
Guideline-Based Approach to End-of-Life Care Decisions in Japan: Practice, Regulation and the Place of Advance Directives

REINA OZEKI-HAYASHI, FUTOSHI IWATA,
SATOSHI KODAMA & MIHO TANAKA

13.1 Introduction

End-of-life decision-making has become an increasingly important issue in Japan, where the super-ageing of the population is progressing. To date, no legislation that specifically addresses medical considerations related to end-of-life care (e.g. advance directives [ADs]), forgoing life-sustaining treatment) has been enacted. End-of-life decision-making on care and medical treatment continues to be dealt with primarily according to the Ministry of Health, Labour and Welfare guidelines, which make no mention of ADs, although they are based on the ideas of ADs and advance care planning (ACP).

Despite the lack of formal AD regulation by way of laws or guidelines, and therefore uncertainty about their place in the end-of-life care context and the potential legal implications of AD implementation, empirical data suggest that ADs are in fact discussed and used in Japanese practice. How these data should be interpreted, however, is far from straightforward. There is evidence, for example, that whilst attitudes towards ADs have become more positive over time, there is still a large discrepancy between such attitudes and AD practice. In light of all this, how do ADs fit into the Japanese legal and sociocultural context, and the end-of-life process in particular? This is one of the questions we consider in this chapter, which begins with an examination of issues related to the withdrawal of life-sustaining treatment through court cases and incidents in the past few decades. We then discuss the process guidelines on end-of-life decision-making, national attitude surveys on end-of-life issues and sociocultural factors that have a potential impact on ADs and ACP in Japan.

13.2 A Brief History of Court Cases Dealing with End-of-Life Decisions

The past 30 years have seen some of the most important issues concerning decision-making on end-of-life care raised in Japan. There is no specific statute that recognises the legally binding nature of end-of-life decisions about ADs and do not attempt resuscitation (DNAR) orders and no legal definition of ADs, and only a few court cases have interpreted the basic murder provisions of the substantive criminal law (Penal Code s. 199)¹ and the general negligence provision (Civil Code s. 709)² that governs end-of-life discussions. Furthermore, no official entity (e.g. public advocate, ombudsperson, public guardian) is tasked with protecting the rights of the elderly and the validity of the medical decision-making process.³ The illegality of active euthanasia has been established in a few cases.⁴ One of the most important developments in this area was the creation by the Ministry in 2007 of so-called process guidelines (see Section 13.3), which are formulated around end-of-life care and treatment more broadly.⁵ Several medical colleges also subsequently created guidelines based on the process guidelines. However, because these guidelines are not legally binding,⁶ it may remain difficult in practice for a patient/family to align a medical care team's strategy with the patient's decision and to obtain judicial relief if the team intentionally

¹ Keiho [Penal Code], Act No 45 of 24 April 1907.

² Minpo [Civil Code], Act No 89 of 27 April 1896.

³ In Victoria, Australia, the Public Advocate is an independent statutory officer who promotes and safeguards the rights and interests of people with disabilities and investigates allegations of abuse of vulnerable Victorians. See Office of the Public Advocate, "The Public Advocate", www.publicadvocate.vic.gov.au/the-public-advocate. See also the Guardianship and Administration Act 1986 (Guardianship and Administration Act 2019) and Medical Treatment Planning and Decisions Act 2016.

⁴ Hanrei-Times No. 877, 148 [in Japanese]. The Tokai University Hospital case was the first case in which a doctor was convicted of homicide, and thus differs from previous cases in which family members were convicted of homicide.

⁵ Ministry of Health, Labour and Welfare, "The Decision-Making Process for Terminal Medical Treatment" (Process Guidelines) (May 2007). The title of the guidelines was changed to "The Decision-Making Process for Final Stage of Life" (Process Guidelines) (March 2015) and was changed again to "The Decision-Making Process for Final Stage of Life Treatment and Care" (Process Guidelines) (March 2018).

⁶ Our discussion is based on the idea that regulations and law are not limited to case law or administrative guidance with or without penalties. Rather, they include "soft laws", such as guidance provided by medical colleges and professional medical societies. Soft laws can eventually be taken into consideration by the courts when it comes to judgments on the reasonableness of conduct or standard of care or justification (or excuse) in criminal law.

or negligently ignores the patient's wishes,⁷ although relief may be provided by the courts by taking into consideration whether the conduct concerned fell below the standard of care in tort cases or can be excused or justified in murder cases. In this sense, the Ministry's process guidelines and medical colleges' guidelines offer a regulatory tool to aid the courts in interpreting relevant laws. There have been calls for enactment of a Natural Death Act (known as the AD Bill) by the Japan Society for Dying with Dignity and non-partisan Diet members, although such legislation has yet to be realised by the Japanese government, and is unlikely to be so in the near future.⁸

Most developed countries, including the United States and Australia, have a similar medico-legal framework to that of Japan, and treatment without patient consent is considered unlawful under civil and, in rarer situations, criminal law. In other words, patients

⁷ We understand that there are situations in which statutory protection would benefit patients in terms of respecting their wishes. Yet, given the developments in and limitations of living will (LW) and AD discussions in the United States and other countries over the past 40 years, the enactment of ADs may not be a panacea for improving end-of-life care. Even with such statutory protection, it is clear that many people do not have ADs. Moreover, because people cannot predict their future, greater weight is often placed on family agreement than on a patient's AD. See, e.g., S.M. Wolf et al., "Forty Years of Work on End-of-Life Care – From Patients' Rights to Systemic Reform" (2015) 372 *New England Journal of Medicine* 678.

