

Chapter 4

End-of-Life Care, Advance Directives, Withholding and Withdrawing Life-Sustaining Treatment, and the Goals of Medicine



Abstract End-of-life care is a universal topic in bioethics throughout the world, with each region, religion, and culture claiming its own position. A comparison of these positions, however, is not the aim of this chapter. Although Japan imported the practice of issuing advance directives (ADs), it has not gained popularity, and I doubt that it will do so in the near future. In addition, from a global perspective, taking into consideration the high infant mortality rates and low adult life expectancy in LMICs, it is fair to assume that AD is not commonplace in those countries. The way in which AD is enacted also depends on local law and culture and is therefore highly contextualized.

In this chapter, I also take up the issue of withholding and withdrawing of life-sustaining treatment, especially the removal of artificial ventilation. There has also been much discussion surrounding the “equivalence principle,” which supports withholding and withdrawing. My colleagues and I have challenged this consequentially based idea in an Open Peer Commentary published in the *American Journal of Bioethics* (2019); we wrote this commentary from an East Asian perspective, and I will briefly introduce it.

Finally, in the current era of rapid development in medicine, I have sensed subtle changes in the goals of medicine as perceived by both patients and physicians (Original Article). The emergence of immune-checkpoint inhibitors, for example, may be enough to lead patients to think, “Perhaps if I try to live just a little longer, some dramatic treatment will be developed in the very near future.” From comfort care with QOL in the twentieth century to the idea of “a little bit more time in order to be cured” is emerging at the bedside.

No one can avoid death. Ultimately, all physical beings die. Topics in bioethics concerning the end of life include the process of dying and the values—both explicit and implicit—that we hold around this issue. Even actions that may seem to be similar on the surface may have different ethical underpinnings. Discussion around advance directives (ADs) exemplifies this.

4.1 Advance Directives (AD)

In 1998, a survey targeting the general population in Japan yielded some useful descriptive ethical data that helps us to understand the effectiveness of an AD in Japan. Eighty percent of respondents indicated that they would like to express their intents and wishes [1]. What does this mean? Perhaps more importantly, what were the values held by those in the 20% who did not wish to express them?

Issuing an AD may appear to be an expression of unlimited respect for autonomy that ensures that one's own self-determination prevails even after the capacity for decision-making is gone. It also indicates concerns for family. Most respondents who wanted to issue an AD believed that "I want to lessen the burden that my family will shoulder when I'm in the terminal phase of life," indicating that consideration for family was another strong motivator, at least in Japan. Another common response was "because opinions may differ even within my family [1]".

In Japan, the act of issuing an AD seems to incorporate both self-determination as well as concern for one's own family. In other words, respect for autonomy coexists with concern for the family.

The 20% who responded that they would not issue an AD included (in roughly equal proportions) those who noted the theoretical limitations ("I cannot foresee the future") as well as those ascribing from the start to *omakase* ("my family and physician should decide"). Thus, the response that "no AD will be created" represents a coexistence of theoretical limitations and *omakase*.

In response to a question about the level of adherence to the AD, just over 10% responded that their AD should require strict adherence, noting that this was not something for which they would seek a substitute judgment. The general notion surrounding the AD in Japan is that it would ideally serve as a reference against which one's best interest judgment might be determined (that is, the wishes of the individual in question are unclear, so another person must select the best course of action). The question remains: is this consistent with the backdrop against which the AD was developed in the West? Advance directives are technically the same the world over, but the context that gave rise to them, namely respect for autonomy, is not necessarily congruent with the Japanese type of AD.

As of April 2019, roughly 110,000 (0.1% of the population aged 15 years and older) members were registered at the Japan Society for Dying with Dignity (registrants are those leaving a living will). Influenced by the Patient Self-Determination Act of the US in 1990, Japan imported the AD, but it has not gained great popularity. While there are current efforts to promote advance care planning (ACP), implementation of ACP will most likely be due to efforts to uphold self-determination and will also take into account consideration for the family unit. Best interest judgment and the reduction of wasteful medical spending will also be considerations, although careful oversight and governance will be needed in this regard given the possibility for coercion.

4.1.1 AD: A Global Perspective

During the mid-1990s, in a collaborative research setting representing the US, Germany, and Japan, I stated that the AD would be a tool that would become useful, at least to some degree, in diverse cultural settings. Given the difficulties in imagining that AD would be of any use in areas with high infant mortality rates and where health care access and palliative care are both insufficient, my statement [2] pertained to areas of the world in which modern Western medicine was well-established. The likelihood that modern Western medicine would spread and thrive throughout the entire world is low, and even if we were to reach an era and economic state where this was possible, some cultures and religions may be unwilling to accept Western medical paradigms. Therefore, the likelihood that AD and ACP might become universal and global is also low.

