
Outcomes of Written Living Wills in Japan — A Survey of the Deceased Ones' Families

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A study was recently done to investigate the outcomes of written living wills in Japan, which, unlike the United States, does not legally recognize advance directives. This study collected demographic information and predictors of living will use among families and guardians who used the living will form provided by the Japan Society for Dying with Dignity. According to the results of the study, affliction with cancer and death in a hospital was the best predictor of written living will use. Research on physicians' treatment limitation and withdrawal behaviors in the clinical setting is needed to better understand the actual impact of living wills. Such research can provide a better understanding of where boundaries of self-determination are drawn and how to respect autonomy in Japan.

In the United States, advance directives are legally recognized through the Patient Self-Determination Act (PSDA) and advocated as a means of extending patient autonomy to situations in which individuals may no longer be competent to designate their preferences for the use of life-sustaining or other medical therapies (Emanuel and Emanuel 1989; OBRA 1990; Orentlicher 1990; Emanuel et al. 1991). Nevertheless, the effectiveness of the PSDA remains controversial.

Assistance in completing an advance directive upon hospitalization has been found to be sub-optimal since the most severely ill patients are most likely to lose decision-making capacity after hospitalization (Youngner 1994). Outcomes research reveals that patients with living wills forgo specific treatments but remain intensive users of routine medical services (Morrison et al. 1995). Though the PSDA was designed to broadly empower U.S. citizens with a legal right to exercise self-determination at the end of life, only 10 to 15 percent of U.S. adults have written advance directives and their physicians are often unaware of them (La Puma et al. 1991; Stelter,

Elliot, and Bruno 1992; Schonwetter et al. 1993; Hanson and Rodgman, 1996; Landry et al. 1997; Brennan 1998; Gross 1998).

Outside the United States, international attention is increasingly focused on advance directives. For example, Blondeau, Valois, and Keyserlingk (1998) found overall positive attitudes toward advance directives among patients, nurses, administrators, and physicians in Quebec; though physicians were the least supportive, and 45 percent (n=56) of the participating patients weren't even aware of the existence of advance directives.

In Sweden, Eisemann and Richter (1999) found public support for various aspects of self-determination such as desire for control, fear of over-treatment, and choice of treatment that advance directives are designed to enhance, though only 59 percent of the respondents perceived of an advance directive as useful in the event of a life-threatening illness. In Germany, too, there is evidence of a growing interest in the moral basis of the expression of patient self-determination through advance directives, though skepticism remains (Koch 1998; Meran and Poliwada 1998; Sass 1998).

In Japan, the role and limits of self-determination continue to be controversial among the general public, the judiciary, medicine, and other academic scholars (Kimura 1998). For example, some medical ethicists have questioned the relevance of autonomy, self-determination, and individual freedom (Hoshino 1997; Tsuchida 1998); while others have articulated the need for expression and enhancement of individual autonomy in medical decision making at the end of life (Div. of Policy 1993; Yomiuri Shimbun 1994).

Opinion polls indicate growing public interest in discussing end-of-life issues with physicians, and public support for allowing patients to terminate life-sustaining treatments (Tatara 1995; Guest 1996). However, Japan has no legis-

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lation like the PSDA to authorize expressions of patient autonomy when an individual is incompetent (Kimura 1998). Hence, an advance directive such as a written living will has no legal status, and Japan lacks a legally binding durable power of attorney. As such, the use of a written advance directive in Japan is uncommon — in one study, Japanese nephrologists reported that less than 1 percent of their patients had advance directives (Sehgal et al. 1996).

In another exploratory study, some physicians supported the use of advance directives for end-of-life decision making, while others voiced concern about the potential for conflict with family members, difficulty with withdrawing treatment if requested, and the reluctance to discuss an advance directive when the patient is not terminally ill (Asai et al. 1997). The lack of

legal status and standardized advance directives underscores previous conclusions that there is less opportunity to exercise autonomy in Japan than in the United States (Asai, Fukuhara, and Lo 1995).

Still, a growing number of Japanese people are completing written living wills and many of them have presented them to their physicians. For example, the Japan Society for Dying with Dignity (JSDD), the leading advocacy group for dissemination and recognition of written living wills in Japan, had 88,548 members as of September 1998 (JSDD 1998), and studies have begun to address the role of various advance directives such as the DNR order and other types of living wills in Japan (Kai et al. 1993; Fukaura et al. 1995; Tomonaga 1997; Kimura 1998).

