Direct communication between a patient and physician and between a patient and his or her family members does not always occur in a health care setting.⁷ Japanese physicians and family members traditionally have tried to make medical and social decisions in the best interests of patients without telling them the truth and without asking for their preferences. Patients have tended to assume that their physicians and family members would make the best overall decisions for them, while taking their wishes into consideration. They therefore assume that there is no need to communicate their wishes to their caregivers and close relatives. 10 It also is argued that the sick and their family members share common values that are rooted in Japanese culture, so that patients' wishes for health care can be perceived through implicit communication. This type of nonverbal communication has been called "ishin-denshin" in Japan: when someone does not explicitly ask a favor from someone else, the other person should infer what is desired and provide the inferred favor accordingly. 10,11

We suspect that the traditional belief in the existence of common preferences regarding health care and ishin-denshin could be false or, at best, illusory. Regardless of willingness to meet others' wishes and regardless of mutual expectations, if wishes or values become highly diverse or complicated, indirect communication no longer works. If such beliefs are fictitious or outdated, substituted judgment for competent patients should be discouraged. A recent report that reviewed published data regarding Japanese patients' preferences for the use of advance directives suggested that advance directives were desired by approximately 80% of the general public and physicians. 12 Another study reported that few people actually formalized their preferences for health care treatment in written form, and physicians tended to make their decisions according to the family's wishes; this occurs in Germany and the United States, as well as in Japan. 13

The purpose of this study is to assess how accurately family members and physicians can predict patients' wishes about medical care and treatment, including dialysis and cardiopulmonary resuscitation (CPR), under various medical scenarios. To the best of our knowledge, no other study to date conducted in Japan has aimed to

assess the ability of family members and physicians to understand and/or predict the wishes of patients. We targeted patients who had been undergoing long-term dialysis treatment, their families, and their physicians.

METHODS

This study was ethically and methodologically approved by the committee of the Department of Clinical Research, Sakura National Hospital, in 1997.

One of the authors previously participated in an informal clinical study group consisting of 20 nephrologists at 16 hospitals throughout Japan. We decided to ask the physicians at those hospitals to join our survey. Two of the nephrologists at 1 hospital did not respond: 18 physicians in 15 hospitals took part in the study, and they were asked to include up to 30 of their ambulatory dialysis patients in the

Table 1. Patient Characteristics

| Mean age (y) | 57 ± 12 (23-87) |
|----------------------------------|--------------------------|
| Sex | |
| Female | 144 (36) |
| Male | 254 (64) |
| Duration of dialysis (y) | $8.3 \pm 5.5 (1.7-30.4)$ |
| Dialysis modality | , |
| Hemodialysis | 283 (71) |
| Continuous ambulatory | |
| peritoneal dialysis | 115 (29) |
| Level of education | |
| Graduated from middle high | |
| school | 96 (24) |
| Graduated from high school | 192 (48) |
| Graduated from 2-year college | 16 (4) |
| Graduated from 4-year | |
| university or higher | 73 (18) |
| Level of annual income (yen) | |
| <3,000,000* | 145 (36) |
| 3,000,000~5,000,000† | 74 (19) |
| 5,000,000~7,000,000‡ | 41 (10) |
| 7,000,000~10,000,000§ | 26 (7) |
| 10,000,000~12,000,000 | 11 (3) |
| >12,000,000¶ | 17 (4) |
| Cause of end-stage renal disease | , |
| Chronic glomerulonephritis | 255 (64) |
| Diabetic nephropathy | 50 (13) |
| Polycystic kidney | 17 (4) |
| Nephrosclerosis | 15 (4) |
| Unknown | 19 (5) |
| Other disease | 19 (10) |

NOTE. N = 398. Values expressed as mean \pm SD (range) or number (percent).

*US \$27,000

†US \$27,000 ~ 45,000

‡US \$45,000 ~ 64,000

§US \$64,000 ~ 91,000

|US \$91,000 ~ 110,000

¶US ~ \$110,000

study. Questionnaires were sent to the physicians on September 1, and the sampling was terminated on November 30, 1997. The questionnaire was delivered to patients who agreed to participate in this study. Participants were chosen consecutively and on the basis of convenience by their physicians, and sampling was terminated when 30 patients had been enrolled. Family members were handed the questionnaire from the patients at their homes so there was an opportunity to discuss their answers, but it was clearly stated on the first page of the questionnaire: "Please do not discuss the answers with each other."

The 3-page questionnaire consisted of questions about patient preferences regarding CPR and dialysis treatment (see appendix online with article at www.ajkd.org). We used a 5-point Likert scale consisting of "Yes," "Probably yes," "Uncertain," "Probably not," and "No." Patients' wishes regarding CPR were determined by using 3 health scenarios. The first scenario asked whether they would want CPR if they experienced cardiopulmonary arrest in their current condition: current health status is defined as "the state of the patient's health when the patient answers the questionnaire." It should be noted again that all our subjects were ambulatory patients who could visit their clinics without assistance. The second scenario asked whether they would want CPR if the same thing happened when they had serious dementia. In this scenario, the patient has lost self-perception, is unable to recognize his or her family, and has become completely dependent. The third scenario inquired about their wishes for CPR if they had terminal cancer with an expected survival of 6 months. In this scenario, the patient is mentally competent and pain can be controlled by medication. The survival rate with discharge after CPR was stated to be less than 10%. The survey also inquired about patients' wishes regarding continuation of dialysis treatment in the second and third scenarios (serious dementia and terminal cancer). Finally, patients were asked about their experiences of discussing their preferences for CPR and dialysis therapy discontinuation with their families and physicians and how accurately they thought their physicians and family members would understand and represent their general preferences. Patient demographics also were explored. Medical charts of patients were viewed by their nephrologists to obtain information about type and duration of dialysis therapy and patients' underlying diseases. At the same time, we asked family members and physicians about patients' preferences for CPR and dialysis to assess their ability to predict their patients' wishes in various scenarios. Preferences for CPR and dialysis were scored on the same 5-point Likert scale described earlier.

The accuracy of estimates by physicians and family members was assessed by means of weighted κ coefficient. A κ value exceeding 0.75 was considered to be "excellent agreement"; a value between 0.4 and 0.75, "fair to good agreement"; and a value less than 0.4, "poor agreement." We used STATA, release 8 (StataCorp, College Station,TX) for statistical analysis.

RESULTS

Patient characteristics are listed in Table 1. Of 450 patients asked to participate, 412 agreed to answer the questionnaire. Three hundred ninety-eight complete sets of questionnaires were re-

Table 2. Family Members' Understanding of Patients' Preferences About CPR

| | | | Pa | atients' Preferenc | es · | | |
|-------------------------|-----------------|-----------|-------------------|--------------------|----------------|-----|-------|
| Family's Estimation | | Yes | Probably Yes | Uncertain | Probably No | No | Total |
| Current situation | Yes | 67 | 25 | 17 | 21 | 19 | 149 |
| | Probably yes | 20 | 13 | 17 | 17 | 15 | 82 |
| | Uncertain | 14 | 10 | 15 | . 21 | 23 | 83 |
| | Probably no | 10 | 0 | 6 | 13 | 20 | 49 |
| | No | 2 | 1 | 2 | 3 | 18 | 26 |
| | Total | 113 | 49 | 57 | 75 | 95 | 389 |
| | Agreement, 68.3 | 32%; expe | cted agreement, 5 | 57.34%; к coeff | cient, 0.2573 | | |
| If demented | Yes | 11 | 6 | 7 | 17 | 19 | 60 |
| | Probably yes | 1 | 7 | 12 | 23 | 19 | 61 |
| | Uncertain | 1 | 7 | 18 | 24 | 48 | 98 |
| | Probably no | 6 | 4 | 6 | 36 | 55 | 107 |
| | No | 3 | 1 | 0 | 10 | 54 | 68 |
| | Total | 22 | 25 | 43 | 110 | 194 | 394 |
| | Agreement, 68.2 | 21%; expe | cted agreement, 6 | 60.76%; κ coeff | icient, 0.1899 | | |
| If with terminal cancer | Yes | 8 | 7 | 10 | 14 | 22 | 61 |
| | Probably yes | 2 | 5 | 6 | 18 | 19 | 50 |
| | Uncertain | 2 | 8 | 13 | 26 | 50 | 99 |
| | Probably no | 2 | 6 | 12 | 32 | 67 | 119 |
| | No | 5 | 1 | 0 | 9 | 49 | 64 |
| | Total | 19 | 27 | 41 | 99 | 207 | 393 |
| | Agreement, 66. | 30%; expe | cted agreement, 6 | 61.02%; κ coeff | icient, 0.1432 | | |

| | | | Pa | atients' Preferenc | es | | |
|-------------------------|-----------------|-----------|-------------------|--------------------|----------------|-----|-------|
| Family's Estimation | | Yes | Probably Yes | Uncertain | Probably No | No | Total |
| If demented | Yes | 22 | 19 | 23 | 21 | 17 | 102 |
| | Probably yes | 1 | 12 | 19 | 23 | 18 | 73 |
| | Uncertain | 4 | 9 . | 35 | 33 | 40 | 121 |
| | Probably no | 2 | 2 | 7 | 25 | 31 | 67 |
| | No | 1 | 0 | 2 | 10 | 17 | 30 |
| | Total | 30 | 42 | 86 | 112 | 123 | 393 |
| | Agreement, 67.4 | 13%; ехрє | cted agreement, 5 | 8.68%; к coeff | icient, 0.2117 | | |
| If with terminal cancer | Yes | 46 | 38 | 20 | 24 | 10 | 138 |
| | Probably yes | 15 | 33 | 26 | 21 | 18 | 113 |
| | Uncertain | 13 | 21 | 17 | 11 | 22 | 84 |
| | Probably no | 4 | 7 | 7 | 12 | 13 | 43 |
| | No | 0 | 1 | 2 | 3 | 7 | 13 |
| | Total | 78 | 100 | 72 | 71 | 70 | 391 |

Agreement, 68.99%; expected agreement, 61.87%; κ coefficient, 0.1867

Table 3. Family Members' Understanding of Patients' Preferences for Continuation of Dialysis Treatment

turned, which included responses of the patient, family members, and physician, giving a final response rate of 88%. (There were no responses from family members in 14 sets of questionnaires.) Some respondents did not answer all the questions, so the number of responses to each question varied from 389 to 398.