4.2 Withholding and Withdrawing Life-Sustaining Treatment (Especially Artificial Ventilation)

Currently in Japan, active euthanasia is illegal, but passive euthanasia, that is, withholding life-sustaining treatment in response to requests by the patient's or the legal surrogate decision-makers is not [3]. Palliative medicine is well-developed in Japan, and palliative care is covered by the national health insurance system. Theoretically, any Japanese person may go to any country where physician-assisted suicide is legal and die there, although there are few reports of Japanese people taking advantage of this option.

The unresolved controversy is that of withdrawing life-sustaining treatment, especially artificial ventilation, from terminally ill patients. This issue has caused some frustration to Japanese patients, families, and healthcare professionals for quite some time.

In 2006, a surgeon withdrew ventilator support from a patient at Imizu Municipal Hospital in Toyama Prefecture, resulting in the patient's death. In response to this, police investigated the case and filed charges, but the case was ultimately dropped due to a lack of evidence. The Ministry of Health, Labour and Welfare (Japan) issued guidelines in 2007 about decision-making procedures for terminal stage patients with no hope of recovery. These guidelines indicate that judgments about withdrawal should be based on the patient's wishes and be made by the medical care team. However, these are abstract guidelines. Moreover, at present (as of December 2019) there is no legal precedent in the Japanese Supreme Court pertaining to the withdrawal of ventilation and thus the fear that a physician might be prosecuted for homicide is legitimate. Furthermore, even if one does not face legal charges, the media in the "village society" may likely impose significant social sanctions on the physician in response to any charges filed by the police.

However, with regard to withholding medical care, there has been no litigation thus far, and as palliative medicine is well developed, negative analysis of this issue by the media has been infrequent. In this way, there are large disparities regarding the awareness of withdrawal and withholding treatment. I would argue that these disparities are caused by differences in legal and cultural interpretations of these two issues.

4.2.1 *Legal Perspectives*

Some countries consider withholding and withdrawing ventilation from a terminally ill patient as (legally) the same action. Underlying this reasoning is a basic application of the equivalence principle, which allows for both withholding and withdrawing treatment because the result (death) is the same in both cases. This consequentialist-based ideology is prevalent outside of Japan. However, a small portion of legal experts in Japan maintain that withdrawing a ventilator from a terminally ill patient is a “commission” leading directly to the patient’s death and thus define this as homicide. The most inhibiting factor is that the Supreme Court has yet to address any case involving the withdrawal of an artificial ventilator from a terminal patient. As stated above, physicians are hesitant to do so, as they fear criminal prosecution. Accordingly, in clinical settings, they continue with futile treatment until the patient’s heart stops. This portrays the practical effects of Japan’s judicial negligence. Police and the courts take action only after an incident occurs, which delays judicial decision on this matter—in this case, for decades.

4.2.2 *Cultural Perspectives*

I was surprised to read Ursin’s assertion about the situational dependency of judgments pertaining to withholding and withdrawal of treatment at the end of life, which criticized the radical application of the equivalence principle [4]. This article was from the Netherlands. I applaud Ursin’s courage in criticizing the overarching and prevailing equivalence principle. In response my colleagues and I wrote an *American Journal of Bioethics* Open Peer Commentary, presenting East Asian perspectives on this matter [5, 6].

In our commentary, we cite the *Jinen hōni* (自然法爾), used often by *Shinran* (1173–263), the founder of the *Jōdō Shinshū* sect of Buddhism. We also refer to the Confucian virtue of *jin* or *ren* (仁) as reasons why the radical equivalence principle is not well accepted in Japan.

The *Jinen hōni* presents the idea that there are no actions committed by humans; rather the world exists in accordance with the laws of nature. The ideology of

leaving things to nature carries through to the placing of moral value upon non-action rather than action. In fact, medical professionals and patient families in Japan often use the phrase “leave it to nature.”

A similar way of thinking not mentioned in the *AJOB* OPC is well illustrated in *Jūgyūzu* (Ten Ox-Herding Pictures), which consists of ten images and accompanying short poems in Zen iconography that use the herding of an ox as an analogy for training the mind on the path to enlightenment. This was composed by Zen priest *Kakuan* of the *Rinzaishū* sect (a form of Buddhism) during the Běisòng era (960–1127) in China.

There is no need to decorate or whitewash—just be as you are (*arugamama*). As it is told by the green mountains and blue waters, the beauty of the wide world fills my eyes. Sit quietly, and just behold everything in its *natural* ebb and flow. —(Translated from the original, “*arugamama*.” Author’s insertion and emphasis)

This “naturalness” or “*arugamama*” is often mentioned by patients and their families as the patient’s life is coming to an end, with those involved stating, “Doctor, please let me go as I am (*arugamama*)” or “Doctor, please let her/him go naturally.”