⁸ Interestingly, not only medical professionals but also ordinary citizens are strongly opposed to the enactment of end-of-life legislation (discussed in Section 13.5). In 2012, a group of non-partisan Diet members proposed a draft Bill for Respecting the Patient's Decision in End-of-Life Care Act (provisional name; hereafter, "draft AD Bill") that would offer immunity to physicians if they withheld or withdrew life-sustaining treatment in accordance with a patient's AD. As of 2020, however, the proposed draft AD Bill had yet to be submitted to the National Diet. See note 23. At present, it has no real prospect of being enacted, and, more importantly, there has been strong criticism of the efficacy of this type of enactment and the side effect of such a statute (namely, that physicians may try to strictly follow the literal meaning of the statute rather than considering its main purpose and spirit). Even in the United States, there is strong criticism of the effectiveness of this kind of legislation (e.g. Natural Death Act and ADs legislation) for improving the quality of end-of-life care. Wolf et al. (note 7) argued that the quality of end-of-life care has not improved in the 40 years since enactment of a patient's right to refuse treatment (LWs) and AD legislation. Considering that the enactment of LW and AD legislation in other developed countries has not proved to be a panacea, it is at least debatable whether Japan needs to follow their path in legislating ADs (see note 7). Some researchers and advocacy groups for severely disabled patients are concerned that legislation on death with dignity would not ensure respect for the rights of severely disabled people, specifically their right to receive life-supporting treatment. See further E. Nakazawa et al., "Why Can't Japanese People Decide? Withdrawal of Ventilatory Support in End-of-Life Scenarios and Their Indecisiveness" (2019) 11 *Asian Bioethics Review* 343, 344.

have the right to refuse treatment at any time, especially before treatment is initiated, which is basically the same as what the informed consent theory requires, although courts in Japan typically do not use the expression “informed consent”. However, it is debatable whether the right of patients to refuse treatment automatically guarantees the withdrawal – upon patient request – of life-sustaining treatments to which they themselves consented. The Japanese courts view the withholding and withdrawal of treatment to impose different duties on medical professionals;⁹ that is, once they start treatment, it is their duty to continue it to preserve the patient’s life. Many doctors believe that a patient with amyotrophic lateral sclerosis (ALS), for example, can legally refuse ventilator support; however, once the patient is placed on ventilator support, doctors are legally bound to continue using the ventilator even if the patient asks them to remove it unless the patient’s condition becomes terminal (the courts use the expression “imminence of death”). Whilst there is no case law or legislation that definitively resolves this matter, it could be argued that an answer, at least to some extent, can be found in the Ministry’s process guidelines, an argument we make in this chapter.

Several provisions in Japanese criminal law address the protection of human life, such as prohibiting homicide (Penal Code s. 199) and aiding suicide (Penal Code s. 202), although suicide itself is not punishable by law. These two provisions are generally understood as making it clear that terminating one’s life cannot be justified simply as an autonomous decision because the Penal Code prohibits assisting death, even if it is the victim’s autonomous wish. In light of these provisions, the most important question for our purposes is how much leeway is allowed, or to what extent the withholding or withdrawal of treatment should be considered permissible.

Two criminal cases, the 1998 case of Kawasaki Kyodo Hospital and the 2000 case involving Imizu Municipal Hospital, were the major drivers of the development of the Ministry’s process guidelines, which embody the concept of patient autonomy, with the medical care team taking on a facilitating role. Uncertainty over whether medical professionals would face legal consequences as a result of withdrawing medical treatment was

⁹ T. Irie [Former Judicial Research Officer of the Supreme Court of Japan], “Saikosai Tokino Hanrei: Keiji (Saikousai Heisei 21 12/7 Kettei) [Supreme Court Recent Case: Criminal]” (2012) 1446 *Jurisuto* 91, 93 [in Japanese].

a central focus of both cases, pushing the Ministry to address end-of-life care more extensively by creating the process guidelines.¹⁰

The most important judgment concerning the withdrawal of treatment and active euthanasia in Japan is the 2009 Supreme Court ruling in the Kawasaki Kyodo Hospital case. In that case, an attending physician had removed an endotracheal tube from a patient who was in a comatose state owing to bronchial asthma with the consent of the patient's family. The physician had then administered intravenous muscle relaxants to ease the patient's death.¹¹ The physician was charged with and convicted of murder by the court in 2005. In 2007, the Tokyo High Court reduced the sentence in half, to one year in prison, suspended for three years, a sentence affirmed by the Supreme Court in 2009. This was the first Supreme Court case concerning the issue of end-of-life decisions. The court decided that it was premature to consider whether the physician's conduct (i.e. withdrawing the tube and injecting lethal drugs) was justifiable or excusable as an exception to murder. According to the court, only after objective criteria have been met can the issue be considered (e.g. the "imminence of death" condition was not clearly established in this case). More specifically, because no brain death test had been conducted, and no consultation with the hospital president or peer physicians had been sought, the court maintained that it did not need to discuss the validity of withdrawing treatment as an exception to the murder provision. Even assuming that the removal of the endotracheal tube had been done with the family's consent, the physician's explanation was considered legally insufficient and inaccurate, that is, not a valid basis for consent, because the physician was not herself aware of the patient's medical diagnosis and prognosis.