Sixty-four percent of patients were men, and 71% were undergoing hemodialysis for long periods (average, 8.3 years). Sixty-four percent of patients had chronic glomerulonephritis, and 13%, diabetic nephropathy. Of 398 family members, 79% were spouses, 16% were the patient's children, and 4% were close relatives. Eighteen nephrologists participated as substitute decision makers for their patients. All were caring for dialysis patients at the 15 hospitals surveyed.

Understanding by family members of patient preferences regarding CPR and dialysis therapy, agreement rate, expected agreement rate, and κ coefficient are listed in Tables 2 and 3. Results for physicians are listed in Tables 4 and 5. Correct agreement rates of family members ranged from 66.6% to 68.99%, and those of physicians, from 60.45% to 75.25%. As listed in the tables, κ coefficients for each question ranged from 0.1432 to 0.2573 for patients and their family members and 0.0693 to 0.1433 for patients and their physicians.

Figure 1 and Table 6 show patients' perceptions of the accuracy of their family members' and physicians' understanding of their prefer-

ences. One hundred eighty-five patients (47%) thought their families could accurately or almost accurately judge their overall wishes regarding life-sustaining treatment, including CPR or dialysis therapy, and 120 patients (31%) thought their physician could do so. Conversely, 218 family members (56%) thought they could accurately or almost accurately judge the patient's overall wishes, and 196 physicians (50%) thought they could do so. Table 6 shows the mutual understanding regarding patients' preferences about CPR and dialysis discontinuation. Among patients and family members, κ coefficients were 0.2214, and among patients and physicians, 0.0974.

Whether discussion took place with family members and physicians regarding patient preferences for CPR is shown in Fig 2. Thirty percent of patients answered that they had discussed their preferences for CPR with their family members, and only 5%, with their physicians.

We reanalyzed only results in which the patient believed that a family member would accurately or almost accurately judge their preferences (n = 185): the κ coefficient increased, but did not exceed 0.4 (Table 7, question A). Reanalyzing only results in which patients thought they had already discussed their preferences with family members (n = 114), the κ coefficient also increased, but did not exceed 0.4 for any scenario (Table 7, question B). When reanalyzing results in which patients believed their physicians would accurately or almost accurately judge their pref-

Table 4. Physicians' Understanding of Patients' Preferences About CPR

| | | | Pa | atients' Preferenc | es | | |
|-------------------------|-----------------|-----------|-------------------|--------------------|----------------|-----|-------|
| Physicians' Estimation | | Yes | Probably Yes | Uncertain | Probably No | No | Total |
| Current situation | Yes | 50 | 19 | 24 | 24 | 34 | 151 |
| | Probably yes | 46 | 25 | 21 | 28 | 38 | 158 |
| | Uncertain | 13 | 3 | 8 | 13 | 12 | 49 |
| | Probably no | 3 | 3 | 4 | 7 | 10 | 27 |
| | No | 4 | 0 | 0 | 5 | 3 | 12 |
| | Total | 116 | 50 | 57 | 77 | 97 | 397 |
| | Agreement, 60.4 | 45%; expe | cted agreement, 5 | 7.35%; к coeff | icient, 0.0728 | | |
| If demented | Yes | 1 | 0 | 1 | 0 | 6 | 8 |
| | Probably yes | 2 | . 5 | 5 | 11 | 15 | 38 |
| | Uncertain | 3 | 1 | 4 | 13 | 16 | 37 |
| | Probably no | 10 | 15 | 28 | 56 | 77 | 186 |
| | No | 6 | 4 | 5 | 31 | 83 | 129 |
| | Total | 22 | 25 | 43 | 111 | 197 | 398 |
| | Agreement, 75.2 | 25%; expe | cted agreement, 7 | '2.05%; к coeff | icient, 0.1146 | | |
| If with terminal cancer | Yes | 1 | 0 | 2 | 2 | 4 | 9 |
| | Probably yes | 2 | 5 ^ | 6 | 15 | 27 | 55 |
| | Uncertain | 1 | 1 | 5 | 13 | 8 | 28 |
| | Probably no | 10 | 12 | 13 | 47 | 87 | 169 |
| | No | 5 | 9 | 15 | 23 | 84 | 136 |
| | Total | 19 | 27 | 41 | 100 | 210 | 397 |
| | Agreement, 72.8 | 36%; expe | cted agreement, 7 | '0.84%; κ coeff | icient, 0.0693 | | |

erences (n = 120), the κ coefficient showed the same tendency (Table 7, question C). Only 19 patients answered that they had already discussed their preferences with their physicians, so we did not analyze this result.

DISCUSSION

Patient preferences regarding CPR and withdrawal of dialysis therapy from the same participants were analyzed in detail and have been published.¹⁵ Thus, the purpose of this study is to assess how accurately family members and physicians can predict those patients' preferences in the same medical scenarios.

Our results suggest that the decision-making process in the Japanese clinical setting presents several ethical problems. First, neither family members of long-term dialysis patients nor care-

Table 5. Physicians' Understanding of Patients' Preferences for Continuation of Dialysis Treatment

| | | Patients' Preferences | | | | | , |
|-------------------------|-----------------|-----------------------|--------------------|-----------------|----------------|-----|-------|
| Physicians' Estimation | | Yes | Probably Yes | Uncertain | Probably No | No | Total |
| If demented | Yes | 5 | 2 | 6 | 8 | 7 | 28 |
| | Probably yes | 12 | 23 | 27 | 29 | 34 | 125 |
| | Uncertain | 5 | 7 | 26 | 27 | 18 | 83 |
| | Probably no | 7 | 7 | 25 | 37 | 49 | 125 |
| | No | 1 | 3 | 4 | 12 | 17 | 37 |
| | Total | 30 | 42 | 88 | 113 | 125 | 398 |
| | Agreement, 68.4 | 11%; expe | ected agreement, 6 | 34.29%; κ coeff | icient, 0.1433 | | |
| If with terminal cancer | Yes | 29 | 30 | 18 | 10 | 17 | 104 |
| | Probably yes | 34 | 42 | 37 | 35 | 25 | 173 |
| | Uncertain | 12 | 15 | 6 | 14 | 13 | 60 |
| | Probably no | 4 | 13 | 11 | 9 | 13 | 50 |
| | No | 0 | 0 | 1 | 4 | 4 | 9 |
| | Total | 79 | 100 | 73 | 72 | 72 | 396 |
| | Agreement, 66.7 | 73%; expe | ected agreement, 6 | 33.07%; к coeff | icient, 0.0990 | | |

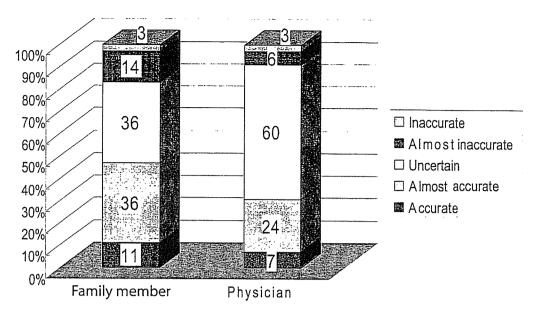


Fig 1. Patients' perceptions of the accuracy of their family members' and physicians' understanding of their preferences. Family members, n = 390; physicians, n = 395; all numbers in figure shown as percentages.

giving physicians could correctly assess or predict their patients' current or future preferences in terms of health care better than could be expected by chance alone. Concordance rates were consistently low regardless of the medical scenario or patient quality of life in certain hypothetical situations. Our findings strongly suggest that the tacit communication currently assumed to exist in Japanese clinical settings cannot satisfy patients' health-related preferences and fails

to respect their autonomy. We believe that our data constitute reliable evidence against the Japanese belief that one's wishes are intuitively known to others and thus can be realized without explicit communication (ishin-denshin).