Anecdotal cases have provided a limited understanding of the outcomes of having a living will (Ohi 1998). The purpose of this research was to investigate whether the Japanese people who died after obtaining a JSDD written living will in Japan, had or had not made use of the document.

Methods

Deaths that occurred among the membership of the JSDD were the focus of this investigation. While at least two other formal advance directives are known to exist in Japan (Sass, Veatch, and Kimura 1998), this organization was selected as the population for investigation since its membership is by far the largest and thus most representative of people who have completed a written living will in Japan. The JSDD was established in 1976 to help people complete a written living will. For an annual fee of ¥5,000 (about \$50) individuals 15 years old or older can register for membership with this nonprofit, volunteer organization. All registered members receive a standard written living will as well as support from the JSDD if questions or conflicts arise.

According to its organizational policy, the JSDD conducts telephone interviews of all members who fail to renew their membership. When the

reason for nonrenewal is the member's death, the JSDD tries to ascertain the circumstances. From January 1993 to December 1996, we mailed questionnaires to 2,267 family members and guardians who reported a death to the JSDD. The questionnaires were mailed within two weeks of notification of the member's death. Their responses were collected at the head office of JSDD in Tokyo and were the source of data for this investigation.

The questionnaire included a demographics section, structured questions about four major variables, and a request for comments from the family member or guardian about living wills. The major variables addressed whether the registrants presented their written living wills to their physicians, their timing of presentation, whether their physicians executed their written living wills, and the relationship between the patient and the family or guardian who responded to the questionnaire.

For purposes of this research, we defined "completing a living will" as registering with the JSDD and receiving a written living will, and "presenting a living will" as giving a completed written living will to a physician. Physicians who limited life-sustaining treatments in accordance with the written living will were defined as having executed a living will. Since written living wills have no legal status in Japan, a patient can present the document to his or her physician and request its use, but agreement to accept and subsequently execute it depends on the discretion of the physician (Kimura 1998). Because strong public voices oppose physician-assisted suicide in Japan, physicians may resist accepting and executing living wills that appear to limit care or to hasten a patient's death. On the other hand, failure to implement a living will can render a physician vulnerable to litigation by the surviving family, though malpractice claims against physicians are unusual in Japan.

We conducted descriptive statistics on all demographic and major variables. We divided subjects into two groups: those patients or families who presented the patient's written living will to a

physician and those who did not. This analysis was performed to determine if gender, age, place of death, and place of residence would predict written living will presenting behavior. Univariate comparisons were made using χ^2 tests. Multivariate analysis was conducted to examine the association between

- written living will use and the deceased subjects' *age*, controlling for their gender, age, and place of death;
- written living will use and the deceased subjects' *cause of death*, controlling for their gender, age, and place of death; and
- written living will use and the deceased subjects' *place of death*, controlling for their gender, age, and cause of death.

Cochran-Mantel-Haenszel statistics were calculated with Statistical Analysis System (SAS) version 6.1 (The FREQ Procedure 1990).

This study has several limitations. First, the well educated, largely metropolitan-based membership of the JSDD is not representative of the general Japanese population, though it is the most representative group of Japanese people who have completed a written living will. Second, our respondents were family members and guardians of people who had obtained living wills, and their reports of implementation and

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execution may not be completely accurate. Still, because the family is highly involved in medical decision making in Japan (Hoshino 1997; Fetters 1998; Kimura 1998), we believe that family reports are largely reliable. Third, we did not have access to patient medical records or death certificates,

Table 1.- Demographic Characteristics of Descendents

Variables of Interest	Number	Percent
Gender		
Male	966	59.4%
Female	660	40.6%
Age		
30 to 39	3	0.2%
40 to 40	28	1.7%
50 to 59	109	6.7%
60 to 69	378	23.2%
70 to 79	545	33.5%
80 or older	563	34.6%
Cause of Death		
Neoplasms	765	47.0%
Circulatory system	275	16.9%
Respiratory system	214	13.2%
Cerebrovascular	148	9.1%
All other disease	105	6.5%
Liver disease	45	2.8%
Unknown	45	2.8%
Renal disease	29	1.8%
Place of Death		
Hospital	1,351	83.1%
Home	256	15.7%
Special home or healthcare facility for aged	13	0.8%
Other	6	0.4%
Place of Residence		
Kanto District (Toyko, Yokohama Metro)	1,053	64.8%
Kinki District (Osaka, Kyoto, Kobe)	225	13.8%
Chubu district (Central Japan)	153	9.4%
Kyushu-Okinawa district (Southern Japan)	85	5.2%
Chugoku-Shikoku district	48	3.0%

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Table 1. – Demographic Characteristics of Descendents (Cont.)