In its ruling in the case, the Tokyo High Court (one of eight appellate courts) included the following frank statement: "A fundamental solution to the problem of death with dignity in such cases would require the enactment of a Death with Dignity Act, or alternatively, a set of guidelines". ("Namely, the court felt uncomfortable . . . creat[ing] leeway to allow active euthanasia and/or [the] withholding and withdrawal of treatment through interpretation", explained Judge Kunio Harada, one of the three judges.¹²) In other words, the issue of death with dignity

¹⁰ This is relevant to our discussion of ADs because, like ADs, the process guidelines on end-of-life patient care are predicated on the central concept of patient autonomy.

¹¹ *Hanrei-Times* No. 1185, p. 114; >*Hanrei-Times* No. 1237, p. 153; *Hanrei-Times* No. 1316, p. 147 [in Japanese].

¹² K. Harada, "Shumatuki-iryo To Keiho [Terminal Stage and Criminal Law]" (15 April 2009) 1377 *Jurisuto* 86, 109 [in Japanese].

should be the subject of a broader national consensus, the outcome of which should be a law or set of guidelines rather than something to be decided by the courts amidst their prevalent deference to the legislative and executive branches.

In the Imizu Municipal Hospital case, which occurred in 2000, an attending physician had discontinued the use of a ventilator in seven terminally ill patients at the request of the patients or their families. All of the patients died following the discontinuation of ventilator support.¹³ In response to media reports, the hospital director publicly apologised for the physician's "unethical" decisions. The police subsequently investigated the patients' deaths and filed a report with the local prosecutor's office in 2008 indicating that there was no need for punitive action. The case was dropped in 2009 on the ground that causation could not be established (i.e. the causes of the deaths were unclear).¹⁴ This case understandably created considerable confusion and uneasiness in the medical field.

In 2007, soon after the Tokyo High Court decision on the Kawasaki case and the reporting of the Imizu case, the Ministry issued process guidelines on the withdrawal of life-sustaining treatment,¹⁵ followed by the publication of more specific end-of-life care guidelines¹⁶ by several professional associations.

13.3 The Process Guidelines

The Ministry's process guidelines, which came into force in 2007, are not linked to any legislation and have no penalties,¹⁷ nor are ADs explicitly mentioned therein. Nevertheless, these guidelines are widely regarded as

¹³ "The Suspicious Death: The Hospital in Toyama Prefecture 'Seven Patients Euthanised' 50-Year-Surgeon Switched off Artificial Ventilators from Patients" (25 March 2006) *The Mainichi* [in Japanese]; "The Hospital 'the Physician Withdrew Treatments' after Switching off Artificial Ventilators from Seven Patients; They Died 'Ethically Problematic'" (26 March 2006) *The Asahi Shimbun* [in Japanese].

¹⁴ "Removing Artificial Ventilators in the Imizu Municipal Hospital: Two Physicians Not Prosecuted" (21 December 2009) *The Yomiuri Shimbun* [in Japanese].

¹⁵ See note 5.

¹⁶ The "2014 Guideline on End-of-Life Care in Acute Care and Intensive Care" (compiled collaboratively by the Japanese Association for Acute Medicine, Japanese Society of Intensive Care Medicine and Japanese Circulation Society), the "2007 Guideline on End-of-Life Care" (Japan Medical Association) and the "2012 Guideline for Decision Making Process of Elderly Care: Focusing on the Use of Artificial Hydration and Nutrition" (Japan Geriatrics Society).

¹⁷ Although the conduct of healthcare professionals in breach of these guidelines is not directly punishable, whether or not they acted in accordance with them may matter if

representative of the Ministry's official position on end-of-life care issues, and are thus the currently most influential document in this arena. The process guidelines consist of two core elements: (1) respect for patients' wishes, which is stated as the most important principle in the guidelines¹⁸ and (2) decision-making led by the healthcare team (i.e. not by the attending physician alone). The guidelines stipulate that the healthcare team shall make healthcare decisions through repeated discussions with the patient and his or her family, with particular emphasis on respect for the patient's choice. They also specify that if a patient cannot express his or her wishes, then the healthcare team shall decide on the best course of care in light of the family's wishes. The guidelines further recommend that if it is difficult for the healthcare team to reach consensus with the patient/family, a committee comprising multiple experts should be set up for consultation purposes.¹⁹ In this manner, the process guidelines place significant emphasis on consensus-building amongst those involved in the patient's end-of-life care. Notably, it is clearly stated that the issue of active euthanasia is outside the scope of the guidelines, meaning that no change is imposed by the guidelines regarding the illegality of active euthanasia (i.e. administration of lethal drugs).

The process guidelines purposely specify only procedural matters in relation to end-of-life treatments, rather than the substance of those treatments, which is why they are referred to as "process" guidelines. There are two main reasons why the guidelines do not prescribe which treatments can be withheld or withdrawn: (1) it is difficult to prescribe which treatments are permissible/impermissible, as a variety of situations exist depending on patients' type of illness and prognosis, their wishes and family situation, and their relationships with doctors, nurses and care workers (also, because existing guidelines rarely address these issues, the relevant committee in the Ministry responsible for developing these guidelines felt that it was up to medical and care specialists/societies to develop specific guidelines as appropriate); and, more importantly and (2) to improve the quality of care at the end of life, it is necessary to

they are accused of having civil, criminal or administrative liability. In that sense, the process guidelines are loosely binding on healthcare professionals.

