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Original Paper

Advance Directives and Other Medical Decisions Concerning the End of Life in Cancer Patients in Japan

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The purpose of our survey was to investigate the experience of physicians regarding advance directives and other medical decisions concerning the end of life. A postal questionnaire was sent to 500 Japanese physicians who were most involved in medical care of terminal patients. A total of 339 (68%) physicians responded. In dealing with terminal patients, approximately half gave priority to their patients' wishes for medical care, if known, regardless of the patient's competency. Of the respondents, 149 had been presented with advance directives by their patients and 35% followed all advance directives presented in their practice. Cardiopulmonary resuscitation (CPR) for arrested patients to enable their family to be at the bedside at the time of the death was common. More than 60% of the respondents thought that active euthanasia and assisted suicide were never ethically justified. Our study indicates that the wishes of patients are currently not always given top priority in medical decisions concerning the end of life. © 1998 Elsevier Science Ltd. All rights reserved.

Key words: advance directives, patient's wishes, cardiopulmonary resuscitation, Japan, physician, medical decisions concerning the end of life, euthanasia
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INTRODUCTION

THE TERMINATION of life support, advance directives and euthanasia have recently been the subjects of sustained ethical debate in Japan. Two well-publicised 'euthanasia' cases in the 1990s have attracted public attention to physician-assisted death [1, 2]. Cases of the death of patients in a persistent vegetative state, involving withdrawal of artificial nutrition and hydration and withholding of antibiotics, were reported in the mass media in 1997. In these reports, the absence of advance directives or substitute consent of the patients' families was questioned [3, 4].

In 1992, the Bioethics Council of the Japan Medical Association officially declared for the first time that a physician should respect patient autonomy and written advance directives of a patient with terminal disease should be followed [5]. A public opinion poll by the Ministry of Health and Welfare also revealed that most respondents surveyed thought that the use of advance directives, including a written document and explicit oral expression, would be preferable and approximately half thought that advance directives should be legally regulated [6]. Currently, more than 75 000 people have participated in the Japan Death with Dignity Association and have formulated a living will [7]. Previous studies conducted in the 1990s also suggested physicians' positive attitudes toward advance directives and their willingness to respect patients' wishes regarding medical care [8, 9].

Alternatively, informed consent and truth telling to patients with serious illnesses are still controversial [10, 11], and strong involvement of the family may alter a physician's decision [11, 12]. Some physicians believe that they should prolong a patient's life as long as possible [13, 14]. These factors could compromise the implementation of a patient's wish or advance directives in medical decisions concerning the end of life. One study has suggested that observance of do-not-resuscitate orders (DNR orders) varied and some resuscitation procedures were performed despite explicit orders not to do so, depending on whether a patient's family

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or an attending physician was at the bedside or not at the time of cardiac arrest [15].

Hospice care was introduced in Japan in the 1970s and it is estimated that there are currently 21 hospice programmes, which are primarily hospital-based. Terminally ill patients are typically cared for and die in hospitals on general units, although a few are cared for in clinics and at home [16]. A majority of these patients tend to remain within subspecialties. Therefore, attitudes of physicians, who engage in diagnostic procedures and cancer therapy in general units in hospitals, toward medical decision concerning the end of life have a tremendous impact on the medical care of terminal patients with cancer.

Little is known about the extent to which Japanese physicians give priority to their competent patients' wishes or advance directives, or to what extent Japanese patients have expressed their wishes with regard to medical decisions concerning the end of life. No nationwide survey of physicians in Japan who are most involved in the care of terminal patients has ever been conducted to investigate current decision-making procedures at the end of life, nor have physicians' attitudes towards physician-assisted death been studied.

The purpose of our survey, therefore, was to investigate the experience of physicians regarding medical decisions concerning the end of life, including advance directives. We were especially interested to discover to what extent physicians gave priority to their patients' wishes in various medical situations.

PATIENTS AND METHODS

Because we were interested in the experience of physicians who are most involved in medical care of terminal patients, we approached physicians who were members of the Japan Society for Cancer Therapy (15 453 members at the time of the survey). We targeted the members whose specialties include internal medicine and its subspecialties. A postal questionnaire was sent in November 1996 to 500 physicians who were randomly selected from the 2086 internist members of the society. A reminder was sent to non-respondents in December 1996.

The questionnaire asked about their experience with regard to wishes or advance directives about unwanted medical intervention presented by their patients, the rate of observing or overriding these, and the occurrence of cardiopulmonary resuscitation (CPR) for arrested terminal patients in order to enable their family to be at the bedside at the time of cardiac death (CPR for patient's family). The questionnaire also asked about the ethical implications of assisted suicide, euthanasia, and other medical decisions concerning the end of life.