The Japanese Society of Dialysis Therapy reported that more than 230,000 patients were undergoing long-term dialysis treatment in Japan as of December 31, 2003. Average age for the introduction of dialysis therapy was 65.4 years,

Table 6. Mutual Understanding Regarding Patients' Preferences About CPR and Dialysis

| | | **** | P | atients' Perc | eption | | |
|---------------------------|-------------------|-------------|-------------------|---------------|-------------------|------------|-------|
| | | Accurate | Almost Accurate | Uncertain | Almost Inaccurate | Inaccurate | Total |
| Patients and family | | | | | | | |
| Family's understanding | Accurate | 6 | 5 | 7 | 3 | 0 | 21 |
| | Almost accurate | 32 | 87 | 52 | 23 | 3 | 197 |
| | Uncertain | 4 | 34 | 74 | 21 | 2 | 135 |
| | Almost inaccurate | 0 | 16 | 7 | 6 | 2 | 31 |
| | Inaccurate | 1 | 0 | 0 | 2 | 3 | 6 |
| | Total | 43 | 142 | 140 | 55 | 10 | 390 |
| | Agreement, 91.99% | 6; expected | d agreement, 76.8 | 86%; к сое | fficient, 0.2214 | | |
| Patients and physician | | | | | | | |
| Physician's understanding | Accurate | 2 | 12 | 13 | 0 | 0 | 27 |
| | Almost accurate | 10 | 50 | 95 | 8 | 6 | 169 |
| | Uncertain | 10 | 29 | 116 | 13 | 7 | 179 |
| | Almost inaccurate | 4 | 3 | 14 | 2 | 1 | 24 |
| | Inaccurate | 0 | 0 | 0 | 0 | 0 | 0 |
| | Total | 26 | 94 | 238 | 23 | 14 | 395 |
| | Agreement, 81.90% | 6; expected | d agreement, 79.9 | 95%; κ coe | fficient, 0.0974 | | |

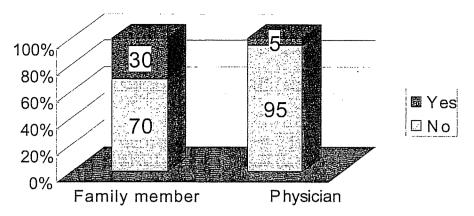


Fig 2. Patients' answers for the question, "Have you ever discussed your preferences regarding CPR with your family members or physicians?" For family members, n = 385; physicians, n = 391; all numbers in figure shown as percentages.

approximately 47% of all patients with dialysis treatments were older than 65 years, and 32% were 70 years or older.16 Approximately 15% of Japanese patients undergoing dialysis treatment require special supportive care because of disability. 17 Some of these Japanese patients may not want to continue their dialysis treatment because of their dependence or poor quality of life. Several studies suggested that most Japanese do not desire mere prolongation of life by aggressive intervention. 12 Japanese physicians may pursue more aggressive life-prolonging treatment than in other countries and also tend to give priority to the wishes of a patient's family to prolong the life of the patient despite the patient's own advance directives or informed preferences. 9,13,18 Another study reported that a patient's family

tended to consider that termination of life prolongation is abandonment of their duties. 19 Do-notresuscitate orders rarely are documented and sometimes ignored.²⁰ Under these circumstances. the unconditional introduction of dialysis treatment for dependent and disabled patients without direct consultation with the patient to establish their wishes could constitute a serious infringement of the patient's dignity and preferences. A patient may want to have dialysis treatment continued regardless of his or her medical condition or quality of life, while the family and physician believe that the patient's wishes are the opposite. In this case, a lack of valid communication of patient preferences and intentions could lead to premature termination of life-sustaining efforts. We believe that one of the important goals of

Table 7. Reanalysis of κ Coefficients for Each Scenario With Only the Limited Results

| | Overall | A: Patient's Estimation: Accurate or Almost Accurate | B: Former Discussion: Yes |
|-----------------------|---------|--|---------------------------|
| Patient and family | | | |
| Now: CPR | 0.1445 | 0.3549 | 0.3378 |
| Demented: dialysis | 0.1254 | 0.3020 | 0.2730 |
| Demented: CPR | 0.1430 | 0.2914 | 0.2581 |
| Cancer: dialysis | 0.1067 | 0.2675 | 0.2641 |
| Cancer: CPR | 0.0851 | 0.2652 | 0.2495 |
| | Overall | C: Patient's Estimation: Accurate or Almost Accurate | |
| Patient and physician | | | |
| Now: CPR | 0.0434 | 0.0828 | |
| Demented: dialysis | 0.0859 | 0.1321 | |
| Demented: CPR | 0.0960 | 0.1879 | |
| Cancer: dialysis | 0.0122 | 0.1349 | |
| Cancer: CPR | 0.0742 | 0.1243 | |

NOTE. For A, B, and C; see patient questions 4, 7, and 5.

medicine is to satisfy the rational health-related preferences of patients. Such a target cannot be achieved if family members and physicians continue to believe that their decisions are in agreement with what patients want or might want.

The second interesting finding is the low expectation of participating patients regarding the ability of their family members or physicians to predict their wishes about CPR or continuation of dialysis therapy. As results indicate, only half the dialysis patients expected their family members to make satisfactory substituted decisions, and less than one third believed that about their physicians. Confidence by physicians and family members in the accuracy of their judgment was greater than patients' perceptions. This result suggests that Japanese patients, at least in the clinical setting, have begun to recognize that individuals have different preferences and it is impossible to know these preferences intuitively or to make tacit decisions. In other words, Japanese physicians and even their family members may now be perceived as "strangers at the bedside" by some patients. 21 Our results support this possibility. For satisfactory decision making regarding quality-of-life and end-of-life decisions, explicit communication and inquiry therefore are essential.

Third, our findings are in agreement with outcomes of previous studies about communication among patients, family members, and health care professionals, conducted mainly in the United States, 1,3-5 and the previously mentioned survey by Kai et al. This agreement suggests that despite cultural differences in human relationships between the United States and Japan, family members and physicians are poor substituted decision makers in clinical settings. There seems to be no justifiable reason for the continuation of substituted judgment based on "Japanese specific intuition" without serious reconsideration.

There are several limitations to our study. First, the generalizability of our results is limited, mainly because participants were chosen consecutively and on the basis of convenience by their nephrologists and the survey was performed with physicians in 15 hospitals who also were selected for reasons of convenience from an informal group. Subjects therefore may not be representative of others receiv-

ing dialysis care, although the response rate of pairs consisting of a patient and a family member was as high as 88%. Our results are based on assessment by 18 nephrologists. The ability to judge patient wishes may differ depending on the specialization of the physicians. Another point is that patients with other illnesses may have different communication patterns with their family members or physicians. It also should be noted that answers to the questionnaire may not necessarily reflect respondents' actual preferences or opinions; thus, actual agreement might be different. Finally, we did not ask participants to what extent they had actually discussed their preferences regarding termination of dialysis therapy or CPR under various medical scenarios with their family members or physicians.

In conclusion, family members and caregiving physicians of dialysis patients appear to have very little knowledge of patients' preferences regarding life-sustaining treatment in current and future situations. There seems to be a need for more explicit communication about preferences regarding health care and for more discussion to understand the real wishes of others. It also can be concluded that regardless of cultural differences with respect to an individual's autonomy, routine use of informed consent and advance directives should be expanded for more effective expression of patient health care preferences and greater patient satisfaction.

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Dialysis Patients' Preferences Regarding Cardiopulmonary Resuscitation and Withdrawal of Dialysis in Japan

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• The aim of this study is to show the preferences of Japanese dialysis patients for receiving cardiopulmonary resuscitation (CPR) in their current health status, if they were severely demented, or if they had terminal cancer and to determine their desires about continuing dialysis if they were severely demented or had terminal cancer. A questionnaire survey including the three scenarios was administered to 450 dialysis patients in 15 hospitals in Japan. Three hundred ninety-eight patients completed the questionnaires for a response rate of 88%. The majority of responding patients were men and were undergoing hemodialysis. Only 5% of the patients had discussed their preferences regarding CPR with their physicians, and 29%, with their family members. Forty-two percent of the patients answered that they would want to receive CPR if they experienced cardiopulmonary arrest in their current health status, and 12% answered in the affirmative if they were seriously demented or had terminal cancer. Eighteen percent of the patients would want to continue dialysis if they were demented, and 45%, if they had terminal cancer. Statistical analysis showed that more patients who were working tended to want to continue dialysis if they had terminal cancer than those who were not (53% versus 37%; P < 0.014). Patients' age and preferences did not statistically correlate. Preferences of Japanese dialysis patients for CPR and dialysis vary according to differences in health status, and only a minority would want to receive CPR for cardiopulmonary arrest even in their current health status.

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INDEX WORDS: Medical ethics; patient preference; dialysis discontinuation; cardiopulmonary resuscitation (CPR).

Editorial, p. 1308

APANESE HEALTH CARE and medicine have shown strong dedication to the study and practice of dialysis treatment to improve its quality. The total number of patients undergoing dialysis treatment in Japan comprises approximately one quarter of all such patients in the world. Currently (as of December 1998), more than 185,000 patients are undergoing chronic

dialysis treatment in Japan. Approximately one quarter of the patients are aged 70 years or older, whereas approximately 15% of them reportedly require special supportive care because of their disability.^{2,3} However, in ethical terms, it was not until the mid-1990s that Japanese physicians or researchers started to discuss and investigate such major issues as withdrawal of dialysis or use of advance directives in Japanese clinical settings. A study conducted in 1995 suggested that only 1.9% of the dialysis patients had provided written advance directives, and approximately one third had done so orally. However, the rate of death as a result of cessation of dialysis was not known at that time. Approximately one fourth of the patients were competent and made informed decisions with regard to withdrawal of dialysis treatment.4 Another survey showed that more than 80% of dialysis patients wanted to give advance directives expressing their wish not to undergo unwanted life-support treatment.5

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Received May 30, 2000; accepted in revised form December 15, 2000.