¹⁸ Process Guidelines, para. 1.1.

¹⁹ Whilst informed decision-making by the patient and family is a key aspect of the guidelines, the fact that consensus must be reached between the healthcare team and the patient suggests that patient wishes are perhaps not the most important consideration therein.

consider a longer process of dying without limiting the question to whether to start or stop a particular treatment.

The guidelines also call for improvements in palliative care. The Japanese government responded to that call by implementing measures to promote palliative care and ACP. The Cancer Control Act²⁰ was enacted at almost the same time as publication of the guidelines. The PEACE (Palliative care programme Emphasizing symptom management and Assessment for Continuous medical Education) Project, an educational programme for basic palliative care, was also subsequently initiated. In 2014, revisions to the medical insurance reimbursement system made it a requirement to calculate the “cancer patient management guidance fee”. The mandatory participation of at least 90 per cent of oncologists at each institution in the PEACE Project workshop led to a rapid increase in the number of programme participants.²¹ With regard to ACP, E-FIELD (Education for Implementing End-of-Life Discussion), an educational programme aimed at facilitating ACP, was launched in 2014. Despite these efforts by the government, there is still an insufficient number of medical practitioners who can implement ACP. In 2018, the Ministry revised the process guidelines to bring the idea of ACP into focus and to broaden the scope of the guidelines to include all care settings, such as nursing homes and home care, emphasising the importance of healthcare proxies. It is interesting to note here that even though the 2018 revisions focus on good practice in ACP, there is still no mention made of ADs, although they are based on the ideas of ADs and ACP.

13.4 Issues with the Process Guidelines

The process guidelines fall short in three respects. First, there is no clear definition of what constitutes the “end of life”, or terminal stage of illness, in the main body of the guidelines, even though their title contains the phrase “end-of-life treatment”. Thus, there is ambiguity over when a patient is considered to be “terminal”, and the judgement of whether a patient is facing the end of his or her life is left to the discretion of the

²⁰ A law to promote comprehensive measures against cancer, the leading cause of death in Japan.

²¹ T. Morita and Y. Kizawa, “Palliative Care in Japan: A Review Focusing on Care Delivery System” (2013) 7 *Current Opinion in Supportive and Palliative Care* 207.

healthcare team members assessing the patient's condition.²² The committee responsible for development of the process guidelines felt it was better to leave the issue to the professional discretion of medical specialists, as end-of-life situations vary depending on illness, age and other factors. For example, in neurological diseases such as ALS, it is difficult to define the end-of-life stage owing to the chronic and incurable nature of the diseases, and whether the concept of "end of life" is applicable in this context is a highly complex question. As this lack of clarity may result in inconsistencies in application, further discussion is needed to address this issue.

Second, there have been discussions regarding the ambiguity of whether healthcare professionals who withhold (or withdraw) life-sustaining treatment according to the guidelines should be held liable under criminal or civil law. The process guidelines are not legally binding because, although issued by the Ministry, they lack supporting statutes. Some scholars, including two of the authors of this chapter (Kodama and Tanaka), believe that legislation is necessary to ensure immunity for healthcare professionals who discontinue life-sustaining treatment.²³ Indeed, the Guidelines for the Treatment of Amyotrophic Lateral Sclerosis acknowledge that removal of ventilator support is a difficult issue, as it is currently unclear what the legal basis for doing so would be. Further discussion is warranted to reach social consensus on this issue.^{24,25} Having said that, however, to the best of our knowledge (although no official statistics are available), there has been no instance of a police investigation or prosecution concerning the withholding or withdrawal of life-sustaining treatments since the establishment of the process guidelines in 2007. Even prior to that year, no case of withheld treatment was subjected to police investigation or prosecution. In fact,

²² Ministry of Health, Labour and Welfare, "Press Release Regarding the Revised Guideline on Medical Decision-making Process at the Final Stage of Life: Commentaries on the Guidelines for the Decision-Making Process for End-of-Life Treatment and Care" (2018), www.mhlw.go.jp/file/04-Houdouhappyou-10802000-Iseikyoku-Shidouka/0000197702.pdf [in Japanese].

²³ M. Tanaka et al., "Forgoing Life-sustaining Treatment – A Comparative Analysis of Regulations in Japan, Korea, Taiwan, and England" (2020) 21 *BMC Medical Ethics*.

²⁴ Japanese Society of Neurology (eds.), *Clinical Practice Guideline for Amyotrophic Lateral Sclerosis 2013* (Tokyo: Nanko-do, 2013), pp. 138–9 [in Japanese].

²⁵ Social consensus is key here, as the correct formulation of a law that is fundamentally about ethical uncertainty about which people in Japan could reasonably disagree arguably requires a public consultation process as part of the development of overarching governance of the issue.

no case of withdrawn treatment *not* categorised as active euthanasia (i.e. use of lethal injection, discontinuation of ventilator support in non-terminal patients) has ever been subjected to criminal prosecution (in the 1996 Kokuho Keihoku Hospital case, the police investigated the use of muscle relaxants on a terminal cancer patient but decided not to prosecute). Moreover, only a few police investigations have been conducted in cases involving the withdrawal of ventilators (i.e. 2004 Hokkaido Haboro Hospital case, 2006 Wakayama Medical University Kikoku Hospital case). There is some anecdotal evidence suggesting that healthcare professionals are unlikely to be held liable, criminally or civilly, as long as they follow the process guidelines and subsequent guidelines.²⁶ According to some jurists, including one of the authors of this chapter (Iwata), the process guidelines are broadly interpreted to permit the withdrawal of end-of-life treatment in cases where patients state their clear wishes,²⁷ and even in cases where patients do not explicitly express their wishes. Although some areas of ambiguity remain, there is growing recognition that no penalty will be imposed for withdrawing life-sustaining treatment in accordance with the guidelines. Further qualitative and quantitative research covering healthcare professionals, as well as national data on treatment withdrawal, is needed to understand the impact of the guidelines on the practice of healthcare professionals, however.