Variables of Interest	Number	Percent
Place of residence, cont.		
Hokkaido district (Northern Island of Japan)	30	1.8%
Tohoku district	26	1.6%
Participant's Relation to Deceased		
Spouse	979	60.2%
Child	225	13.8%
Relative	78	4.8%
Siblings	47	2.9%
Parents	9	0.6%
Unknown	6	0.1%
Other	1	0.0%

and were unable to corroborate the reported cause of death. This fact is unlikely to be a significant source of error because every effort was made to distribute the questionnaire as soon as possible after notification of a member's death. Finally, survey research is not the preferred method for describing the medical treatments actually used and the duration of their use. Elucidating this information was beyond the scope of this investigation. This study was approved by the Japan Society for Dying with Dignity Ethics Committee, and informed consent was obtained from all respondents to the questionnaire.

Results

Of the 2,267 questionnaires mailed, the organization received 1,799 responses (79 percent), though there was missing information on 173 of the questionnaires. This yielded a total of 1,626 (72 percent) usable instruments. Demographic data from this sample are illustrated in Table 1. Completed questionnaires were returned for 966 (59.4 percent) deceased males, and 1,108 (68 percent) of the deceased people were aged 70 years and over. The mean age at the time of death was 74.2 years. The most common

etiology of death was cancer, a cause which afflicted 47 percent (n=765) of these people. The majority of subjects (65 percent; n=1,051) had resided in Kanto district, an area that includes Tokyo and Yokohama. Other major population centers such as the Kinki district that includes Kyoto, Osaka, and Kobe, and the Chubu district that includes Nagoya, had a relatively lower representation. In most cases, the informant was the spouse (60 percent; n=979) or child (31 percent; n=504) of the deceased.

Sixty-four percent (n=1,040) of the registrants were known to have presented their written living wills to their physicians. According to their families' reports, 96 percent (n=998) of their physicians agreed to accept the patients' written living wills when the patients presented them. Fifty-eight percent (n=603) of all registrants who presented their written living wills were men.

The timing of the presentations of written living wills to physicians varied: 56 percent (n=583) occurred during hospitalization, 19 percent (n=193) during routine outpatient visits to their hospitals; and 25 percent (n=264) during visits after receiving a diagnosis of terminal illness.

We grouped subjects into those presenting written living wills to their physicians and those who did not, and compared the two groups by their demographic variables. We found no

of people aged 70 years or older presented their written living wills to their physicians than those aged 69 years or younger. However, when we examined this association controlling for