To ensure compatibility of responses, the following definitions were used for the terms used in the questionnaire.

Advance directives refers to wishes regarding unwanted medical intervention presented in advance by a competent patient to guide future medical care when the patient becomes incompetent. It includes oral advance directives and a document such as a living will. Since there are currently no legal regulations about advance directives in Japan, we did not limit it to written documents only.

Assisted suicide refers to assistance offered to a competent patient who is suffering uncontrollably and explicitly wishes to terminate his or her life by providing knowledge or drugs to precipitate the advent of death.

Euthanasia refers to precipitating the advent of death of a competent patient who is suffering uncontrollably and explicitly wishes to terminate his or her life by direct interference by the physician, for example, the injection of a lethal drug.

Life-terminating acts without the patient's explicit and persistent request for comatose terminal patients refers to administer lethal drugs to terminate the life of an incompetent patient whose explicit wishes are not known [17].

The responses for the rate of observance of presented advance directives and CPR for patient's family were ranked from 1 (none) to 5 (all), and attitudes of respondents towards advance directives on a four-point Likert scales including 'agree definitely', 'agree somewhat', 'disagree somewhat', and 'disagree definitely'. Ninety-five per cent confidence intervals (CI) were calculated.

The four responses were dichotomised to 'agree' and 'disagree'. Group means were compared using the independent *t* test. The chi-square test for independence was used to test differences between two independent categorical variables. The McNemar's chi-square test for changes was used to test differences in attitudes of the respondents depending on certain acts or behaviours.

A P value less than 0.05 was considered significant. Data were analysed against practice experience, respondents' religious beliefs, number of terminal patients in practice who had died in the previous 6 months, overseas medical research or training, and experience with patients expressing advance directives.

RESULTS

Response rate and respondents

Of the 500 questionnaires sent out, two were returned due to incorrect addresses. Of the remaining 498 questionnaires, 341 were returned and two respondents informed us that they decided not to participate in the survey because of retirement or suspension. As a result, 339 subjects participated in the survey, yielding a response rate of 68%. The characteristics of the respondents are shown in Table 1. Our respondents were predominantly men and their subspecialties varied. Approximately one-third had engaged in research and/or clinical practice in other countries, and 29 respondents reported a religious affiliation, including 14 Buddhists and nine Christians.

Table 1. *Characteristics of respondents*

Total number	339
Mean age (range, years)	43 (26-69)
Men (%)	320 (94)
Specialty (%)	
Respiratory medicine	61 (18)
Haematology or oncology	61 (18)
Gastrointestinal tract	96 (28)
Internal medicine	113 (33)
Others	8 (3)
Mean practice experience (range, years)	18 (2–45)
Number (%) with religious beliefs	29 (9)
Mean number of terminal patients in the past 6 months (range)	15 (0–150)
Mean number of terminal patients in practice who died in the past 6 months (range)	9 (0–80)
Medical research or training in foreign countries (%)	109 (32)
Experience of advance directives expressed by their patients	149 (44)

All characteristics of the respondents were independent except that respondents who had experience in other countries were older than those who had not, but this experience did not correlate with any of the answers given. A total of 149 respondents (44%; 95% CI 39–49%) had been presented with advance directives by their patients.

Priority of patient's wishes in medical decisions concerning the end of life

The questionnaire asked how the respondents reached medical decisions for a terminal patient and to what extent they respected patient's explicit wishes for terminal care (Table 2). In this question, the patient's wishes expressed in advance included medical interventions that a patient did or did not want, not only wishes regarding unwanted medical interventions, as in the advance directives defined in our questionnaire.

Approximately half of the respondents gave priority to their patients' current or advance wishes in terminal care when they were known, regardless of the patients' competence, while others gave priority to a competent patient's quality of life (QOL) or an incompetent patient's family's wishes in similar cases. Approximately 20% tried to respect a competent patient's wishes even if they had not been explicitly expressed. They tended to give priority to patient's QOL rather than the family's wishes when the patient was competent, while the family's wishes were considered more important than the physician's perception about the patient's QOL when the patient was incompetent. All of the respondents' characteristics were independent of their decisions in the four situations.

Experience regarding advance directives

The questionnaire asked the respondents about advance directives presented by their patients and its contents. Among 149 respondents who had received advance directives from their patients, 49% reported that less than 10 patients had presented advance directives, 16% indicated 10–99 patients, and 77% reported more than 100 patients. Another 30% did not report the number of such patients. On average, 10% of the patients whom the respondents had cared for presented them with advance directives (95% CI 5–15%).

Medical situations patients referred to in their advance directives included no chance of recovery (reported by 60 respondents), irreversible unconsciousness (47), suffering from intractable pain (17), and persistent respiratory distress (15).