Third, while the process guidelines are an important, if problematic, development in determining the framework for end-of-life patients, the lack of proper legislation on ADs in Japan remains a concern, as patient-

²⁶ For example, the “2012 Guideline for Decision Making Process of Elderly Care: Focusing on the Use of Artificial Hydration and Nutrition” (Japan Geriatrics Society) has an appended list of lawyers and law professors, including four former and one current Supreme Court Justices and a former High Court Judge who was involved in the 2007 Kawasaki case decision, which supported the guideline, and the following statement: “It is practically unlikely to have any judicial intervention if medical teams withdraw AHN [artificial hydration and nutrition] and treatment based on the draft Guidelines. If there was any judicial intervention, it would be highly inappropriate”, www.jpn-geriatrics.or.jp/proposal/pdf/jgs_ahn_gl_2012.pdf [in Japanese].

²⁷ In Japan, there is no standard “AD form” that is provided by law or administrative guidelines. There is, however, a notarial system that can be used for such purposes, and there are also various AD documents prepared by healthcare systems, local governments, regional medical associations, the Japan Death with Dignity Association and other public institutions and private companies. Patients and their families can share these documents with healthcare professionals in the hope that they will inform treatment decisions. Although there is no law governing the handling of such written documents, they are usually included in patients’ medical record.

centred decision-making can be difficult to enforce without it. In the specific context of emergency care settings (ambulance transport), for example, there may be significant gaps between the attitudes of, and measures taken by, paramedics and municipal ambulance departments and processes for respecting the wishes of the patient as set forth by the guidelines. For example, a family member in distress in the face of an emergency situation may request ambulance transport against the prior wishes of the patient, with resuscitation being attempted as a result. In other words, ADs may not be utilised in the field of emergency transport. What should be done when a person who does not wish to receive cardiopulmonary resuscitation (CPR) is rushed to hospital with cardiopulmonary arrest? This issue concerning DNAR has been debated since the 2010s.²⁸ If a patient with DNAR wishes experiences a sudden physical change, his or her family may call an ambulance, even though doing so runs contrary to the patient's wishes. In other situations, such as those in elderly care facilities, facility staff may not be fully aware of every resident's wishes regarding CPR. Once an ambulance arrives, paramedics provide emergency treatments (e.g. life-prolonging treatments) even if the patient has written a living will (LW) or the family has conveyed the patient's wish not to receive CPR, with the doctor's confirmation (it is widely and wrongly believed that paramedics are legally required to administer CPR). Studies show that when elderly individuals suffer cardiac arrest, they are unlikely to recover even with aggressive treatment. At best, they become vegetative or comatose. Nonetheless, CPR is still sometimes performed by the paramedics of some ambulance departments, who believe that doing so is a legally binding duty, despite the development of a national policy to respect a person's wish at the end-of-life stage, including the inclusion of the ACP concept in the revised 2018 process guidelines.

Moreover, the importance of legislation, guidelines and other measures by local medical control councils to educate paramedics on the provision of medical treatment and to review their practices has been highlighted by the Ambulance Department's committee on this issue. The current prevailing interpretation is that it is "not illegal" to transport a patient without performing CPR, or to not transport him or her at all in accordance with his or her wishes, if those wishes are confirmed by the

²⁸ Y. Nakagawa et al., "Do Not Attempt Resuscitation Order in Japan" (2017) 4 *Acute Medicine & Surgery* 286.

attending physician.²⁹ In the emergency context, procedures vary by locality, and there are no uniform national rules. In the event of an emergency, confirmation of the patient's intentions should be sought from the attending physician (family doctor), and, if the attending physician cannot be reached, the relevant decision may be made by an online medical control physician.

13.5 Public Attitudes towards Advance Directives

In this section, we discuss the attitudes of the general public and health-care professionals towards ADs and ACP. It is interesting to note that in some Japanese publications, AD is not used in its conventional sense to refer to something prepared by the individual in question, but rather to an individual's presumed intentions based on discussions with family members, which makes it difficult to perform cross-study comparisons. Hence, a broader understanding of the concept of ADs may be more appropriate in the Japanese context, especially given the emphasis on the role of the family in patient-centred care, which will be further discussed in Section 13.6.