Supported in part by the Grant for Scientific Research Expenses for Health and Welfare Program; and Funds for Comprehensive Research on Long-Term Chronic Disease (Renal Failure).

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0272-6386/01/3706-0014\$35.00/0 doi:10.1053/ajkd.2001.24525 In terms of religion and culture, Japan might differ from Western countries. A public poll in 1995 showed that only 32% of the people surveyed answered that they were religious (26% Buddhist, 2% Shinto, and 1% Christian), and those who identified themselves as atheists were in the majority (63%). Surprisingly, a majority of

secular Japanese people (70%) expressed an alleged belief in Buddhist cause-and-effect thinking and claimed to practice both Buddhist and Shinto religious activities on a daily basis. 6 Japanese psyche and behavior also have been strongly influenced by the traditional Chinese philosophy of Confucianism for centuries. Although it has been argued that Shinto views death as curse and abhorrence and that Confucianism never mentions heaven and exclusively values matters of this world, 7,8 thus accounting for a desire to sustain life at all costs, a recent survey conducted in Japanese suggested that both Shinto and Buddhism seemed to accept "being natural" in the terminal stages of life, thus implicitly denying extraordinary life-sustaining treatments.9 In addition, as a result of the persistent influence of Confucianism, as well as Shinto, interdependence and harmony have great significance as social values. Japanese ethical decision making is situation bound, based on the complex cultural rules of relationship and interdependency. Decisions therefore are not made ahead of time because the situation is unknown, and ethical dilemmas are resolved depending on the variables prevalent at the time. 10

Although Japanese attitudes toward medical decision making, including life and death decisions, undoubtedly have been affected by the recently introduced idea of patient autonomy and an increasing number of Japanese seem to desire self-determination,9 cultural and religious influences have made current medical decision making in Japan highly complex, and no conclusive evidence shows that a single religious or moral principle, such as respect for autonomy, dictates Japanese decision making in health care. It should also be noted that ethical attitudes in clinical practice and moral values of the Japanese may be undergoing a drastic change because of the modern means of global communication and the resulting exposure to the strong and rapidly growing influence of Western, especially American, culture.11 For example, recent surveys of the general public and patients showed that the majority of Japanese want to have their advance directives respected and followed. 12,13 Conversely, another survey showed that approximately 80% of respondents who are elderly have no intention to write advance directives and approximately 40% would want others to make medical decisions even when they are competent.¹⁴

In some Western countries with well-developed health care ethics, the ethical significance of termination of unwanted life-support treatment has been clearly recognized. Reliable data have been published by many researchers regarding patients' preferences for various life-prolonging interventions, including cardiopulmonary resuscitation (CPR) and the continuation or termination of dialysis. In addition, the contemporary situation regarding withdrawal of dialysis has been well documented. 15-24 Conversely, there has been a serious lack of reliable data with regard to ethical decision making in clinical settings in Japan, especially regarding patients' wishes or preferences for life-support treatment. The current practices with respect to CPR and withdrawal of dialysis also have not been shown. No study has investigated in which type of medical situation and for which level of quality of life (OOL) patients would want to receive such lifesupport treatment as CPR or continue dialysis treatment. If it turned out that a considerable number of dialysis patients would want not to receive CPR or dialysis if they were seriously disabled or had lost competency, ethical scrutiny and reconsideration of current dialysis practices might be called for.

The purpose of our survey is to show the preferences of Japanese dialysis patients regarding CPR and dialysis treatment. Would Japanese dialysis patients want to receive CPR if cardiopulmonary arrest occurred in their current health status? Would they want to continue dialysis treatment or receive CPR if they were severely demented or had terminal cancer? We also aim to investigate the relationship between patients' preferences in this regard and their characteristics, including patient age, sex, level of education, annual income, duration of dialysis treatment, whether they had discussed their preferences regarding CPR with family members or physicians, current engagement in a job, or type of dialysis (hemodialysis or continuous ambulatory peritoneal dialysis).

SUBJECTS AND METHODS

One of the authors participated in a private clinical study group consisting of 20 nephrologists at 16 hospitals through-

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out Japan. We decided to ask the physicians at these hospitals to join our survey. Two of the nephrologists at one hospital did not respond; therefore, 18 physicians in 15 hospitals were included on the survey. These physicians were asked to include up to 30 of their ambulatory dialysis patients on the study. A postal questionnaire (Appendix) was then sent to those patients who agreed to participate on this study. Selection of patients was consecutive, and sampling was terminated when a sufficient number of patients had participated.

The three-page questionnaire consisted of three questions about patient preferences in terms of CPR and two questions about continuation or termination of dialysis treatment. We used a five-point Likert scale consisting of "Yes," "Probably yes," "Uncertain," "Probably not," and "No." Patients' wishes regarding CPR were estimated by using three health scenarios.

The first scenario asked whether they would want CPR if they experienced cardiopulmonary arrest in their current health status; in this questionnaire, current health status refers to "the way the patient's health is at the moment the patient answers the questionnaire." It should be noted that all our subjects were ambulatory patients who could visit their clinics without help. The second question asked whether they would want CPR if they experienced cardiopulmonary arrest when they were seriously demented. In this scenario, the patient has lost self-perception, is unable to recognize his or her family, and has become completely dependent. The third question inquired about their wishes in terms of CPR if they had terminal cancer with an expected survival of 6 months. In this scenario, the patient is competent and pain can be controlled by medication. The rate of survival leading to discharge after CPR was described as less than 10%. The survey also inquired about the patients' desires regarding continuation or termination of dialysis treatment in the second and third scenarios (serious dementia and terminal cancer). Finally, patients were asked whether they had discussed their preferences regarding CPR in various situations with their family or physicians. Patients' demographics were also explored. Medical charts of patients who consented to participate in the survey were viewed by the patients' nephrologists to obtain information about type and duration of dialysis and underlying diseases.

Data Analysis

Responses of "Yes," and "Probably yes" were combined into "Yes," and "Probably not" and "No," into "No." "Uncertain" was unchanged. The three categorized responses were statistically analyzed. Confidence intervals of 95% were calculated for each category. Analysis of variance and unpaired t-test were performed for numerical variables. Chisquare test for independence was used to test differences in proportions among independent categorical variables. Kruskal-Wallis and Spearman rank-sum tests were used to test differences among ordered and categorical variables. P less than 0.05 is considered significant. Bonferroni's inequality was used to determine cutoff values of statistical significance when multiple comparisons were made. For example, P less than 0.0166 was considered the cutoff value when three comparisons per one variable were made.

RESULTS

Characteristics of Participants and Response Rate

Patients' characteristics are listed in Table 1. Of the 450 patients asked to participate, 412 patients agreed to answer the questionnaire. Three hundred ninety-eight patients' completed questionnaires were returned, and 14 questionnaires were excluded because of incomplete responses. The overall response rate was 88%. The majority of responding patients (64%) were men and had been undergoing hemodialysis for 8.3 ± 5.5 years. Many of them had chronic glomerulone-phritis (64%) and diabetic nephropathy (13%). Most patients (94%) had never discussed their preferences regarding CPR with their physicians, and only one third (29%) had done so with their family members.

Patients' Preferences for CPR and Dialysis in Three Situations

Patients' preferences regarding CPR and dialysis are listed in Table 2. Forty-two percent of the dialysis patients participating in this study expressed a preference for receiving CPR for cardiopulmonary arrest in their current health status. Significantly fewer patients (12%) answered that they would want to undergo CPR in situations in which they were severely demented or had terminal cancer, with no difference in preference between the two hypothetical situations. Regarding continuation of dialysis, 18% of the patients would want to continue dialysis if they were seriously demented, and 22% were uncertain about their wishes. Significantly fewer patients (18%) would want to continue dialysis if they were demented compared with if they had terminal cancer (45%).