As another example of this concept, I would like to introduce the reader to the concept of *jin* (or *ren*), which corresponds to sentiment, the core of which is a feeling of affection. This concept represents a posture of securing, preserving, educating, and nourishing all things as one body with the same root. As such, one’s attentiveness would be focused on the patient, regardless of whether they are cognizant of this or not. This sentiment of the family becomes the desire of the family to be with the patient. What connects both the family’s sentiment and that of medical professionals is the notion of *jin* (or *ren*); this casts a negative light on withdrawal of medical care at the end of life.

In sum, the fear of prosecution and sanctions by the media and culture are two factors relevant to this issue. In the *AJOB* OPC, my colleagues and I have argued that decisions to withdraw the ventilator should be made contextually, on a case-by-case basis, and engaging the virtues of the attending physicians. However, in other cultural contexts, I suspect that other reasons may cast doubt on the radical application of the equivalent principle. Cultural diversity also influences judgments pertaining to withholding and withdrawal treatment—another reason why global dialogue is needed in the field of bioethics.

4.3 Subtle Changes in the Goals of Medicine

I was working as a resident of internal medicine in the early 1980s. Dominating our objectives at the time was the acknowledgement of the sanctity of life—otherwise known as the value of enabling a patient to continue living for even one more minute. To this end, my colleagues, supervisors, and I performed cardiac massage for terminal patients with solid cancers when their hearts stopped. From the early

1990s, I served as a part-time hospice physician for more than a decade. I never used an artificial ventilator or epinephrine injections in my hospice care. In the first place, the hospice settings had no ventilators or epinephrine; all I had was a stethoscope, a manometer, and a large supply of morphine ampules. Patients arriving at the hospice room would often comment that “the room looks like a hotel room that I could arrange as I please.”

Around the turn of the century, I noticed a subtle change in the bedside “goal of medicine” among both patients and physicians. This change reflected more emphasis on prolonging life, in the hope that new life saving treatments be developed, rather than accepting death.

In a poem by *Ryōkan* (a Buddhist monk in the *Soto* sect from the *Edo* era, 1758–1831), he writes,

Things which to the end we cannot completely discard

Even if one abandons all preoccupations, honor, social status, wealth, and family, there are still things which we human beings cannot completely discard. The final self that one should cast off [egotism; to insist upon one’s own views and intentions, and not abide by the words of others] is surely the preoccupation with life.—(Translated from the original by the author)

This subtle change in the goal of medicine is already occurring. How to deal with this change will certainly become a central ethical and social challenge by the middle of the twenty-first century. (See Original Article).

Original Article

The Goals of Medicine: Time to Take Another Look

Akira Akabayashi^{1,2}, MD, PhD; Eisuke Nakazawa¹, PhD; Arthur L. Caplan², PhD

¹Department of Biomedical Ethics, School of Public Health, The University of Tokyo Graduate School of Medicine, Tokyo, Japan

²Division of Medical Ethics, Department of Population Health, New York University School of Medicine, New York, NY, USA

Introduction

In May 2018, President Donald Trump signed into federal law the Right-to-Try (RTT). This legislation approved the use of unapproved phase one drugs by patients based upon patient choice, a doctor’s certification that death is imminent, and the fact that no other valid treatment options are available [1]. Other nations have also instituted expanded access or compassionate use programs to honor patient requests. In the US, RTT has been criticized for undermining patient safety, while not actually creating access [1–3]. A private system to implement compassionate use requests

has been created and performed much better [4]. There is, however, a deeper issue associated with RTT. That is, a subtle change in patient goals in seeking treatment.

Heightened Interest in Compassionate Use (CU)

PubMed was searched for the terms “expanded access,” “compassionate use,” and “right to try.” Fig. 4.1 summarizes changes that have occurred over the past 40 years. A marked increase in the number of CU-related articles published is evident, particularly within the last decade. As PubMed is simply a search engine for publications in the medical field, the increase in this number is not a direct indication of an increase in medical researcher interest. However, an increase in published articles on any clinical subject is evidence that the issue is emerging as significant. A LexisNexis Academic media database search for *New York Times* in 2009 and 2018 showed an increase of articles mentioning “expanded access” from 6 to 42, “compassionate use” from 4 to 16, and the “right to try” 13 to 35. On this basis we suspect that patient requests for RTT or CU are becoming increasingly common.