First, we examine the results of a national attitude survey on end-of-life issues administered by the Ministry in 2018. National attitude surveys are conducted every five years. Although ADs are not legally binding, they were included in the survey because of the efforts of the Japan Society for Dying with Dignity, which has been calling for the discontinuation of futile life-sustaining treatments in Japan since the Quinlan³⁰

²⁹ The final report of the Ambulance Agency (Ambulance Service Planning Division of the Fire and Disaster Management Agency) working group on DNAR, of which Iwata was a member, was issued in 2018. The 2018 report includes the details of initiatives by a number of prefectural ambulance departments (e.g. Hiroshima City). According to the Hiroshima City Ambulance Service initiative, paramedics can transport patients with DNAR wishes without any aggressive treatment or leave the scene without any intervention if the patient's doctor confirms that he or she is in fact at the end-of-life stage and wishes to receive no CPR. This is the service's way of respecting patients' wishes, as made clear by the patients' own writing or a family statement. For further details, see N. Higuchi, "Kyukyugenba-to-DNA: Houteki-kenen [The Scene of Emergency and DNA: Legal Concern]" (2021) 33 *Pure-Hosupitaru Kea* [Prehospital Care] 22 [in Japanese].

³⁰ In 1975, Karen Ann Quinlan lost consciousness and stopped breathing after returning home from a party. She had no prospect of recovering consciousness. Her parents filed a lawsuit to stop the life-sustaining treatment, because Karen did not want to live on a ventilator. In March 1976, the New Jersey Supreme Court ruled 7–0 that the right to privacy guarantees the right to withdraw life-sustaining treatment, and in this case, the parents could make the decision for Karen. The Quinlan case shed light on the difficult

case in the United States. Furthermore, the Science Council of Japan and other organisations also took up the issue of ADs in the wake of the Tokai University Hospital case. Both the general public and physicians (66 and 77 per cent, respectively) expressed support for ADs in the survey. However, within these groups, only 8 and 6 per cent, respectively, responded that they had completed their own ADs.³¹ The AD completion rate in Japan is quite low compared to that in Western countries (e.g. 36.7 per cent in the United States³²), a phenomenon discussed in further detail later in the chapter. The rate of agreement with AD legislation was almost the same for physicians and the general public, with 20 per cent supporting AD legislation, 40 per cent responding that such legislation was unnecessary and 10 per cent opposing it. With respect to the use of written ADs, almost 50 per cent of healthcare professionals responded that they do not use any specific document, but discuss patients' wishes regarding end-of-life treatment when patients ask them to do so.³³ It has been suggested that these results reflect traditional Japanese attitudes; that is, the Japanese consider it more "comfortable" to have things decided in a certain way through family conversations rather than through written ADs.³⁴

Second, we consider the attitudes of physicians towards ADs, as demonstrated by various studies over the past two decades. In a study conducted in 2003, nearly 70 per cent of general practitioners responded that they would not change their treatment even if informed of the

question of what should and should not constitute life. The right-to-die movement is trying to help the courts better define the boundaries between life and death and fulfil their mission of preventing murder while respecting the desire to preserve human dignity. For further details, see I.M. Kennedy, "The Karen Quinlan Case: Problems and Proposals" (1976) 2(1) *Journal of Medical Ethics* 3.

³¹ These figures correspond to the results of a 2018 study by Tsuda et al., which found that only 1.9 per cent of patients had written ADs and that 32 per cent entrusted their decision-making to doctors or family members (see further S. Tsuda et al., "Impact of Patients' Expressed Wishes on Their Surrogate Decision-Makers' Preferred Decision-Making Roles in Japan" (2018) 21 *Journal of Palliative Medicine* 354).

³² K.N. Yadav et al., "Approximately One in Three US Adults Completes Any Type of Advance Directive for End-Of-Life Care" (2017) 36 *Health Affairs* 1244, 1247.

³³ Ministry of Health, Labour and Welfare, *Report of the Awareness Survey on End-of-Life Medical Treatment* (2018), pp. 89–90, www.mhlw.go.jp/toukei/list/dl/saisyuiryo_a_h29.pdf [in Japanese].

³⁴ M. Mori and T. Morita, *The Evidence of Advance Care Planning* (Tokyo: Igakushoin, 2020), p. 135 [in Japanese].

presence of an LW³⁵ for the following reasons: (1) official formats for and the regulation of LWs are lacking; (2) the process for ascertaining the wishes of patients with dementia or interpreting what death with dignity means to individual patients according to their LWs is unclear; (3) the timing for the use of LWs is unclear; and (4) an ethical challenge to following LWs arises when patients and/or their families decline a treatment based on a misunderstanding of its effectiveness.³⁶ A 2010 survey of palliative care physicians found the proportion of physicians who “always” or “very often” ask their patients about existing ADs to stand at 46.9 per cent. The proportions who “always” or “very often” recommend that patients designate a healthcare proxy or complete an AD in the event they lose their decision-making capacity were 40.4 and 30.3 per cent, respectively.³⁷ The discrepancy in physician attitudes in the two studies is likely explained by the very different study populations: the 2003 study focused on general practitioners, whilst the 2010 study concerned specialised palliative care physicians.

Interestingly, an annual survey of the bereaved families of patients with LWs conducted in 2019 by the Japan Society for Dying with Dignity (which promotes the use of LWs) revealed that 85 per cent of the families had provided the patients’ LWs to their healthcare providers and that 94 per cent of LWs were honoured, although the survey provided no details on what changes had been made to treatments or which wishes were followed by doctors.³⁸ Whilst these data demonstrate a high degree of respect for LWs amongst healthcare providers, members of the Japan Society for Dying with Dignity often use a prescribed form of LW that is well recognised by healthcare providers, which makes it much more likely that their LWs will be respected and implemented.