Statistical Relations Between Patients' Characteristics and Their Responses

Statistical analysis showed that patients' preference for CPR or dialysis were not significantly related to age, level of education, annual income, duration of dialysis treatment, whether they had discussed their preferences regarding CPR with family members or physicians, or type of dialysis (hemodialysis or continuous ambulatory peritoneal dialysis). There were only two significant relations between patient characteristics and pref-

Table 1. Patient Characteristics

| Mean age (y) | 57 ± 12 (23-87) | | | | |
|------------------------------|-------------------------|--|--|--|--|
| Sex | | | | | |
| Women | 144 (36) | | | | |
| Men | 254 (64) | | | | |
| Duration of dialysis (y) | 8.3 ± 5.5 (1.7-30.4) | | | | |
| Dialysis | | | | | |
| Hemodialysis | 283 (71) | | | | |
| CAPD | 115 (29) | | | | |
| Level of education | | | | | |
| Graduated from middle high | | | | | |
| school | 96 (24) | | | | |
| Graduated from high school | 192 (48) | | | | |
| Graduated from 2-year | | | | | |
| college | 16 (4) | | | | |
| Graduated from 4-year | | | | | |
| university or higher | 73 (18) | | | | |
| Level of annual income (yen) | | | | | |
| <3,000,000 | 145 (36) | | | | |
| 3,000,000-5,000,000 | 74 (19) | | | | |
| 5,000,000-7,000,000 | 41 (10) | | | | |
| 7,000,000-10,000,000 | 26 (7) | | | | |
| 10,000,000-12,000,000 | 11 (3) | | | | |
| >12,000,000 | 17 (4) | | | | |
| Underlying diseases | | | | | |
| Chronic glomerulonephritis | 255 (64) | | | | |
| Diabetic nephropathy | 50 (13) | | | | |
| Polycystic kidney | 17 (4) | | | | |
| Renal sclerosis | 15 (4) | | | | |
| Unknown | 19 (5) | | | | |
| Other diagnosis | 19 (10) | | | | |
| Current engagement in a job | | | | | |
| Yes | 181 (46) | | | | |
| No | 204 (51) | | | | |
| Experience of discussion | | | | | |
| about preferences | | | | | |
| about CPR* | | | | | |
| With physician | | | | | |
| Yes | 19 (5; 95% CI, 3-7) | | | | |
| No | 372 (93; 95% CI, 91-95) | | | | |
| With family members | | | | | |
| Yes | 114 (29; 95% Cl, 24-34) | | | | |
| No | 276 (69; 95% Cl, 64-74) | | | | |

NOTE. N = 398. Values expressed as mean \pm SD (range) or number (percent) unless noted otherwise.

Abbreviations: CAPD, continuous ambulatory peritoneal dialysis; CI, confidence interval.

*Percentages do not necessarily add up to 100% because some respondents did not answer all questions. Seven respondents (2%) did not answer a question about the experience of discussion about CPR with physician, and eight respondents (2%) did not answer a question about the experience of discussion about CPR with family members.

erences: women were less likely than men to wish for dialysis to continue if they were seriously demented (9% versus 23%; P < 0.001), and more patients who were working would

want dialysis to continue when they had terminal cancer than those who were not working (53% versus 37%; P < 0.014). No other significant relationship was detected.

DISCUSSION

Our study showed for the first time in Japan the preferences of patients undergoing dialysis for receiving CPR and having dialysis continued or terminated in several situations. We believe that our results may shed new light on health care ethics involved in the care of Japanese dialysis patients, as well as in the care of patients who need a life-support system to survive.

There appear to be some differences between our responding dialysis patients and those in North America.²² The preferences of our patients for receiving CPR if cardiopulmonary arrest occurred in their current health status and in the case of terminal cancer seem quite low (42% and 12%, respectively) compared with a study published in the United States in 1995 that showed more than 80% of dialysis patients surveyed would want to receive CPR in their current health status and more than one third, in the case of terminal illness. Forty-five percent of our respondents would want to continue dialysis treatment in the case of terminal illness compared with the majority of patients in the North American study. However, the preferences of dialysis

Table 2. Dialysis Patients' Preferences for Receiving CPR and Continuation of Dialysis Treatment: Response

| | Yes | Uncertain | No |
|---|------------|------------|------------|
| Preference for receiving CPR | | | |
| In the current health status If they were | 42 (37-47) | 14 (11-17) | 44 (39-49) |
| demented If they had a terminal | 12 (9-15) | 11 (8-14) | 77 (73-81) |
| cancer Preference for | 12 (9-15) | 11 (8-14) | 77 (73-81) |
| continuing dialysis If they were | | | |
| demented If they had a terminal | 18 (14-22) | 22 (18-26) | 60 (55-65) |
| cancer | 45 (40-50) | 18 (14-22) | 36 (31-41) |

NOTE. Values expressed as percent (95% confidence interval). N = 398.

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patients for both the application of CPR and continuation of dialysis treatment in case of severe dementia do not show a significant difference between the two studies.

Why would only a minority of our responding patients want to undergo CPR if cardiopulmonary arrest occurred in their current health status? Unfortunately, our study could not determine the reason for this because none of the patient characteristics investigated, including age, sex, level of education, or annual income, showed a significant correlation with the desire for CPR. It is possible that our questionnaire omitted asking important questions about patients' personal and social backgrounds, such as living status, hobbies, history of psychiatric illness, comorbidity, subjective perception of activities in daily life, and religious affiliation. These factors are likely to affect patients' preferences for resuscitation in their current health status, and undoubtedly, further research should be conducted in this regard.

The low rate of preference for CPR under their current health conditions might be caused by their self-perceived QOL. One study showed that the health-related QOL of Japanese dialysis patients was remarkably less than that of the general population.²⁵ However, we cannot confirm whether this speculation is correct because we did not assess our responding patients' QOL. If the average QOL of the patients surveyed in the present study was significantly less than that of American dialysis patients, it might be argued that patient QOL has an important role in determining patient preference for CPR. To find an answer to such speculative concerns, further research is needed.

Another possible reason for the low rate of preference of dialysis patients for CPR if cardio-pulmonary arrest occurred in their current health status may be that the success rate we provided in the scenario (<10%) was unacceptably low. However, to the best of our knowledge, there are no data regarding the success rate of CPR specifically for dialysis patients in Japan. It therefore is quite possible that their preference for CPR would be different if we had offered a different success rate. ¹⁹

Furthermore, it should be noted that to date, no studies have been conducted regarding their pref-

erences for CPR on Japanese patients with various chronic or life-threatening illnesses other than chronic renal failure. It therefore is unknown whether the preferences for CPR by our respondents are different from or similar to those of other patients with different diseases. Data available at this time suggest that approximately 80% of the general public would want to have life-prolonging interventions discontinued if they had an incurable, painful, terminal disease: a majority of patients with various underlying illnesses believe that they would want to die at home without aggressive life-prolonging interventions if they were terminally ill, and two thirds of them would want sufficient pain control rather than life prolongation.^{26,27}

As mentioned, the preferences of dialysis patients for either CPR or continuation of dialysis treatment in case of serious dementia do not show significant differences between the two studies conducted in Japan and North America. The reason for this can be argued that participating patients in both Japan and North America might believe that 6 months of conscious life. even with terminal cancer, is preferable to continuing life without feeling or thinking or even being a person. This speculation is consistent with our finding that the preferences of our dialysis patients for continuation of dialysis treatment between the second (serious dementia) and third (terminal cancer) scenarios were significantly different. Results of our study are also compatible with those of previous surveys of healthy persons conducted in Japan suggesting that significantly more members of the general public would want to continue life-sustaining intervention in case of terminal cancer than in case of severe consciousness disturbance.²⁶ It is hypothesized that even in a culture in which the image of human beings as completely integrated mind-body units, rather than distinct and separate units of mind, body, and spirit, has been dominant for centuries, living in a state of severe dementia may not be acceptable for many Japanese patients.28,29

The finding that no more than one fifth of dialysis patients would want to receive CPR (12%) or dialysis treatment (18%) in case of severe dementia needs to be taken seriously because if a majority of patients prefer not to

undergo life-prolonging intervention when they become incompetent, more extensive and effective use of advance directives should seriously be considered. Reported preferences of the Japanese for the use of advance directive seem to vary, as mentioned, but it is likely that at least some of the general public and patients have positive attitudes toward advance directives and desire to exercise control over their medical care by using such directives when they become incompetent, 12-14,26,30 For example, a public opinion survey by the Ministry of Health and Welfare showed that 85% of the Japanese surveyed believed the use of advance directives including a written document and explicit oral expression would be preferable, and approximately half believed that advance directives should be legally regulated.26,30 It was also found that more than 80% of Japanese physicians believed patients' advance directives should be respected.31,32 It therefore seems fair to argue that advance directives could have a significant role in realizing the wishes of patients who desire selfdetermination in Japanese medical care.

There are several limitations to our study. First, the generalizability of our results is limited, mainly because the participants were chosen consecutively and on the basis of convenience by their nephrologists. Moreover, the survey was conducted among physicians in 15 hospitals that were also selected for reasons of convenience from among an informal group. The subjects therefore may not be representative of many others involved in dialysis care, even though the response rate was as high as 88%. It should also be noted that answers to the questionnaire might not necessarily reflect the respondents' actual preferences or opinions; thus, de facto results might be different. More importantly, our present questionnaire did not include questions about patient QOL or personal and social background.

In conclusion, the present study suggests that the preferences of Japanese dialysis patients for administration of CPR and dialysis treatment vary according to health status. A minority of dialysis patients seems to desire CPR in their current health status, and only less than 20% would want to have either CPR administered or dialysis treatment continued in case of dementia.

It is also suggested that a minority of the patients would want to have dialysis treatment continued, and less than 20% would want to have CPR administered in case of terminal cancer. Further research is needed to investigate patients' psychosocial factors, which could affect dialysis patients' preferences in this regard.

APPENDIX

A QUESTIONNAIRE TO DIALYSIS PATIENTS

Definition of Cardiopulmonary Resuscitation

If cardiopulmonary arrest occurred, you need cardiopulmonary resuscitation (CPR) to stay alive. We would like to describe what CPR is like in the following section.

First, to maintain blood oxygenation, a tube is put into your throat and oxygen is pushed into your lungs through the tube. The tube is usually connected to a machine called an artificial ventilator. Second, to maintain blood circulation, a physician or nurse starts to press your chest repeatedly and continue it. Third, drugs will be injected into your vein to aim at keeping your blood pressure and heart beats, and when necessary, an electric shock will be given.

