Respecting Autonomy in Difficult Medical Settings: A Questionnaire Study in Japan

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Some people in Japan are still comfortable with the paternalistic role of doctors, but others wish that their own decisions would receive a greater amount of respect. A total of 747 students of universities and colleges and 114 parents of these students participated in a questionnaire survey. Most of the participants thought that autonomy should be respected in situations involving death with dignity and euthanasia, whereas it should not be respected in attempted suicide and involuntary admission of

individuals with mental illness. A cluster analysis revealed that the participants could be divided into the following groups: aid in dying advocates (n = 577), complete libertarians (n = 109), protectors of the mentally ill (n = 90), complete paternalists (n = 29), and questionables (n = 27). The assertion of independence score of the Scale for Independent and Interdependent Construal of the Self showed a significant difference among the 5 clusters. These findings suggest that the traditional paternalistic relationship between doctor and patient is undergoing a gradual transformation in Japan.

Key words: autonomy, paternalism, brain death, euthanasia, suicide

Japan has been seen as a country of paternalism (Higuchi, 1992; Leflar, 1996). During the feudal period, which ended in 1868, people were subjects of the Emperor or Shogun, and there was a clear and unshakeable hierarchy of social classes. This hierarchy was deeply ingrained in every aspect of the national life; people higher on the social ladder were always decision makers, and it was considered a virtue for people lower on the social ladder to "obey" the suggestions, recommendations, or commands of their superiors. Even after the Meiji Restoration, these traditions remained. Medicine was characterized by physicians possessing professional knowledge and techniques and patients relying on the good will and decisions of these professionals. Japanese patients still have difficulty making their own decisions in medical situations (Annas & Miller, 1994). Concepts such as individualism, autonomy, and self-determination are very new to the Japanese (for a historical review of Japanese psychiatric services, see Ikegami, 1980).

Current advancements in biomedical technology have created unique situations that no one expected even a decade ago. The Organ Plantation Act in Japan was passed in 1997. The act allows organ donation by individuals who are brain-dead with the patient's advance directive and under permission of the family members. This act has generated clinical, political, and ethical arguments nationwide, and people have become more aware of choices regarding the definition of death (brain death or conventional heart death). Even before this enactment, a growing number of people became members of the Japan Society for Dying With Dignity. These people want to die in peace at the end of their lives without artificial medical procedures that would temporarily prolong their lives. In a similar vein, people have become more in favor of euthanasia. However, in court cases of "euthanasia" in Japan, very little attention has been paid to living wills or advance directives of patients.

Unlike clinical situations related to modern medicine, psychiatric practices have been equipped with a law allowing involuntary admission for patients who are not dangerous to self or others but in need of treatment and protection. Civil commitment of people suffering from severe mental disorders dates back to the pre-Meiji Restoration era. With the current mental health legislation, it is the specialist's view of the patient's condition rather than the patient's danger that justifies coerced admission (Kitamura et al., 1998; Salzberg, 1991).

The introduction of Western ideology during the Meiji Restoration, and particularly the enactment of the current constitution under the American occupation after World War II, seems to have gradually influenced the national sentiment in terms of respecting autonomous decisions in medical matters. This trend may be further complicated by the rapid development of biomedical technology. To clarify the current attitudes of the Japanese toward autonomy in these kinds of clinical situations, we carried out a questionnaire survey. Previously, such research was done only among medical staff, not among ordinary Japanese people (Hashimoto & Nakatani, 1983; Takeo, Satoh, Minamisawa, & Mitoh, 1991). We hypothesized that Japanese sentiment toward individual decision making would be different across different medical settings and that these attitudes toward autonomous decision making in medical matters could, to some extent, be explained by interdependence or in terms of relating others. Thus, we expected that people who pay more attention to how others view them in everyday life will emphasize, in medical settings, the importance of how doctors and "reasonable persons" suggest things. In contrast, people who pay more attention to how they themselves think in everyday life will emphasize, in medical settings, the importance of patients' own views and value judgments.