Third, we discuss research conducted in nursing home settings, in which ADs play an important role. A relatively high proportion of ADs are created in nursing homes, presumably because the residents of geriatric healthcare facilities are elderly people, many with declining cognitive

³⁵ The term “living will” is used instead of AD in this section on empirical data about public attitudes where that term is employed in the study being discussed.

³⁶ Y. Masuda et al., “Physicians’ Reports on the Impact of Living Wills at the End of Life in Japan” (2003) 29 *Journal of Medical Ethics* 248.

³⁷ K. Nakazawa et al., “Palliative Care Physicians’ Practices and Attitudes regarding Advance Care Planning in Palliative Care Units in Japan: A Nationwide Survey” (2014) 31 *American Journal of Hospice and Palliative Medicine* 699.

³⁸ The Japan Society for Dying with Dignity, “Goizoku Anketo [Bereaved family questionnaire 2019]”, <https://songenshi-kyokai.or.jp/archives/2131>, p. 9 [in Japanese].

function. Prior confirmation is necessary, as such residents are unlikely to be able to express their wishes should a sudden change in their medical condition occur. In one study of nursing home care providers, 28 per cent indicated that they encourage their residents to express their wishes regarding end-of-life care at the time of admission, regardless of whether they are in the final stage of life, and 70 per cent declared that it is their policy to confirm the wishes of residents at the time of admission.³⁹ In a recent survey, more than half of nursing homes responded that they have adopted a particular AD format (with some variation). These ADs are basically instructional directives and include documents providing explanations and/or informed consent for end-of-life care in nursing homes.⁴⁰ However, personal choice-type directive formats were more often introduced during admission to the nursing homes that took part in the survey. They require the signature of a family member (68.3 per cent), the resident himself or herself (48 per cent) and/or a staff member (31.0 per cent). Amongst explanation-and-consent directives, which are more common in end-of-life care situations, 97.2 per cent require the signature of a family member.⁴¹ Therefore, it appears that, unlike ADs in Western countries, ADs in Japanese nursing homes place heavy emphasis on family involvement, and it is debatable whether such ADs can be considered the equivalent of those in Western countries.

In terms of why ADs appear to be more common in the nursing home setting, additional funding for end-of-life care became available in 2006 as an initial step to provide economic support for terminal care in Japanese nursing homes,⁴² and such funding could well have been a catalyst for increasing the number of ADs produced in nursing homes. To be eligible for the funding, nursing homes are required to fulfil five high-level care requirements: employ a registered nurse as the team leader, provide end-of-life care guidelines on admission, operate a 24-hour on-call nursing system, provide staff training in end-of-life care and have private rooms available for residents. Every resident is also required to have a diagnosis of the end-of-life (terminal) stage made by a physician, and informed consent in relation to end-of-life

³⁹ J. Okochi, "End-of-Life Care at Nursing Homes" (2020) 2 *Geriatrics* 532 [in Japanese].

⁴⁰ Y. Takezako et al., "Advance Directives in Japanese Nursing Homes" (2013) 45 *Journal of Pain and Symptom Management* 63, 65.

⁴¹ *Ibid.*, p. 67.

⁴² E.g., Minna No Kaigo [Nursing for Everyone], "The Government to Consider Additional Funding for End-of-Life Care in Nursing Homes" (2021), www.minnanokaigo.com/news/kaigogaku/no975/ [in Japanese].

care preferences (e.g. CPR, artificial nutrition) must be obtained from residents or family members. It thus appears that discussions regarding advanced end-of-life care are encouraged in nursing homes to a greater extent than in other settings.⁴³

13.6 Sociocultural Factors Related to the Completion Rate of Advance Directives

Finally, we discuss several sociocultural factors that may contribute to the completion and implementation rates of ADs in Japanese medical and care settings.

13.6.1 *Family-Centred Decision-Making*

In Japan, family-centred decision-making is prioritised because people remain influenced by the family-centric beliefs inspired by Confucianism.⁴⁴ In a study examining the facilitators of and barriers to the completion of ADs from the patient perspective, the participants regarded such completion as a parental responsibility owed to children.⁴⁵ Amongst the views they expressed were that written ADs allow for a death without any futile life-prolongation and free their children from a caregiving burden should they become disabled. These views motivated the participants to complete ADs. However, some participants expressed negative views concerning how ADs function in actual decision-making. They were aware of the decision-making norm in Japanese society whereby family consensus typically overrides patient autonomy. The study's authors suggested that the participants understood family-centredness to constitute values shared across the generations, as they themselves had fulfilled the responsibilities expected by their families throughout their lives.

Similarly, Nakazawa et al. found that, in addition to concerns over uncertainty and propriety with respect to successful AD implementation, the involvement of cultural preferences in family-centred decision-making near the end of life also influences AD practice by physicians.

⁴³ See note 41.

⁴⁴ J. Kwak and W.E. Haley, "Current Research Findings on End-of-Life Decision Making among Racially or Ethnically Diverse Groups" (2005) 45 *Gerontologist* 634.

⁴⁵ S. Tsuda et al., "Group-Based Educational Intervention for Advance Care Planning in Primary Care: A Quasi-experimental Study in Japan" (2019) 18 *Journal of Asia Pacific Family Medicine*.