These procedures are called CPR. The rate of survival leading to discharge after CPR is about 10% of patients who receive CPR.

Questions to Patients

 If your heart and breathing had stopped in your current health status because of cardiac or brain stroke, would you want to have CPR?

Yes Probably Yes Uncertain Probably No No

- Suppose that you have developed serious dementia from Alzheimer's disease. You have lost self-perception, are unable to recognize your family, and have become completely dependent. Your medical status requires help for diet, walking, and having a bath.
- 2A. Would you want to continue dialysis treatment in the situation described above?
 - Yes Probably Yes Uncertain Probably No No
- 2B. Would you want to have CPR if your heart and breathing had stopped in the situation described above because of cardiac or brain stroke?

Yes Probably Yes Uncertain Probably No

- Suppose that you have terminal cancer with an expected survival of 6 months. You are alert and competent. Pain can be controlled by medication.
- 3A. Would you want to continue dialysis treatment in the situation described above?
 - Yes Probably Yes Uncertain Probably No No
- 3B. Would you want to have CPR if your heart and breathing had stopped in the situation described above because of cardiac or brain stroke?

Yes Probably Yes Uncertain Probably No No 4. Have you ever discussed your preferences regarding CPR with your family members?

Yes No

5. Have you ever discussed your preferences regarding CPR with your physician?

Yes No

We would like you to fill in the following questions.

Date of birth:

Sex:

Occupation (If yes, please describe details): Level of education:

Annual income:

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TEACHING AND LEARNING ETHICS

How do bioethics teachers in Japan cope with ethical disagreement among healthcare university students in the classroom? A survey on educators in charge

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J Med Ethics 2006;32:303-308. doi: 10.1136/jme.2004.011577

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Received 15 December 2004 In revised form 18 July 2005 Accepted for publication 22 July 2005 **Objective:** The purpose of this study was to demonstrate how educators involved in the teaching of bioethics to healthcare university students in Japan would cope with ethical disagreement in the classroom, and to identify factors influencing them.

Methods: A cross sectional survey was conducted using self administered questionnaires mailed to a sample of university faculty in charge of bioethics curriculum for university healthcare students.

Results: A total of 107 usable questionnaires were returned: a response rate of 61.5%. When facing ethical disagreement in the classroom, coping behaviour differed depending on the topic of discussion, was influenced by educators' individual clear ethical attitudes regarding the topic of discussion, and was independent of many respondents' individual and social backgrounds. Among educators, it was commonly recognised that the purpose of bioethics education was to raise the level of awareness of ethical problems, to provide information about and knowledge of those issues, to raise students' sensitivity to

ethical problems, and to teach students methods of reasoning and logical argument. Yet, despite this, several respondents considered the purpose of bioethics education to be to influence students about normative ethical judgments. There was no clear relationship, however, between ways of coping with ethical disagreement and educators' sense of the purpose of bioethics education.

Conclusions: This descriptive study suggests that educators involved in bioethics education for healthcare university students in Japan coped in various ways with ethical disagreement. Further research concerning ethical disagreement in educational settings is needed to provide better bioethics education for healthcare students.

he importance of bioethics education in medicine, nursing, and health care has long been recognised. Bioethics education for healthcare university students has been examined and discussed internationally and, regardless of nation, a certain consensus has been reached about the purpose, pedagogy, subjects of study, and the issue of who should teach bioethics. 1-10 However, there are also issues that have been neither sufficiently scrutinised nor extensively discussed yet. One of these is the question of how bioethics educators cope with ethical disagreement among students when teaching bioethics.

This problem is, in our opinion, extremely important in the field of bioethics because there are many bioethical areas where ethical opinions have not yet reached consensus—for example, direct donation of an organ from a brain dead patient; ways to approach a situation when opinions differ among proxies in the case of a patient who no longer has decision making power, and ethical decisions concerning abortion and voluntary euthanasia.11-15 Even if all facts about these issues were to be understood and recognised by students and teachers alike, ethical disagreement would inevitably prevail. The reason being, as Stevenson accurately points out, is that: "It is logically possible, at least, that two men should continue to disagree in attitudes even though they had all their beliefs in common, and even though neither had made any logical or inductive error, or omitted any relevant evidence."16

Despite this need to deal with ethical disagreement, however, a dearth of research persists on how bioethics educators cope with ethical disagreement in the classroom. No studies to date in the field of bioethics have examined this issue; nor have there been either discussions or surveys on

this issue in Japan. In order to reveal the current ways of coping with ethical disagreement, therefore, we conducted a cross sectional survey on educators involved in the teaching of bioethics to healthcare university students in Japan. This study's primary objective was to learn how educators cope with ethical disagreement inside the classroom and to clarify the factors that influence the way they cope. We hypothesise that educators' individual and social backgrounds, their understanding of the purpose of bioethics education, and their individual ethical attitudes toward the topic of discussion are related to how educators cope with ethical disagreement among students and, also, to how they deal with a student who asks for the solution to an ethical problem.

METHODS

Our sample consisted of faculty in charge of bioethics curriculum for healthcare students—that is, nursing, medicine, pharmacology, public health, social work, etc in both medical schools and nursing schools in Japan. Bioethics education was defined as any and all subjects related to ethical issues of health care—that is, ethics, philosophy, medical ethics, professional ethics, and bioethics. A cross sectional survey was conducted using a self administered questionnaire sent by ordinary post. At the time of this study, in 2003, there were a total of 80 medical schools and 103 nursing schools in Japan.

We developed an original questionnaire in Japanese and conducted a pilot study on a sample of nurses and graduate students in the field of bioethics at two universities (University of Miyazaki, 10 participants; Kyoto University three participants). The questionnaire was edited and revised

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according to participants' comments regarding case content and questions. Questionnaires were posted to each school's dean or department chair, accompanied by a letter explaining the details of our research. Each school dean or department chair was asked to forward the questionnaire to the faculty in charge of the university's bioethics curriculum. A book token to the value of 1500 yen was also included for each respondent in token of our gratitude for those who responded to our questionnaire. One month later, we followed up by posting a reminder.

The questionnaire was written in Japanese and divided into four sections. Section 1 asked for participants' individual and social background; section 2 described a group discussion on informed consent and direct donation in which opinions among students were divided (table 1).

Questions that followed the cases in section 2 asked: 1) what one would answer if a student asked one's own ethical attitude regarding the case in question (select 1 out of 6 answer choices, including "others" in case A and 1 out of 7 answer choices, including "others" in case B [shown in table 4]); 2) how one would cope with ethical disagreement between students (select 1 out of 5 answer choices, including "others" [shown in table 5]), and 3) what one would do if a student asked for the "right answer" (select 1 out of 7 answer choices, including "others" [shown in table 5]). Section 3 asked educators to indicate the purpose of providing bioethics education to healthcare university students. A total of nine statements, including "others", were listed regarding the purpose of bioethics education, asking participants either to agree or to disagree. Section 4 consisted of the Robert Wendland case. This vignette asked how one would cope with disagreement among ethics committee members regarding the treatment plan of a conscious but incompetent patient if one were the committee chair.14 Participants responded in their own words. The results of section 4 will be presented in a separate report.

A statistical analysis was performed using a Yates-corrected χ^2 test; Fisher's exact test (for expected vales of χ^2 test below 5); McNemar χ^2 test, and the independent t test. We divided the sample by age (20–50 years of age, above 50 years of age) and by specialty (medical, non-medical). When examining the differences in answers between case A and case B using the McNemar χ^2 test, we created two groups for each respective case: group 1 chose a specific answer choice and group 2 chose any other answer choice. A significant difference was a p value of 0.05 or less. A logistic

Table 1 Two cases for small group discussion Case A: The importance of informed consent in clinical research on You are discussing "the importance of informed consent in clinical research (Declaration of Helsinki, article 22: ethical validity)" with a group of students. Conclusion following discussion Student group A: Completely agree with article 22 and assert that sufficient informed consent in clinical research is necessary regardless of Student group B: By explaining accurately the study's risks, subjects will become unnecessarily anxious and the number of people who agree to participate will decrease. Accordingly, although important, wouldn't it be better not to explain serious risks that occur only occasionally. Case B: Regarding a brain dead patient's wish for direct donation You are discussing "when a brain dead patient (donor) has expressed her wish to donate one of her organs to a relative and the relative has also consented, should one prioritise donation to the relative over other patients in need of an argan? Conclusion following discussion Student group A: To specify the recipient in accordance with the donor's Student group B: To specify a recipient is unjust and impermissible.

regression model analysis was used in order to substantiate the results of univariate analysis. Independent variables included respondents' age; sex; religion; primary field of specialty; years of teaching; participation in research ethics committees; participation in hospital ethics committees, and whether or not they supported a specific theory of ethics.

RESULTS

Number of respondents and response rate

Questionnaires were sent to the school dean or department chair at all 183 Japanese universities (medical schools, 80; four year nursing schools, 103). A total of nine questionnaires were returned unanswered from seven institutions because of "the absence of an applicable faculty member in charge of the bioethics curriculum"; from one institution because "all surveys are returned at the administration level for faculty have little time to spare", and from one institution that did not provide a reason. The remaining 174 questionnaires were delivered to faculty in charge of the university's bioethics curriculum. A total of 110 institutions returned questionnaires, but three institutions provided from two to eight anonymous responses and we could not determine which questionnaire was returned from those who were in charge of the university's bioethics curriculum. Therefore, a total of 107 (110-3 = 107) questionnaires were used for statistical analysis—the response rate was 61.5% (107/174).