METHOD

Participants

The participants were 747 students attending six nonmedical universities, a college, and a technical (nursing) college, as well as 114 parents of students attending the college. This was a convenience population. The mean age of the participants was 23.8 (SD=10.1) years, ranging between 18 and 65. There were 231 men and 620 women; the sex of 10 of the participants was unknown. Among the parents, there were 52 fathers and 61 mothers as well as 1 parent of unknown sex. Of the 861 participants, 64 (7.4%) had reportedly taken a course in psychiatry, 491 (57%) in psychology, 53 (6.2%) in health sciences, 42 (4.9%) in nursing, and 76 (8.8%) in social welfare. None of the student participants attended a medical school. Their education in psychiatry, if any, was part of their nonmedical professional education.

Measurements

Attitudes toward "difficult" areas in medicine. We constructed a questionnaire to tap the attitudes of participants toward respecting patients' autonomous decision making in six "difficult" areas in medicine: brain death, organ donation from brain-dead bodies, death with dignity, euthanasia, suicide, and involuntary

admission of individuals with mental illness. Both brain death and organ donation from brain-dead bodies were rated as 1 (should be banned), 2 (should be allowed with both the patient's prior desire and family member's permission), or 3 (should be allowed only with the patient's prior desire). The remaining four items were rated either 1 (should be banned; "protected" in suicide; "justified" in involuntary psychiatric admission) or 2 (patient's decision should be respected). For further calculation, the first two choices for brain death and organ donation from brain-dead bodies were combined to compare with the third choice because, as described in the Results section, very few participants marked the first choice.

Autonomy versus harmonization with others. The Scale for Independent and Interdependent Construal of the Self (SIICS; Kiuchi, 1995) was used. This scale consists of 16 items with a 2-point scale (0 or 1). The SIICS is based on the theory of Markus and Kitayama (1991), who proposed that the concept of self is divided into independent and interdependent construals that influence cognition, emotion, and motivation. They further suggested that the former would be linked to Western culture and the latter would be linked to Japanese culture. A factor analysis was performed with OBLIMIN rotation; the number of factors was determined by Kaiser's criterion using an eigenvalue of 1 as a cutoff point (Hasui et al., 1999), which yielded three factors. Items having high factor loadings on the first factor included "I assert my opinion," "I generally have my own way of doing every thing," and "I generally assert my rights and interests." We interpreted this factor as reflecting assertion of independence. Items having high factor loadings on the second factor included "I often think of how to make use of my abilities" and "I make full use of my talents." We interpreted this factor as reflecting a confidence in talent. The items having high factor loadings on the last factor included "I do what I want to do even if others oppose" and "I keep my will even if others oppose." We interpreted this factor as reflecting persistence of will. Three subscale scores were calculated by adding the scores of items with high loadings on each factor. Higher scores indicate stronger attitudes regarding the three aspects of autonomy, respectively.

Demographic variables. Questions were asked regarding sex, age, occupation, grades (if students), and special courses taken.

Procedures

Packets of questionnaires were distributed to the students in classrooms along with brief instructions. Questionnaires were collected during the same class period. The students of one of the colleges were requested to give a copy of the questionnaire to

their parents with an invitation letter describing the purpose and nature of the study. Parents' questionnaires were returned by mail. The students were given a debriefing afterward.

The participants' responses to items of attitudes toward "difficult" areas in medicine were tabulated. Because we were interested in patterns in the participants' attitudes toward these matters, a series of nonhierarchical cluster analyses were performed using the scores for the five items to measure the distance between participants who answered all six items (n = 832). SPSS–X's Quick Cluster was adopted (SPSS Inc., 1986). This software has an algorithm equivalent to McQueen's k-means clustering method and the distances between cases are measured by the squared Euclidean distance. After obtaining meaningful clusters, cases of these clusters were compared in terms of demographic variables and SIICS.

RESULTS

Participants' Attitudes Toward the Six Difficult Medical Situations

About two thirds of the participants showed a preference toward respecting patients' (prior) will, if it was agreed on by their family, in terms of both recognizing brain death and organ donation from the brain-dead bodies (Table 1). Around 30% of the participants thought that the patients' will would suffice to justify both recognition of brain death and organ donation from the brain-dead bodies. In contrast to these two related issues, the participants' response toward death with dignity and (although to a slightly lesser extent) euthanasia was much more favorable toward respecting the patients' (prior) will. More than 90% of the participants preferred respecting patients' own decisions in relation to death with dignity and more than 80% preferred to respect patients' decisions regarding euthanasia. However, they were more protective in cases of suicide and with individuals with mental illness requiring involuntary admission. Thus, over 70% and 60%, respectively, of the participants thought that coercive intervention was justifiable in these situations.

