthcare system where all citizens can equally receive the world's highest level of medical services. For this reason, medical staffs strive to provide life-prolonging treatments universally as much as possible regardless of patients' backgrounds and situations. However, whether they provide the medical treatment that the patient wishes to receive remains to be clarified.¹

Recently, a shocking report was released about a patient with amyotrophic lateral sclerosis who had been receiving life-prolonging treatment with a ventilator connected to the tracheostomy tube because she was awake and alert but could not move her limbs or breathe independently. However, about her current situation, the patient expressed that "It wasn't supposed to be like this" but ended up in that situation before she finally hoped for "active euthanasia." She had continuous talks about her future progress and treatment for her disease with the chief physician and seemed to have finally decided her treatment at an early stage of the disease. Of course,

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it was clearly explained to her beforehand that “active euthanasia” was not accepted legally in the country. However, as a result, she was puzzled over her current situation, because it was unlike the condition that she imagined in the early stage of the disease. She wished for active euthanasia because she felt that her “reality was not accepted.” It was in a situation that she could not declare her intentions by herself, and the remark to relieve herself of her suffering moved many Japanese to tears.

Japan has not established a legal system to support informed consent in a terminal care settings, which sometimes causes confusions like that of the patient. When recovery from an illness is no longer possible, “death with dignity” becomes an option, in which the dying person’s intention is to have a natural death without receiving further life support. An increasing number of patients who opt for this end-of-life decision in a way that their families can understand are gradually increasing even in Japan. This is a totally different situation from euthanasia.

Each patient has different wishes for the kind of medical treatment they want to receive at the end-of-life. Desires and responses to life-prolonging treatments are also different. Data from the Ministry of Health, Labour and Welfare (MHLW) show that approximately 70% of the patients are unable to decide or express their preferred medical treatment and care in life-threatening situations.

In May 2007, the MHLW released the “Guidelines on the decision-making process for end-of-life care.” It stated that patients’ wishes should be respected and that crucial decisions should be made by medical treatment and care teams. However, the guidelines do not mention the immunity requirements for discontinuing life-prolonging treatment once started.² This means that the patient must plan carefully in advance, because the treatment could not be regressed once given.

When one faces end-of-life, it is often unpredictable. No one can predict when a stroke, myocardial infarction, or dementia will occur. Some have offered the opinion that terminal care wishes should be discussed with family and close friends on a regular basis and that a third party should be informed about these wishes beforehand. However, unlike some Western countries, Japan’s legal system lags behind in this regard.³

Accordingly, in recent years, in Japan, advance care planning (ACP), or life meeting with family and care managers has been recommended, where terminal care wishes can be discussed in advance.⁴ An advanced care directive (ACD) is also helpful, as it allows patients’ wishes to be respected when the need arises in a terminal care setting by documenting their end-of-life care preferences and preparing a notarial deed beforehand.⁵

The ACD is the only device for deciding end-of-life care by giving directions on terminal care in advance in case one becomes unable to communicate these wishes in the future. Prior arrangements are important for smooth implementation when the need arises by designating a medical proxy who should be informed in case of an emergency. One must have a family discussion with experts in the field about these documents and should be informed of the best management measures.⁶

Individuals are urged to consider these major decisions ahead of time before it is too late.

DISCLOSURE STATEMENT

The author has no conflicts of interest related to this study.

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Appendix 1: Contents of the advance care planning

An advance care planning (ACP) is a process that enables individuals to make plans about their future healthcare. It is applicable to adults at all stages of life. Participation in ACP has been shown to reduce stress and anxiety for both patients and their families, and leads to improvements in end-of-life care. The components of ACP include: 1) a substitute decision maker and 2) an advance care directive.

Appendix 2: Contents of the advance care directive

An advance care directive (ACD) informs medical doctors on the type of care patients prefer if they are unable to make medical decisions and/or speak for themselves in the following scenarios: 1) serious accident, 2) severe and terminal illness, 3) coma, and 4) severe confusion or late stages of dementia. Forms are available for individuals to fill out and inform physicians about their end-of-life care preferences, such as 1) a healthcare power of attorney (POA), 2) living will, and 3) “Do not resuscitate” order. One can change the ACDs at any time but must ensure that the substitute decision maker receives a copy of the revised ACD. However, ACDs are not legally recognized in Japan. According to a 2017 survey by the Ministry of Health, Labor and Welfare, 66% of surveyed individuals supported the idea of ACD but only approximately 8% had an ACD prepared previously.