Unwanted medical interventions mentioned by patients included CPR (reported by 75 respondents), life-prolonging acts in general (29), mechanical ventilation (26), and blood transfusion (15). Another 21 respondents reported advance directives that asked for sufficient palliative care. CPR was by far the most frequent unwanted intervention indicated in the advance directives, and total parenteral nutrition and intravenous fluid were mentioned as unwanted life-prolonging acts. Patients' wishes that all medical intervention should be terminated at a certain point were also expressed in the advance directives.

Approximately one-third of the respondents whose patients presented them with advance directives followed all of them, 57% followed more than half, and only 7% answered that they followed less than one-quarter (Table 3). Among the 133 reported reasons to follow or override a patient's advance directives, the most frequent reason for following a patient's advance directives was the respondent's belief that a patient's rights and wishes in medical care should be respected (60 respondents). This was followed by the respondent's judgement that the patient's QOL was poor (9), and the perception that life-sustaining treatment was futile (6). In contrast, the reasons for overriding advance directives varied and they included family wishes to sustain a patient's life (23), high possibility of recovery (5), and absence of the patient's family at the bedside (3). All of the respondents' characteristics were independent of their experience with advance directives.

Attitudes and observance towards advance directives

The respondents' attitudes towards advanced directives and medical decisions concerning the end of life based on advance directives are shown in Table 3. Approximately 90% regarded advance directives as useful for the provision of care for their terminal patients, and significantly more respondents who had been presented with advance directives by their patients did so than those who had not (95% versus 85%, chi-square = 8.96, $P < 0.003$). However, there was a considerable number of respondents who expressed concern about withdrawing or withholding life support from a terminal patient based on the advanced directives. Significantly

Table 2. Priority of patients' wishes in medical decisions concerning the end of life (respondents = 339)

	% of respondents (95% CI)	
	Patient competent	Patient incompetent
Patients' wishes about terminal care were known		
Patients' wishes given priority	59 (54–64)	51 (46–56)
QOL* of patient given priority	20 (16–24)	10 (7–13)
Family's wishes given priority	4 (2–6)	20 (16–24)
No experience	12 (9–16)	15 (11–19)
Patient's wishes about terminal care were unknown		
Patients' wishes given priority	19 (15–23)	NA
QOL* of patient given priority	41 (36–46)	21 (17–25)
Family's wishes given priority	27 (22–32)	64 (59–69)
Possibility of recovery	–	8 (5–11)
No experience	1 (0.9–1.1)	2 (1–3)

*For incompetent patients, this relates to the physician's perception of the patient's QOL. NA, not applicable; QOL, quality of life; CI, confidence interval.

Table 3. Attitude of respondents to advance directives

	% of respondents (95% CI)
Respondents received advance directives ($n = 149$)	
Never followed advance directives presented by patients	1 (0–2)
Followed approximately 25%	6 (2–10)
Followed approximately 50%	15 (9–21)
Followed approximately 75%	42 (34–50)
Followed all advance directives presented	35 (26–43)
Respondent believed ($n = 339$):	
Withdrawal of life support based on patient's advance directives could lead to patient's family's lawsuit against murder	52 (47–57)
Withholding life support based on patient's advanced directives could lead to patient's family's lawsuit against murder	40 (35–45)
Withdrawal and withholding life support could mean abandoning a terminal patient	14 (10–18)
Advance directives are useful for medical decisions concerning the end of life in Japan	89 (86–92)

more respondents (52%) said they feared being sued for murder by a patient's family if they withdrew life support, even in observance of a patient's advance directives, than if they withheld it (40%; McNemar's chi-square $= 26$, $P < 0.0001$).

Respondents who did not regard advance directives as useful for the provision of care for their terminal patients and those who considered that not prolonging the life of a patient even if it was in accordance with the advance directives was the equivalent of abandonment, had significantly longer clinical experience than respondents who thought otherwise (mean length of experience 21 years versus 17 years, $t = 2.7$, $P = 0.008$, and 22 years versus 17 years, $t = 3.7$, $P = 0.0002$, respectively).

CPR for the patient's family

Respondents were asked about their experience with CPR for arrested terminal patients in order to enable their family to be at the bedside at the time of the death (CPR for patient's family). Only 4% (95% CI 2–6%) of the respondents had never performed CPR for patient's family, while 7% (95% CI 2–12%) had performed it in all cases. A total of 42% (95% CI 39–45%) performed it for one-quarter of their cases, 25% (95% CI 20–30%) for half their cases, and 20% (95% CI 16–24%) for three-quarters of cases.

