



Figure 1 Sampling scheme of respondents.

in the UK which deals with patient autonomy in the case of terminal illness.

The 1991 Patient Self Determination Act in the United States requires all hospitals, nursing homes, and home health agencies to advise patients of their rights to accept or refuse medical care and to execute an advance directive.¹⁰⁻¹¹ This is usually a written directive for end of life care, a living will and/or a durable power of attorney created to help interpret what a patient's wishes might have been in light of his or her present condition and its possible treatment. Some studies have demonstrated, however, that only 10-15% of US adults have written advance directives, and often their physicians are unaware of them.¹²⁻¹⁴ One study suggests that doctors were ignoring their patients' instructions about their end of life treatment preferences.¹⁴ Encouraging results from a recent randomised, controlled trial revealed, however, that simple computer generated reminders can increase the rates of discussion and completion of advance directives among elderly patients with serious illness.¹⁵

Few Japanese studies have examined the situation of people with advance directives and physicians's attitudes and beliefs toward life sustaining treatment and advance directives.⁶⁻¹⁶⁻¹⁷ The purpose of this study was to investigate Japanese physicians's experiences with patients who had a living will at the time of death and their attitudes toward living wills, the most commonly used advance directive in Japan.

METHODS

Based on a survey of 1626 families, which looked at patients who had obtained and showed their living wills to their physicians,⁶ we constructed a database of 551 physicians who, according to either a family member or a guardian had seen a living will and followed it when the patient died. The patients who were the topic of this previous investigation had obtained a living will from the JSDD. Between 1995 and 1996 a family member or guardian had notified the JSDD of the patient's death. Within two weeks of receiving the notification of the

patient's death, the JSDD mailed a questionnaire designed to collect data about the patient's death, including the name and address of the deceased patient's physician. For 92 (16.7%) physicians, the address or physician's name was incorrect, and they were hence excluded. The remaining 459 physicians, all reported by family members as having seen and followed the patient's living will, were the target subjects of this research. (figure 1).

For the purposes of this study, we defined "obtaining a living will" as registering with the JSDD and receiving a standardised written living will, and "presenting a living will" as showing a completed written living will to the patient's physician. Physicians who limited life sustaining treatment in accordance with the written living will were defined as having "followed the living will".

The major variables of the structured, anonymously administered instrument included the physician's response to being shown a living will, the impact of the living will on communication with the patient and family, the impact of the living will on clinical care, and physician demographics. To analyse these structured items, we tabulated and calculated the frequency distributions according to those who gave written opinions, those who did not, and the totals.

The final item on the instrument asked for physician comments about living wills. We analysed this qualitative data using the process of immersion/crystallisation.¹⁸⁻¹⁹ Three investigators formed the primary analysis team (Masuda, Fetters, and Mogi) and independently identified domains and subthemes from multiple readings of the descriptions of the respondents. Subsequently, we developed a master list of areas of concern and subthemes that incorporated each investigator's contributions. Differences in interpretation were minimal.

Though the survey was distributed anonymously, a small number of respondents volunteered contact information. This provided a unique opportunity to conduct a re-evaluation of the study's results by some family members or guardians: we contacted 12 who were available by phone to verify our results.²⁰ They all supported the breadth and depth of the

Table 1 Physicians' receipt of and response to living wills

	Physicians' comments(+) n=(%, /120)	Physicians' comments(-) n=(%, /181)
Did you receive the patient's living will, and if so, how did you respond?		
1. I received the living will, agreed to it, and executed it.	91 (76)	53 (29)
2. I received the living will, and agreed to it, but I did not execute it.	12 (10)	11 (6)
3. I received the living will, but neither agreed nor disagreed with it.	4 (3)	1 (1)
4. I received the living will, but disagreed with it, and refused to execute it.	0 (0)	0 (0)
5. I never received the living will.	0 (0)	105 (58)
6. Other	13 (11)	11 (6)
Did you have more opportunities to communicate with your patient and his/her families after receiving the living will?		
1. Yes	65 (54)	38 (21)
2. No	24 (20)	23 (13)
3. No, because the patient died suddenly.	11 (9)	5 (3)
4. I never received the living will.	0 (0)	105 (58)
5. Others	20 (17)	10 (6)
Did you change your course of therapy as a result of receiving the living will?		
1. Yes	27 (23)	11 (6)
2. No	78 (65)	57 (31)
3. I never received the living will.	0 (0)	105 (58)
4. Others	15 (13)	8 (4)

(+) These physicians supplied personal comments; (-) these physicians did not supply personal comments.

analysis. This study was approved by the ethics committee of the Department of Geriatrics, Nagoya University School.