Respondents' background

Respondents' individual and social backgrounds are shown in table 2.

Field of other specialty included religious studies, law, psychology, cultural anthropology, literature, and physiotherapy. More respondents in health care (nursing, medicine, physiotherapy) than in non-health care (philosophy and ethics, bioethics, religious studies, law, psychology, cultural anthropology, literature) were older than 50 years of age

| Age distribution | 20–29 | 0 (0) |
|---------------------------------------|-------------------|-------------------|
| (years) | 30-39 | 3 (2)8) |
| | 40-49 | 29 (27.1) |
| | 50-59 | 40.(37.4) |
| 4.0 | 60-69 | 30 (28.0) |
| | 70-79 | 1:(0.9) |
| | No response | 4 (3.7) |
| Sex | Female | 30 (28:0) |
| | Male | 74 (69.2) |
| | No response | 3 (2:8) |
| Faith/religion | No. | .79 (73.8) |
| | Yes | 22 (20.6) |
| | No response | 6 (5:6) |
| Primary field of | Philosophy/ethics | 24 (22.4) |
| specialty | Bioethics | 9 (8.4) |
| | Nursing | 23 (21.5) |
| | Medicine | 38 (35:5) |
| | Other | 10 (9.3) |
| | No response | 3 (2.8). |
| Period of involveme | | 1–33 yrs (SD 7.0) |
| with bioethics education for stude | No response | 4 (3.7) |
| in health care | DIS . | |
| Ethics committee | Yes | 60 (56.1) |
| member : | No | 43 (40.2) |
| (research) | No response | 4 (3.7) |
| Ethics.committee | Yes | 26 (24.3) |
| member. | No | 78 (72:9) |
| (hospital) | No response | 3 (2.8) |
| Ethical theory/posit | | 34 (31.8) |
| | No | 67 (62.6) |
| | No response | 6 (5:6) |

(81.9%: 50.0%, p = 0.001) and female (37.7%: 16.3%, p = 0.027). Non-healthcare respondents tended to support a specific ethics theory more often than respondents in health care (53.7%: 20.0%, p = 0.001) and years of teaching were longer as well (9.9 years: 7.0 years, p = 0.045). More respondents older than 50 years of age tended to participate in hospital ethics committees than younger ones (31%: 9.4%, p = 0.024). No statistically significant associations existed between religion and any other characteristics.

Respondents' understanding of the purpose of bioethics education

Respondents' understanding of the purpose of bioethics education for healthcare university students is shown in table 3.

The majority of respondents recognised the following objectives: to provide information regarding bioethical issues; to raise students' sensitivity to ethical problems, and to teach students appropriate methods of reasoning and logical argument. There were several respondents who, on the other hand, considered the purpose of bioethics education to be to influence students about normative ethical judgments and promote behaviour change. The majority of respondents did not consider raising a student's cultural level and level of sophistication to be an objective.

A relationship between respondents' understanding of the purpose of bioethics education and individual and social background was observed. Female respondents (93.3%) included raising students' sensitivity to ethical problems as a purpose more often than male respondents (73.0%) (p=0.042). Respondents who had religious affiliations (36.4%) tended to include creating social consensus concerning ethical issues as a purpose more often than those who had no such affiliations (13.9%) (p=0.028). In addition, those who perceived having students hold a certain ethical position as a purpose tended to have fewer years of teaching (4.8 years: 9.2 years, p=0.01).

A logistic regression model analysis confirmed the results of univariate analysis above: female respondents tended to include raising students' sensitivity to ethical problems as a purpose (p = 0.03, R = 0.169); respondents who had religious affiliations tended to include creating social consensus concerning ethical issues as a purpose more often than those who did not have any such affiliations (p = 0.01, R = 0.222),

Table 3 Respondents' understanding of the purpose of bioethics education Number of respondents who replied; "yes" to the following objectives: N (%) To raise students' sensitivity to 84 (78:5) ethical problems To teach students appropriate 80 (74.8) methods of reasoning and logical To provide information and 70 (65.4) knowledge regarding those issues To influence students' ethical 35 (32.7) attitudes and promote behaviour To have students hold a certain 22 (20:6) ethical position To create social consensus 21 (19.6) concerning ethical issues To raise a student's cultural level 14 (13:1) and level of sophistication It depends on the student year 6 (5.6) that is, 1st year, 2nd year, etc) 3 (2.8)

N = all numbers (%): n = 107

and respondents who had fewer years of teaching tended to include having students hold a certain ethical position (p = 0.016, R = 0.198).

Respondents' ethical attitudes toward each case

Respondents' ethical positions regarding case A and case B (table 1) are shown in table 4.

The majority of respondents were of the same opinion for case A whereas there was a wide range of opinions for case B. None of the respondents chose the option "not to answer such questions" when asked about their ethical attitudes toward cases A and B. Respondents who had "a clear ethical attitude" were defined as those who agreed with either student group A or B in case A or case B and who did not believe in brain death. In comparing respondents with a clear ethical attitude with those who did not, more respondents (74.7%) had a clear ethical attitude in case A than in case B (47.7%).

No significant relationships were observed between respondents' background and ethical attitudes in either case A or case B, except that more respondents younger than 50 years of age (28.1%) were prone to say: "I have not yet reached an ethical conclusion" in case B than older respondents (5.6%) (p=0.004); a logistic regression model analysis confirmed the relation (p=0.004, R=0.288). No univariate analysis revealed statistically significant relation between respondents' background and their ethical attitudes in the two cases (whether the respondents had "a clear ethical attitude" or not).

Coping with ethical disagreement in the classroom

How educators would cope with ethical disagreement is shown in table 5.

In coping with the differences in ethical positions in the classroom, in both cases the commonest course of action is to "provide students with the teachers' own opinion as one of many possible positions". In case B, however, teachers were less likely to "maintain the position they consider ethically correct and refute an opposing position". Respondents who had a clear ethical attitude in case A (same opinion as student group A or B), when compared with respondents without a clear position, were more likely to "maintain the position that they considered ethically correct and refute an opposing position" (35.0%: 3.8%, p = 0.004).

| Number of respondents who replie chaices N (%) | d "yes" to the follow | ving answer |
|---|-----------------------|-------------|
| | Case A | Case B |
| To answer that there is no one ethically right answer (conclusion) to this problem | 4 (3.7)* | . 19 (17.8) |
| To answer that you have not yet reached an ethical conclusion | 2 (1.9)+ | .14 (13:1) |
| To agree with student group A | 79 (73:8) | 22 (20.6)\$ |
| To agree with student group B | 1 (0.9) | 23 (21.5)\$ |
| To choose not to answer such questions | Ο | 0 |
| Öther Life | 20 (18.7) | 23 (21.6) |
| To answer by saying that one does not believe in brain death | (Not applicable) | 67(5.6)‡ |
| No response | 1 (0.9) | Ö. |
| N = all numbers (%): n=107 *McNemar χ² test, p=0.001 +McNemar χ² test, p=0.004 ‡Respondents who had "g clear elh who agreed with either student group | | |

Table 5 Respondents coping with ethical disagreement in the classroom: selection of answer choices N (%)

Confirm each position and respective reasoning and then point out the logical limitations leading up to each conclusion

How would you cope with differences in ethical positions in the classroom?

| | Case A | Case B |
|--|----------------------|--------------|
| Upon doing so, say: "Neither position is ethically correct": | 4 (3.7) | 8 (7.5). |
| Upon doing so, say: "Please continue to think about this issue", and not mention which position is more justified. | 17 (15.9)† | .29 (27.1) |
| Upon doing so, provide one's own opinion as one of many possible positions. | 44 (41.1) | 53 (49.5) |
| Upon doing so, maintain the position that one considers ethically right and refute an opposing position. | 29 (27.1)* | 8 (7.5) |
| Other No response | 12 (11.2) 1 (0.9) | 9 (8:4) 0 |

How would you cope with a student who asks for the "answer" to an ethical problem

| | Case A | Case B |
|--|------------|-----------|
| To respond by saying that there is no one ethically correct answer | 5 (4.7)‡ | 13 (12.1) |
| To respond by saying that an answer (conclusion) to the problem has not yet been reached at this time. | 2 (1.9) | 6 (5.6) |
| To respond by saying that you have not yet reached a conclusion regarding the problem | 1 (0.9) | 7 (6.5) |
| To respond with what you consider ethically right as one possible opinion | 37 (34.6) | 34 (31:8) |
| To respond with what you consider to be the ethically right answer as the "answer" | 20 (18.7)§ | 10 (9.3) |
| To first explain that you have not yet reached an answer (conclusion) regarding the issue and then respond with one opinion—which you consider to be ethically right | 27 (25.2) | 25 (23.4) |
| Other | 15 (14.0) | 11 (10.3) |
| No response | 0 | 1 (0.9) |

Concerning respondents' background and coping behaviour, more female respondents would not mention which position was more justified in case B (46.7%: 20.3%, p=0.013). As far as the respondents' understanding of the purpose of bioethics education is concerned, the respondents' perceptions that bioethics teachers should aim to have students hold a certain ethical position, or that influencing students' ethical attitudes and promoting behaviour change was a purpose of bioethics education, were statistically independent of respondents' coping behaviour both in case A and case B.