Dramatic Progress in Medicine Over the Past 20 Years

The progress that has been made in medicine over the past 20 years is significant. Twenty years ago, HIV infection was equivalent to a death sentence. Today, the same disease has become a controllable chronic condition. Hepatitis C can now

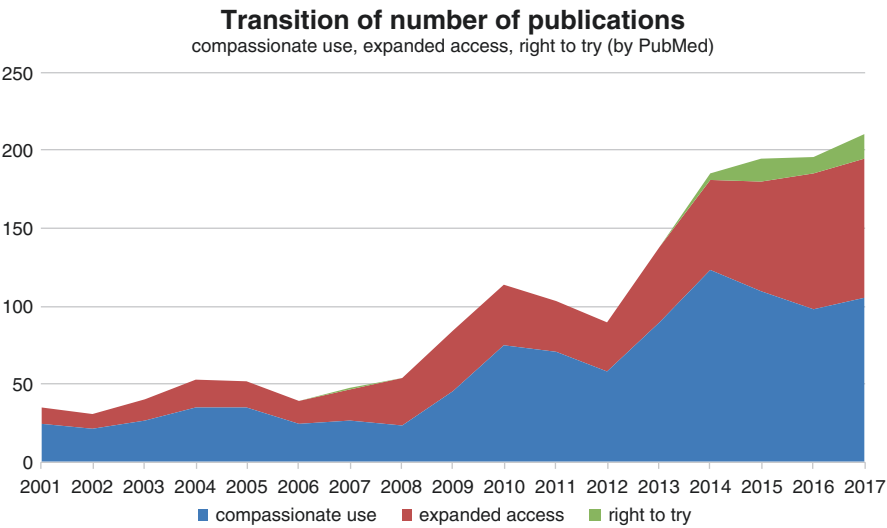


Fig. 4.1 “Expanded access,” “compassionate use,” and “right to try” were searched across the all fields in PubMed excepting for non-English papers. For “compassionate use,” we added the MeSH term. The vertical axis: number of hits. The horizontal axis: year of search

be cured. With the emergence of immune-checkpoint inhibitors [5] such as Nivolumab, many cancer patients who would have until recently been directed to palliative care are now given a realistic extension of functional (high QOL) life expectancy. The evolution of genomic medicine has been dramatic as well [6], and precision medicine is on the brink of major breakthroughs. The time is soon coming when the early prevention of disease onset or controlling the progression of many diseases may well be achieved. In addition, rapid development in regenerative medicine has become a source of hope for patients with diseases with no current viable treatment options, as evidenced, for example, by the pursuit of stem cell remedies.

These facts, as well as extensive media coverage of impending new treatments, evoke a sense of expectation in many patients. For example, some might believe that if they try to live just a little longer, some treatment may be developed in the very near future that could offer a dramatic cure. So a novel goal is emerging—patients are striving to live in the hope of being cured.

The Old Goals of Medicine Are Changing

In 1993, the Hastings Center initiated the Goals of Medicine Project. In the 1996 report, Hanson and Callahan noted four goals of medicine: (1) the prevention of disease and injury and the promotion and maintenance of health; (2) the relief of pain and suffering caused by maladies; (3) the care and cure of those with a malady and the care of those who cannot be cured; and (4) the avoidance of premature death and the pursuit of a peaceful death [7].

With the establishment of the right to self-determination in medical care, beginning in the 1960s, movements to promote dying with dignity and assisted dying gathered momentum. In the 1970s and thereafter, an “increase in QOL” came to be seen as a priority goal for medical care. The central items for medical care in the twentieth century were, therefore, self-determination and QOL. In terms of the goals of medicine, the relief of pain and suffering took a prominent position manifesting, for example, in the growth of palliative care.

Views on Life as Seen from CU and RTL

Views on life in the early twenty-first century have prioritized QOL above all else. However, rapid developments in medical care in the past 10 years brought about a subtle shift—patients now want to “live just a little longer to be cured” and their doctors agree. This contemporary view, “I want to live just a little longer in the hope of being cured,” differs from that of the late twentieth century that prioritized QOL, and a peaceful death.

This emerging view represents a synthesis, drawing together highly publicized cutting-edge medical technology. Immune-checkpoint inhibitors and regenerative medicine are both types of medical treatment that enable the simultaneous achievement of high QOL and potentially, cure. These sorts of developments are touted as offering hope.

However, the goal of cure raises tough ethical questions. What odds are worth pursuing? Do marketing and advertising overpromise what is said to be just around the corner? How should patients and their families be supported when the cures do not appear? And how much should any society spend on desperate patients seeking access to unproven treatments? Hope is important, but how far should encouraging hope of an imminent cure guide patient care and public policy?

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