RESULTS

From a single mailing of 459 questionnaires, we received 301 responses, and of these 149 provided written commentaries that were analysed using qualitative techniques. Interestingly, the comments of 29 of these 149 participants illustrated they had a poor understanding of living wills (figure 1). One hundred and twenty-two physicians were midcareer physicians. One hundred and sixty physicians majored in internal medicine and 141 majored in surgery and other specialties: these other specialties included five orthopaedists, four otorhinolaryngologists, and three radiologists.

While all the physicians surveyed were reported by a family member or guardian as having seen and agreed to the living will, 105 denied ever having seen the patient's living will. Of the remaining 196 physicians, 144 agreed to it and followed it. Of the physicians who reported they had received the patient's living will, 103 physicians said they had discussed the living will with the patients and/or their families after receiving the living will. Remarkably, 38 physicians who acknowledged being shown the living will reported that the living will influenced clinical outcomes (table 1).

PHYSICIANS'S COMMENTS ON LIVING WILLS

Based on our analysis of these comments from the physicians, we identified three areas of concern; (A) concerns about living wills relative to patients, physicians, and families; (B) social context of living wills, and (C) clinical and administrative concerns about living wills.

A. Concerns about living wills relative to patients, physicians, and families

1. Living wills and patients

The respondents mentioned both positive and negative influences of living wills on patient care. The most common concern was these physicians's feelings that they needed to take into account patient's state of mind at the end of life. Some physicians pointed out that patients might change their mind in the face of impending death and raised concerns about the stability of such advance decisions. Issues related to patient knowledge and preparation for making this type of decision were also frequent. For example, a chest physician stated: "I think it is quite meaningful for terminally ill patients to exercise autonomy about life sustaining treatments

Box 2 Dominant concerns and subthemes about living wills in Japan

A. Concerns about living wills relative to patients, physicians, and families

1. Patients
2. Families
3. Physicians
4. Patient/family/physician interaction

B. Social context of a living will

1. Trends favouring completion of a living will
2. Relationship of a living will to "dying with dignity" and "euthanasia"
3. Societal understanding of a living will
4. Need to discuss medical ethics
5. Perception about development of a living will in Western culture and implications for Japan

C. Clinical and administrative concerns about a living will

1. Confusion around the procedures for completing and executing a living will
2. Patient individuality and complexities of implementing a living will
3. Difficulty of explaining when a condition is terminal
4. Complications of second opinions
5. Barriers to effective treatment in curable patients

by presenting a living will. However, autonomy requires a considerable amount of knowledge. Without enough knowledge, a living will could be dangerous."

2. Living wills and families

Some physicians addressed the impact of living wills on their relationships with families. The primary positive perceptions related to increased opportunities to communicate with the family and the underlying essential role the family plays in interpreting the patient's wishes when a patient is no longer able to communicate. For example, a cardiologist described his positive experience, stating: "The living will gave me the chance to have more time to communicate with the patient's family". Potential negative influences were also identified. The most common concern was the feeling that a living will directed too much family energy toward making sure the patient could have a "natural death" without giving enough consideration to understanding the patient's preferences for end of life care. A second concern related to insufficient communication of the

patient's preference to limit end of life care to the family, and the family's subsequent insistence on care incompatible with the patient's directive. For example, some respondents commented on the confusion created when family members request treatments such as cardiopulmonary resuscitation even though the patient has requested a natural death. There were also concerns about the instability of the preference the patient had expressed in the living will and about family members with ulterior motives seeking to change the treatment.