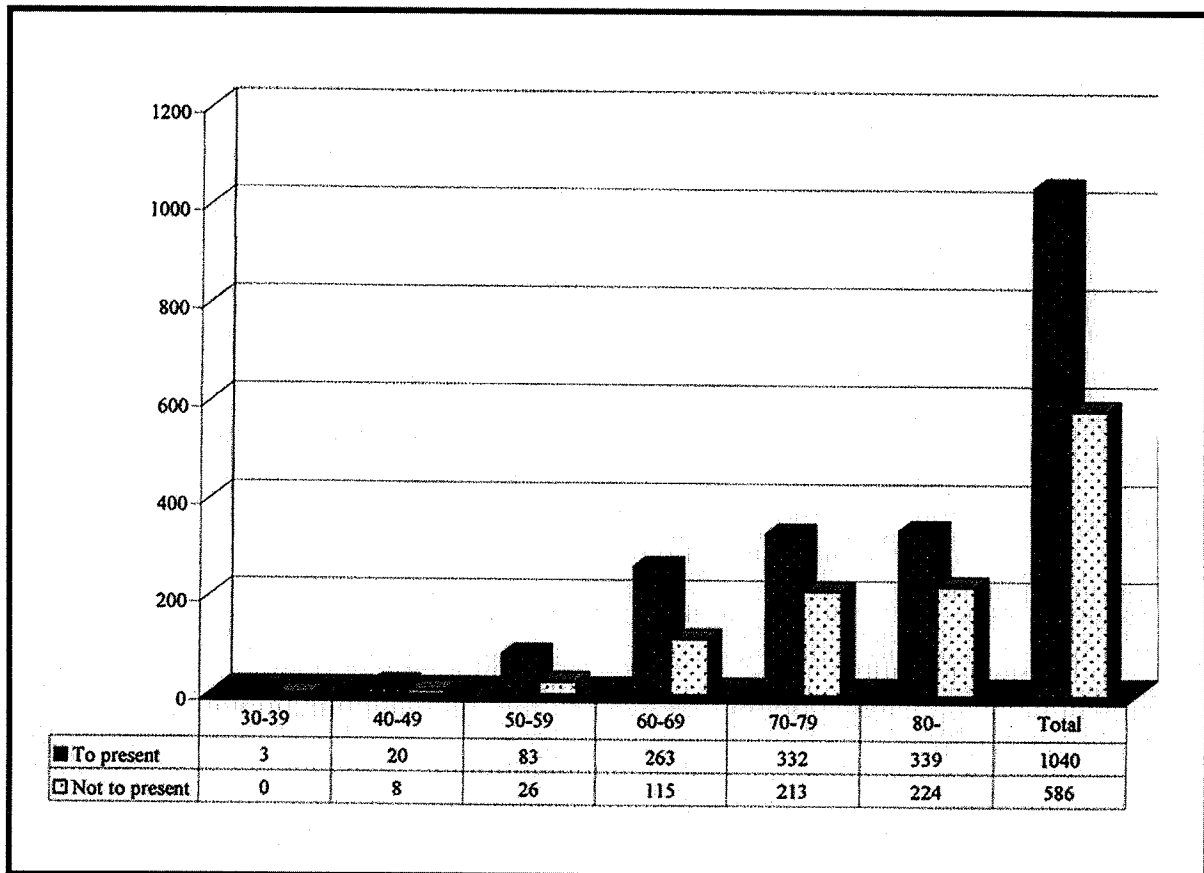


Figure 1.-Association between deceased subjects age and presentation of a living will.

significant differences between the groups related to the deceased patients' gender or place of residence. Fifty-nine percent (n=624) of the people residing in metropolitan areas had presented their written living wills. By region, 52 percent (n=133) presented their living wills in the Kinki district; 58 percent (n=89), in the Chubu district; 62 percent (n=53), in the Kyushu-Okinawa district; 58 percent (n=28), in the Chugoku-Shikoku district; 50 percent (n=15) in the Hokkaido district; and 73 percent (n=19), in the Tohoku district.

The association between the subjects' ages and the presentation of their written living wills to physicians is shown in Figure 1. A greater number

of people aged 70 years or older presented their written living wills to their physicians than those aged 69 years or younger. However, when we examined this association controlling for

their gender, cause of death, and place of death, subject age was not associated with their written living will presenting behaviors. The association between cause of death and presentation of a written living will is shown in Figure 2. Cause of death was significantly associated with written living will presenting behaviors. The proportion of patients presenting a written living will by cause of death was highest for cancers (80.3 percent) and lowest for cardiovascular disease (32 percent) (P<.001).

The place of death was also related to written living will presenting behaviors. As illustrated