†McNemar χ^2 fest, p=0.012; *McNemar χ^2 fest, p<0.0001;

 \pm McNemar χ^2 test, p=0.039; §McNemar χ^2 test, p=0.031

Coping with a student who asks for the right answer In coping with students asking for the "answers", teachers,

In coping with students asking for the "answers", teachers, for case B, were less likely to respond with what they considered to be the ethically correct answer as the "answer".

Significantly more female respondents provided their own opinion as one of many possible positions (53.3%: 28.4%, p=0.029) and tended to answer that they had not yet reached a conclusion regarding the problem (16.7%: 3%, p=0.02) in case A; and more respondents older than 50 years of age (14.1%: 0%, p=0.029) and those who had longer teaching experience (8.6 yr: 3.2 yr, p<0.0001) responded with what they considered to be the ethically right answer as

the "answer" in case B. On the contrary, no significant relationships in case A and case B matched up with respondents' understanding of the purpose of bioethics education.

DISCUSSION

The two cases used in this study relate to informed consent in a clinical trial and direct donation by a brain dead donor. We chose these cases on the supposition that the majority of respondents would, in the first case, hold a clear and common ethical attitude regarding informed consent and would, in the second case, have varying opinions and no specific conclusion. Although our primary purpose was not to test the appropriateness of our supposition in this regard, the results seem to provide support for it. We identified two factors that account for the consistency of opinion on the issue of informed consent: (1) social consensus on the need to respect the research subject's decision, and (2) increased awareness of the Declaration of Helsinki and of the drafting of several ethical guidelines by governmental agencies. 17 18 However, there continue to be discussions and debates about the issue of direct donation in Japan. This topic has continued to be controversial since 2001, when two kidneys were directly donated to two family members in accordance with the wishes of a brain dead donor. Currently discussion concerning direct donation and its legality continues in Japan.15 19 20

This study has the following limitations. First, the study's response rate was only slightly over 60%. The ethical positions and opinions of those who did not respond could very well diverge from the opinions reflected by our sample. Second, the study's sample was limited to faculty in charge of the university's bioethics curriculum and may not reflect the views of other bioethics teachers who are not in charge. The experiences and/or opinions of our respondents may not be the same as other bioethics educators running courses for healthcare university students. Therefore, our target sample should not be regarded as representative. In the early stage of research design, we had to give up surveying all of those who were involved in bioethics education for healthcare university students because of a lack of consistent and systematic methods to identify them in Japan. In addition, although we could conduct a survey on faculty in charge of the bioethics curriculum both in medical schools and in all the four year nursing schools, we could not include educators in charge of healthcare students who learn nursing in junior college nor educators in charge of those who study for other health related professions in other institutions. These factors limited the generalisability of our results.

Third, the study's questionnaire failed to include important questions such as whether the respondent was currently involved in face to face bioethics teaching; how often the respondent confronted ethical disagreement among his or her students in the classroom, and what kind of teaching methods the respondent tended to use. These questions are critical because our results are more meaningful if a considerable number of the respondents report that they engage in face to face education in the classroom or use teaching methods that offer opportunities for extensive classroom discussion or arguments. Although our current study did not yield any clue as to exactly how many respondents were involved in teaching activities and ethical arguments with their students, the age distribution of our respondents, and the current tendency of education methods employed in this field in Japan, suggest that a majority of our respondents involve themselves in small group discussions whenever there is an opportunity for ethical arguments.21-23

Fourth, our study did not clearly define words used in a scenario presented in the questionnaire such as "sufficient",

"serious", or "only occasionally", increasing the likelihood that different respondents interpreted these words differently. More attention should have been paid to word choice in this case in order to obtain more reliable data from research subjects. Finally, we must emphasise that our findings do not reflect the attitudes of educators involved in the teaching of bioethics to students who are not in the field of health care.

Several findings deserve further consideration. First, findings showed that respondents from non-medical backgrounds maintained a particular ethical theory more often than respondents from medical backgrounds. Although our study cannot give a definite answer in this regard, we wish to note that a majority of the respondents from non-medical backgrounds consisted of teachers whose primary subjects included rather abstract and theoretical academic fields such as philosophy/ethics, religion, and law and that such teachers may tend to commit themselves to a certain idea or systematic normative thought. We surmise that the respondents from healthcare backgrounds, by contrast, might approach problems in a practical manner on a case by case basis. Given the specialty of respondents from a non-medical background, they may have had a better understanding of ethical theory than those from a healthcare background. As a result, it is possible that the respondents used their knowledge-for example, theory-to present and justify their ethical attitudes and sentiments.

Second, findings showed that female respondents were more likely than male respondents to include raising students' sensitivities to ethical problems as a purpose of bioethics education for healthcare students. A possible reason may be that more than 70% of the female respondents had backgrounds in nursing and had been educated in nursing ethics to address the significance of ethical sensitivity.24 25 More female respondents than male respondents answered that they had not yet reached a conclusion (case A) and that they could not say what opinion was more valid than another (case B). These findings also suggest that female educators considered it more important to enhance students' ethical sensitivity in each case than to reach a certain conclusion. Third, we also found that age had an impact on attitudes. Respondents under the age of 50 years tended to say they had not yet reached a conclusion; respondents who were 50 years old and over tended to rely on their own opinion as "the answer" to each problem (case B). Although only hypothetical, we believe that this may be a result of educators' developed ethical thought and confidence—products of their life experiences, years of teaching experience, and long held perspectives on bioethical problems.

Fourth, the majority of our respondents identified the purposes of bioethical education as (1) to raise the level of awareness of ethical problems; (2) to provide information and knowledge of those issues; (3) to raise students' sensitivities to ethical problems, and (4) to teach students methods of reasoning and logical argument. The results indicate that many teachers consider it very important for healthcare trainees to acquire the capacity to bring ethical deliberation to bear on complex healthcare issues. On the other hand, respondents who had religious affiliations were more likely than those who did not have a religious affiliation to include creating social consensus concerning ethical issues as a purpose of bioethical education. This finding suggests that those who commit themselves to a certain religious belief tend to hope to share that belief with others, including students in the class, and to develop social consensus in accordance with their religious norms. However, despite the fact that coping behaviours when facing ethical disagreements in the classroom were not related to the respondent's understanding of the purpose of bioethics

education in the current study, the power difference between educators and students opens up the possibility that a certain normative decision could be presented to students in a manner that was authoritative and coercive. This issue is highly relevant to our final discussion point, which follows.

The finding that we think deserves our attention is that educators demonstrate different coping behaviours depending on their individual clear ethical attitudes when facing ethical disagreements in the classroom. This result may be attributed to a respondent's commitment to a certain ethical position and a belief that healthcare workers should act in a certain way in certain conditions. It is necessary, therefore, to determine the nature and scale of the impact of educators' ethical attitudes as well as their religious beliefs on their attitudes and behaviour in the classroom. This is because students in health care will need to address, in the future, a variety of important ethical decisions in research or in clinical practice, and how educators teach bioethics to students could ultimately have a significant impact on students' ethical attitudes. What implications do our results-that when educators confront ethical disagreement, they may refute an opposing position in some instances while keeping quiet in other instances—have on both students and bioethics educators themselves?

At the university level and above, it is often up to the professor in charge to choose the themes on which to focus, the articles and textbooks to use, and the representative sociohistorical cases. Educators also decide how to hold class discussions, how to give lectures, and how to conduct tutorials. At the same time, the educator is in the position of assigning grades to each student—grades often considered very important to the student. This means that the educator has a great deal of discretion and freedom. Let us not overlook, however, that, regardless of cross cultural and national differences, the student is granted relatively little discretion and freedom to decide. This highlights our previous point about the power difference between educators and students.

Although there is no evidence offered by studies from around the world or from Japan that healthcare university students feel pressurised by their educators to project a particular ethical stance, when an educator who maintains "an authoritative role" opposes a student's position with a "strong" rebuttal, the student might lose confidence and begin to hesitate to express his or her ethical stance. Students could also assume that they have to agree with their teacher in order to impress him or her. Additionally, there may be times when a student accepts his or her teacher's opinion uncritically and perhaps never learns how to think in terms of ethics for him or herself. To avoid this, it is necessary to consider how an educator disagrees with his or her students' ethical opinions. We believe that the proper method differs from that of a relentless and unforgiving scholar who opposes a theory in a philosophy or bioethics journal. As long as the educator can fail the student, it is extremely difficult to develop a perfectly equal relationship between educator and student. For precisely this reason, it is necessary to pay attention to how an educator expresses his or her ethical attitudes and how he or she criticises a student's position in order to avoid exerting "authoritative verbal and/or nonverbal pressure".11

On the basis of our findings, we surmise that it is often difficult to predict what type of attitude an educator has towards his or her students. In instances like case A, which deal with gaining social consensus, it is likely that an educator will refute a student if the student's opinion goes against the social norm. It is also likely that differences exist among educators as to which problems have reached social consensus and which issues remain controversial. Students