Attitudes towards assisted suicide, euthanasia and life-terminating acts without the patients explicit and persistent request for comatose terminal patients

We asked the respondents about their attitudes toward assisted suicide, euthanasia, and withdrawal of life support from a competent terminal patient. Opinions about life-terminating acts without the patient's explicit and persistent request for comatose terminal patients were also sought. The results are shown in Table 4. Life-terminating acts without the patient's explicit and persistent request for comatose terminal patients was regarded as never ethically justified by significantly more respondents as compared with assisted suicide or euthanasia (McNemar's chi-square $= 36$, $P < 0.00001$ and McNemar's chi-square $= 48.2$, $P < 0.00001$, respectively). There was no significant difference in attitudes towards assisted suicide and euthanasia. Withdrawal of life support was considered ethically acceptable or justifiable by 67% of respondents. The respondents who regarded withdrawal of life support from a competent terminal patient ethically justifiable tended to have had a shorter clinical experience than those who did not (mean clinical experience: 17 years versus 19 years, $t = 2.2$, $P = 0.03$).

DISCUSSION

The results indicate that the wishes of competent patients or their advance directives are currently not always given top priority in medical decision-making in Japan. Approximately 60% of the respondents gave them priority, but others made their decisions based on other factors, including the patient's QOL, the physician's perception of the patient's QOL, or the family's wishes for terminal care, even when they knew what their patients wanted or would want at the end of life.

Why are competent patients' wishes or advance directives not always granted top priority? First, Japanese terminal patients may not be able to make their advance directives specific enough to guide a physician's decisions [18, 19]. Second, because of the strong influence of a patient's family

Table 4. Attitudes of the respondents towards assisted suicide, euthanasia, life-terminating acts without the patient's explicit and persistent request for comatose terminal patients (n=339)

	% of the respondents (95% confidence interval)			
	Assisted suicide	Active euthanasia	Life-terminating acts without the patient's explicit and persistent request for comatose terminal patients	Withdrawal of life support
Never ethically justified	67 (62–73)	64 (59–69)	83 (79–87)	24 (20–29)
There are some situations in which it is justified	21 (17–25)	21 (17–25)	11 (8–14)	47 (42–52)
Ethically acceptable	4 (2–6)	4 (2–6)	2 (1–3)	15 (11–19)
Should be encouraged	1 (0.9–1.1)	0.3 (0–0.9)	0 (0)	5 (3–7)

in decision-making, their wishes may be respected more than those of patients [11]. In the U.K. and U.S.A. advance directives when known, are assumed to guide treatment decisions [20, 21]. Several of our respondents, however, reported overriding their patients' advance directives because of family requests, demonstrating the same attitudes as reported in a previous international study [12]. Third, Japanese physicians tend to believe that it is an ethical duty of the medical profession to provide any possible intervention, and at the same time to think, as some respondents showed, that withdrawing life support could be ethically and legally wrong [13]. Fourth, both the physician and the patient's family may consider it extremely important for the patient's family to be at the bedside at the time of the patient's death. Most respondents reported performing CPR for the patient's family. Unlike in the U.S.A. or Canada, where ethical principles forbid providing CPR in a way that is known to be ineffective just to convince a patient's family 'everything was done', such an action could well be part of the standard care at the end of life for a substantial number of Japanese physicians [22].

This study has several limitations. The generalisability of our results is limited. Because the internists surveyed were randomly selected from the members of one association, they may not be representative of many other internists involved in medical care of terminal patients. We also failed to obtain responses from some other internists whose specialties were geriatrics or nephrology. A mailing list we obtained from the Society did not include the subjects' characteristics and personal background, except names. Therefore, we could not know what percentage of physicians in each specialty was sent questionnaires and what percentage responded. Belonging to a certain speciality, might influence their attitude to participating in our study.

Our respondents were predominately men and the results failed to indicate attitudes of female internists in Japan towards ethical decisions concerning the end of life. A report of the Ministry of Heath and Welfare indicates that 11.9% of all Japanese physicians were women in 1992 and only 8% were working in national hospitals or medical institutes in 1995 [23]. The response rate of women might have been lower than that of men, although we do not have data to show this.

Physicians who are caring for many patients with cancer may provide their patients with exact medical information which makes it possible for these patients to express their wishes and advance directives more frequently than those who are not. In addition, more than 30% of the physicians did not participate in our study and their attitudes may differ from those who participated. It should also be noted that answers in the questionnaire may not necessarily reflect the respondents' actual behaviour in medical decisions concerning the end of life.

Nevertheless, our study gives an indication of the current situation and the attitudes of Japanese physicians towards medical decisions concerning the end of life in Japan and also suggests possible barriers to implementing competent patients' wishes or advance directives in medical decisions concerning the end of life. We suspect that the situations presented here are not limited only to Japan, and that similar circumstances can be found in some countries where truth telling is still controversial and patients' families are seriously involved in medical decision-making [11, 24].

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