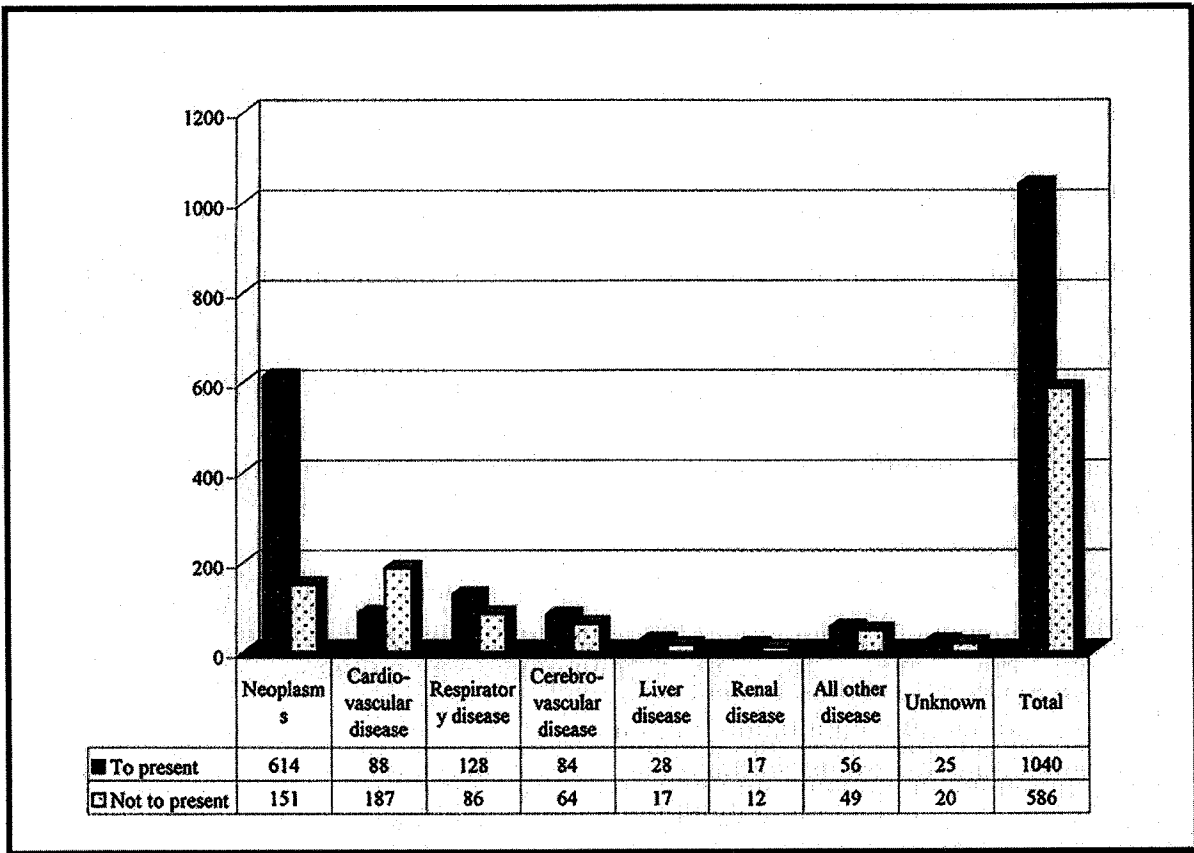


Figure 2.-Association between cause of death and presentation of a living will.