3. Living wills and physicians

Many of the physicians who were shown a patient's living will did not routinely provide life sustaining treatment in their clinical practices, but still felt that living wills had played a valuable role. Again, some physicians emphasised the positive effect of a living will, in that it provided an overarching focus on the patient's preference for palliative care and allowed physicians to plan how to accomplish those goals. Other physicians were more cautious and believed that living wills could result in adverse outcome if handled by a physician lacking technical skills in providing compassionate, palliative care. This negative opinion is summarised by a surgeon who wrote: "There is a chance that physicians with marginal skills and little compassion could take advantage of living wills and carry out terminal care negatively. To make the best use of a living will, at this point, we need not the system first, but physicians with skill and character who can handle terminal care."

B. Social context of a living will

1. Inhumane medical care as a factor driving interest in living wills

Several physicians expressed their belief that the inhumane nature of the medical culture was a driving force behind patients obtaining living wills and reflected the need for physicians to do a better job of focusing on care of the patient. Some attributed the problem to the poor quality of education in palliative care that physicians receive in their medical training. A gastroenterologist wrote: "Physicians tend to have shallow ideas on living and dying. I think that it exposes holes in current medical education. With remorse and sincerity, we have to face the mortifying feelings of a patient who dies in an untrustworthy medical system."

2. Physician perspectives on death with dignity

This survey on living wills stimulated several physicians to mention their own beliefs about "death with dignity". They articulated concerns about the enduring need to respect human dignity regardless of whether the patient has a living will and disappointment that patients cannot seem to die with dignity unless they have completed a living will. For example, one cardiologist stated: "It is more of a problem that people cannot die with dignity without a living will. I consciously try to respect the dignity of every death."

3. Cultural issues associated with living wills and perceptions of death

The term "living will" has been imported directly into the Japanese language and it is pronounced *libingu uiru*. It is written in katakana, the written language that delineates words of foreign aetiology. This writing convention inevitably identifies living wills as distinctly foreign to Japanese culture. For some Japanese, this causes uneasiness, suggesting that it doesn't mix well with Japanese culture, while for others the ubiquitous use of a foreign sounding term for an issue of great importance to all Japanese people is a source of consternation. Those critical of its use, however, have not been able to suggest an alternative phrase, using Japanese terms. Some participants in the survey chided their physician colleagues for their shallow perceptions about the meaning of death. Moreover, they were critical of the superficiality of public discussions about life and death in

Japan. Some alluded to the role indigenous religious/philosophical traditions could play in informing a Japanese sense of a natural death, though these opinions were held by only a minority.

BACKGROUND

At present, a majority of Japanese feel that modern biomedical and mediatechnological innovations affecting human life and death have effected a changed in our common understanding of the process of death and dying. Historically, death was a natural event, and the criteria for death/cessation of heart beat and respiration was unquestioned. An individual's death should be a personal and private matter as well as a familial, communal, and society matter. It has been so regarded for many thousands of years in Japanese society and culture. It is well understood that our traditional sociocultural understanding of human life admits the natural process of death as a positive event marking of the end of life.²¹

Clinical and administrative concerns about a living will

1. Confusion about the procedures for obtaining and following a living will

All respondents are clinicians, and many of them commented on pragmatic issues for obtaining and completing living wills. No official format or regulations exist that support the implementation of a living will in Japan. Some of the respondents requested information from the JSDD about how to apply for a living will and to obtain application forms from bodies other than the the JSDD.

2. Patient uniqueness and complexities of implementing a living will

These physicians work in a variety of clinical settings and commented on living wills based on their clinical experiences. For example, a senior neurologist discussed troubling neurological cases such as occur with dementia, and the difficulty in respecting patient autonomy as the patient's decision making capacity withered away, and family influence increased. Another issue raised was the difficulty of interpreting the individual patient's intended meaning for a death with dignity in the context of clinical uncertainty. Even if the patient's preference was clear, the outcome for any patient could change, based on the response to treatment. One surgeon explained: "With intensive care of stroke patients, some could recover, but with severe functional difficulties. In these cases, if we give up the treatment in the first place, many would die. So should we just leave such patients in a coma since they have a living will? Or can the physician force a long and painful recovery on the patient and his/her family for the physician's own self satisfaction? This really bothers me."