Whilst the physicians in their study generally expressed positive attitudes towards ADs, their practices with respect to ADs, for example, recommending that patients complete ADs, did not reflect those attitudes.⁴⁶

13.6.2 *Character Traits*

According to some studies,⁴⁷ there are several character traits in Japanese culture that may contribute to the low AD completion rate in Japan. First, *omakase* (when someone asks family members, close friends or medical doctors to take responsibility, it is called *omakase*⁴⁸) is commonly seen in elderly Japanese patients. These patients feel unburdened by not having to make difficult decisions for themselves even when they are capable of making their own decisions.⁴⁹ This *omakase* character trait is based on the Japanese psychological factor of *amae*. *Amae* in medical practice is manifested in the attitude of patients who do not wish to make any decisions regarding their course of treatment, but instead have someone else decide what is best for them. Patients can thus both avoid making a difficult decision and taking responsibility for it. If patients ask someone else to decide what is best for them, they can live as usual without thinking about their death, and hence they also do not need to think about an AD. In this sense, *omakase* is a likely cultural factor contributing to the low AD completion rate in Japan.

Second, the “reticence” of many elderly Japanese people, which causes them to hide their real thoughts, may also affect the end-of-life decision-making process. This character trait often interacts with the importance of the family in Japanese culture, as discussed previously. Reticence is often observed in people who, for example, want to avoid overburdening

⁴⁶ See Nakazawa et al., note 8.

⁴⁷ Y. Hirayama et al., “Japanese Citizens’ Attitude toward End-of-Life Care and Advance Directives: A Qualitative Study for Members of Medical Cooperatives” (2017) 18 *Journal of General and Family Medicine* 378, 381; note 45; and S. Bito et al., “Acculturation and End-of-Life Decision Making: Comparison of Japanese and Japanese-American Focus Groups” (2007) 21 *Bioethics* 251.

⁴⁸ R. Voltz et al., “End-of-Life Decision Making and Advance Directives in Palliative Care: A Cross-Cultural Survey of Patients and Health-Care Professionals” (1998) 16 *Journal of Pain and Symptom Management* 153, 159; K. Hirai et al., “Good Death in Japanese Cancer Care: A Qualitative Study” (2006) 31 *Journal of Pain and Symptom Management* 140, 145; and Nakazawa et al., note 8, p. 381.

⁴⁹ R. Ishiwata and A. Sakai, “The Physician–Patient Relationship and Medical Ethics in Japan” (1994) 3 *Cambridge Quarterly of Healthcare Ethics* 60.

their family members, be it financially, physically or emotionally.⁵⁰ In addition, Japanese people tend to consider it important to have good family relationships at the end of life.⁵¹ For example, even if elderly patients would prefer to die at home, they often hide their true wishes and agree to a hospital stay recommended by family members or medical providers because they do not want to be a burden or disrupt family harmony. Patients with this character trait are hesitant to write ADs, as the presence of an AD can constrain family decision-making and impose a burden.

13.6.3 Pursuit of a Good Death

The pursuit of a good death is also an important goal in Japanese culture. Interestingly, this goal has both a positive and negative effect on the making and implementation of ADs. On the one hand, Tsuda et al. found that participants regarded ADs primarily as a means to pursue their ideal death. On the other, the “Good Death Study” targeting Japanese people found one of the most common answers to the question “If you were dying, what would be the most desirable or good thing for you to do?” was “not being aware of death”.⁵² As a result, ADs and ACP are considered “bad luck”, and many people avoid writing ADs or talking about the end of life.⁵³

13.7 Conclusion

Despite being a familiar concept amongst physicians and patients in the end-of-life context in Japan, as evidenced in practice, ADs do not currently have any formal role in the decision-making process at the end of life in Japan. As explained in this chapter, end-of-life decision-making has been under intense discussion since the late 1990s and facilitated

⁵⁰ C. Shimada et al., “Reconsidering Long-term Care in the End-of-Life Context in Japan” (2016) 16 (Suppl. 1) *Geriatrics & Gerontology International* 132, 136.

⁵¹ See Tsuda et al., note 31; and Hirai et al., note 48.

⁵² See Tsuda et al., note 31 and Hirai et al., note 48. This notion of the ideal dying process is also seen in other countries. See, for example, Wolf et al., note 7; A. Fagerlin and C.E. Schneider, “Enough: The Failure of the Living Will” (2004) 34(2) *Hastings Center Report* 30, etc. See also M. Sanjo et al., “Preferences regarding End-of-Life Cancer Care and Associations with Good-Death Concepts: A Population-based Survey in Japan” (2007) 18(9) *Annals of Oncology* 1539.

⁵³ See Nakazawa et al., note 8.

based on guidelines rather than legislation. The development of educational programmes for doctors on palliative care or end-of-life communication and the promotion of ACP to the general public have led to a gradual improvement in the process of end-of-life decision-making in general. However, there are still a number of issues that require further discussion, such as the definition of the end of life, the need for legislation on surrogate decision-makers and ADs, and euthanasia. The lack of any legal force for ADs is particularly problematic because decision-making in Japan tends to be family centred, which can lead to situations in which a patient's own wishes are not respected. Such situations are in fact contrary to the most important principle of the process guidelines, despite there being no provision for ADs within the guidelines themselves. To protect the rights of patients, it is important to continue the discussion on the issue of ADs and the legal weight they have. However, given that many Japanese do not hold positive views on legislating ADs and prefer traditional family-centred decision-making, and given the various sociocultural factors at play, it may be more realistic and practical to explore a more culturally appropriate approach to decision-making based on ACP.