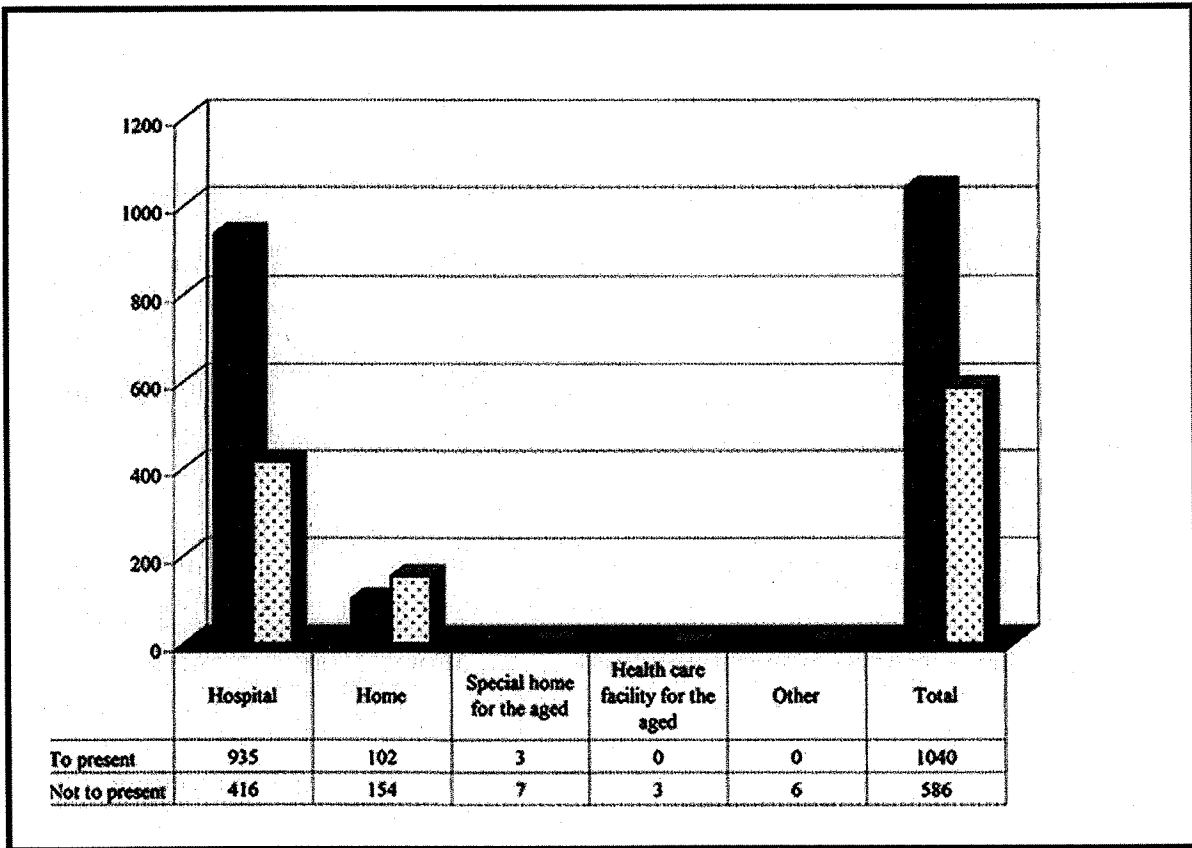


Figure 3.-Association between place of death and presentation of a living will.

in Figure 3, patients who died in hospitals (69.2 percent) were more likely to present their written living wills than those who died at home (39.8 percent) ($P < .001$). These trends did not change when we analyzed the data by calendar year.

Discussion

This is the first large-scale study to examine the outcomes of having a written living will among Japanese people who had obtained their living will from the Japan Society for Dying with Dignity. Their family members and guardians reported that in a majority (64 percent) of cases, the JSDD registrants presented their written living wills to their physicians, and that 96 percent of their physicians reportedly executed the written living will per the patient's request. Still, 36 percent of these people either did not or were not known to have presented the written living will that they had obtained on their own initiative.

Though respondents were not directly asked why the patient's written living will had not been

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presented, statistical modeling shows that sudden cardiac-related death and dying at home were the most important predictors of not presenting the written living will. Other reasons for not having presented their living wills may include a lack of opportunity secondary to sudden death, no need to implement their living wills since care proceeded according to their preferences, or a decision to pursue care that was incompatible with the content of their written living wills.

While cancer is the most common cause of death in Japan, a disproportionately large number of cancer deaths occurred among the study

subjects compared to that of the general population in Japan (Ministry of Health and Welfare 1995). Patients with cancer were more likely to present a written living will than patients with cardiovascular disease, a trend that is similar to previous U.S. studies (Hanson and Rodgman 1996; Jacobson et al. 1996). People who died of cardiovascular causes, particularly if they were acute, may have had less opportunity to present their written living wills. Moreover, a physician might be reluctant to execute the written living will of a heart attack patient refusing life-sustaining treatments if the physician believes the underlying cause is treatable.

In contrast, the preception that cancer is incurable may have been a significant motivational factor for cancer patients to obtain a written living will and to implement it. Additionally, cancer patients may have suffered pain and presented their written living will to obtain analgesics. Like many U.S. physicians, many Japanese physicians are uncomfortable prescribing narcotics at the end of life, but the written living will emphasizes pain relief for the patient (Mizuguchi 1987; Takeda and Uki 1994; Takeda 1996; Kon and Adachi 1997).

In this study, we also found that the location of death correlated with the family's reported use of a written living will. Patients who died in hospitals were more likely to use their written living wills than individuals who died at home. Patients who died at home may have had less opportunity to present their written living will and may not have needed it since they were less likely to receive aggressive life-sustaining treatments in their homes.