3. Difficulty of explaining when a condition is terminal

Many physicians described the difficulty of determining the point when a patient should be considered incurable and the patient's living will implemented. Some patients may have an incurable condition, but still be able to survive for years in a debilitated state requiring only basic medical support. A senior haematologist summarised this concern: "The prerequisite condition for implementing a living will is that the disease is incurable. But it is not always easy to judge whether a patient is really at an incurable stage. Also decision making is hard when a patient's life is expected to be prolonged for another year or so."

4. Barriers to effective treatment in curable patients

Some physicians raised concerns about living wills being used to block the provision of routine, curative treatments. One surgeon was strongly influenced by his experience with a patient who had a living will and refused treatment. His experience was so troubling, he gave up general surgery to become a plastic surgeon. He wrote: "Regarding his living will,

I accepted his family's request not to use dialysis and a respirator for the renal and respiratory failure in his terminal condition. However, in his case, I still believe that we could have cured his colon cancer if only he had cooperated with our treatment. He strongly wanted to deteriorate without any treatment and we failed to change his mind. All of the medical staff were caught feeling like they assisted his suicide. We did try our best to get this very pessimistic patient to open his heart, and it still is a very painful memory."

DISCUSSION

To our knowledge, this represents the first large scale study in Japan to investigate physicians' experiences with, and attitudes towards, patients who died having completed a living will. Because advance directives have no legal standing and living will use is not widespread in Japan, this research provides a unique opportunity to examine the use of a written advance directive to extend patient autonomy to treatment decisions at the end of life. While a family member or guardian reported that these physicians had seen the patient's living will and acted in accordance with the patient's preference as written in the living will, over a third of the physicians denied having seen the living will. This group likely includes physicians who really did not recall seeing the living will, though there may have been physicians reluctant to confirm receipt of the living will.

These physicians highlighted many potential limitations of living wills, including: inadequate communication about how to interpret it; potential liability; the vagueness of living wills; potential for differing patient and family expectations, and other ethical dilemmas. As in previous research, these physicians report that patients have difficulty making advance judgments on complex medical procedures and choices about quality of life since these can change with time and circumstances.²² Others showed that advance directives might be better suited to patients's end of life care goals than those that focused on specific medical interventions.²³ For some physicians, withholding or withdrawal of life sustaining treatment is perceived as harmful to the patient because this action predictably results in the patient's death. It is widely held that Japanese physicians are trained to save lives, not to end them.

Possible study limitations should be addressed. First, the data represented physician reports, and due to the anonymous nature of the investigation, could not be corroborated with other clinical data to assess their accuracy. Second, while patients who have obtained a living will are a minority and might not be representative of the general population, the physicians who were providing care for these patients are probably reasonably representative of Japanese physicians providing care for adult patients. Most respondents were active clinicians providing medical and surgical care to patients in a variety of clinical settings. Third, only half of the physicians who recalled seeing the living will, provided written comments. While their views might differ from others who did not provide comments or who did not respond to the survey, their experiences are still real and compelling.

Currently, when a patient registers with the JSDD, the patient receives two copies of the living will, one for the patient and one for return to the JSDD. Since many physicians denied seeing the patient's living will, physicians should always be given a copy of the living will to keep with the patient's chart. Of the physicians who recalled seeing the living will, almost a fifth reported that it influenced clinical outcomes. Since living wills have no legal standing, this level of compliance could be interpreted as being surprisingly high and, despite the limitations, as real, since many comments illustrated physicians's poignant concerns that patients were allowed to forgo physician recommended treatments. This suggests that many Japanese physicians are willing to respect autonomous patient preferences to forgo treatments as expressed through a written living will. At the

same time, many physicians expressed consternation with interpreting patient preferences while accommodating family inputs in highly variable settings, all in the face of clinical uncertainty, a point that most assuredly reflects the experiences of physicians who have grappled with following written advance directives in the US and elsewhere. Further research tied to clinical settings in which living wills are implemented could provide a more robust understanding of living will use and adherence as advanced expression of autonomy in the cultural context of Japan.

ACKNOWLEDGEMENT

This study was made possible in part by the generous support of the Japan Foundation for Aging and Health. We greatly appreciate the cooperation of the families and physicians who participated in this investigation.

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