These results contrast with one study in the United States that found no correlation with the place of death and use of a living will (Jacobson et al. 1996). It is notable that location of death in our study was distributed similarly to that of the general population in Japan, whereas in the United States there are fewer hospital deaths, a greater number of nursing home deaths, but roughly similar numbers of home deaths. According to 1995 Japanese data, deaths among the general population were distributed as follows:

- 79 percent approximately occurred in hospitals (including hospices and clinics),
- 2 percent in special homes for the aged and healthcare facilities for the aged (facilities somewhat similar to nursing homes),
- 17 percent in their residence, and
- 3 percent in other locations (Ministry of Health and Welfare 1995).

According to 1992 data from the U.S. Institute of Medicine's Committee on Care at the End of Life (1999), deaths in the U.S. population were distributed as follows:

- 57 percent in hospitals,
- 17 percent in nursing homes,
- 20 percent in the home, and
- 6 percent in other locations.

In this study, age did not correlate with the reported use of a written living will, a finding consistent with previous U.S. studies. Using multivariate analysis, Hanson and Rodgman (1996) found no association between increased age and the use of living wills in multivariate analysis. In one study with a similar distribution of participant ages to our study, Jacobsen et al. (1996) reported that older individuals, regardless of their gender, were the most likely to have completed advance directives, but they also found no association between age and the actual use of a written living will.

Conclusion

Patient participation in end-of-life decision making is a controversial issue in Japan. Some advocate adoption of a rights-based approach in Japan in which patients have the option of active involvement in their end-of-life care (Hamano 1997). Others argue the need to consider the sociocultural and religio-philosophical context of Japan (Brannigan 1995; Kimura 1991; Akabayashi, Fetters, and Elwyn in Press). A hierarchical doctor-patient relationship with the doctor

making the decisions is strongly rooted in Confucian philosophy (Kimura 1991). In cases of terminal disease, the physician and the family may make major treatment decisions in behalf of a competent patient (Hoshino 1997; Kimura 1998; Fetters 1998).

Though there are trends toward candid disclosure of the diagnosis and patient participation in decision making (Elwyn et al. 1998), many Japanese doctors and patients are reluctant to openly confront a terminal illness such as cancer because it is perceived as a herald of death. From a global perspective, nondisclosure of the cancer diagnosis is more common than disclosure (Holland et al. 1987; Mizushima et al. 1990; Dalla-Vorgia et al. 1992; Estape et al. 1992; Surbone 1992; Thomsen et al. 1993; Hoshino 1995; Harrison et

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al. 1997). These attitudes, rightly or wrongly, perpetuate the notion that patients will have great difficulty in becoming active decision makers in their terminal care. Many physicians and family members alike fear that open discussion about terminal illness will hasten the patient's death, while others feel that patients should have the option of active involvement in end-of-life decisions.

Given this cultural reality, advance directives hold promise for resolving questions about the use of life-sustaining treatments. Patients who present a written living will clearly indicate their desire to be an active participant in their care. Still, even in the United States, only 10 to 15 percent of the population has completed an advance directive, and there are still many questions about their effectiveness (La Puma, Orentlicher, and Moss 1991; Stelter, Elliot, and

Bruno 1992; Schonwetter et al. 1993; Hanson and Rodgman 1996; Landry et al. 1997; Brennan 1998; Gross 1998).

Further research is needed to understand the utility of a written living will as an expression of patient autonomy in Japan where there is no legal recognition of advance directives. Research on physicians' treatment limitations and withdrawal behaviors is needed to gain a more robust understanding of the impact of living wills on end-of-life decision making in Japan. Such research can provide a better understanding of where boundaries of self-determination are drawn and how to achieve respect for autonomy in Japan.

The debate about the expression and limitation of patient autonomy in the United States marches on. Pellegrino has argued that respect for patient autonomy as practiced in the United States is not necessarily exportable to other cultures because it has developed in a particular North American context (Pellegrino 1992). However, he also argues that respect for "something close to autonomy" may be a universal approach to medical ethics. The development and spread of a standardized written living will by JSDD is, in essence, a test of Pellegrino's postulate.

While the Japanese people who complete written living wills are in a clear minority, they represent a growing interest in the acceptance of "something close to autonomy in Japan." Whether this social movement thrives or withers provides an opportunity for reflection on the centrality and limits of autonomy in Western and non-Western countries when providing care to culturally diverse populations. Further research on written living wills in other countries that have different social, cultural, religious, and philosophical traditions is needed to understand the utility and limitations of advance directives for enhancing patient self-determination at the end-of-life in multicultural settings.

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