Cluster Analyses

Because the participants' response toward respecting patients' autonomous decisions differed in the six medical situations, we performed a series of cluster analyses. The most meaningful clusters were obtained when the number of clusters was set at 5 (Table 2).

Cluster 1 consisted of 90 participants who asserted respect for patients' autonomous decisions in all the situations other than suicide and involuntary psychiatric

TABLE 1
Frequencies of Participants' Attitudes Toward Difficult Medical Situations

Medical Situations	Frequencies (%)
Brain death	
Should be banned	57 (6.6)
Should be allowed with both the patient's prior desire and family member's permission	579 (67.2)
Should be allowed only with the patient's prior desire	220 (25.6)
No answer	5 (0.6)
Organ donation from brain-dead bodies	
Should be banned	20 (2.3)
Should be allowed with both the patient's prior desire and family member's permission	512 (59.5)
Should be allowed only with the patient's prior desire	323 (37.5)
No answer	6 (0.7)
Death with dignity	
Should be banned	74 (8.6)
Patient's decision should be respected	783 (90.9)
No answer	4 (0.5)
Euthanasia	
Should be banned	112 (13.0)
Patient's decision should be respected	743 (86.3)
No answer	6 (0.7)
Suicide	
Should be protected	666 (77.4)
Patient's decision should be respected	182 (21.1)
No answer	13 (1.5)
Involuntary admission of individuals with mental illness	
Should be justified	573 (66.6)
Patient's decision should be respected	268 (31.1)
No answer	20 (2.3)

admission. Therefore, we interpreted this cluster as reflecting protectors of the mentally ill. The second cluster consisted of 109 participants who respected patients' autonomy in all six situations. Therefore, we interpreted this cluster as reflecting complete libertarians. The third cluster consisted of 27 participants who endorsed patients' autonomy only in organ donation from the brain-dead and psychiatric involuntary admission. Because the data from these participants were difficult to interpret, we term this cluster as questionables. The fourth cluster was the largest (n = 577; 69.4%), including participants who recognized the patient's autonomy only in relation to death with dignity and euthanasia. We termed this group as aid in dying advocates. The fifth cluster consisted of 29 participants who denied the patients' decisions in all six situations. We interpreted these participants as being complete paternalists.

Cluster	n	BD	OD	DD	E	S	IA
Protectors of the mentally ill	90	97	98	96	79	3	9
Complete libertarians	109	95	82	100	96	70	60
Questionables	27	0	63	11	11	4	70
Aid in dying advocates	577	3	21	97	94	16	30
Complete paternalists	29	7	0	7	3	17	3

TABLE 2
Rates of Endorsement of Patients' Autonomy by Five
Participant Groups Derived From Cluster Analysis

Note. BD = brain death; OD = organ donation from the brain dead; <math>DD = death with dignity; E = brain dead; S = brain death; A = brain de

Correlates of the Clusters

Sex ratios differed among the five clusters (p < .05). Women were most overrepresented in the cluster of questionables (78%), followed by the clusters of aid in dying advocates (76%), complete paternalists (72%), and complete libertarians (67%). The sex ratio was the lowest among protectors of the mentally ill (61%). There was no difference in age across the five clusters, F(4, 821) = 1.4, ns.

The participants' educational background did not differ among the five clusters, $\chi^2(4, N=832)=1.1$, ns, for psychiatry; $\chi^2(4, N=832)=2.0$, ns, for psychology; $\chi^2(4, N=832)=4.4$, ns, for health sciences; $\chi^2(4, N=832)=3.3$, ns, for nursing; and $\chi^2(4, N=832)=0.4$, ns, for social welfare.

Of the three SIICS subscales, only the assertion of independence score showed a significant difference among the five clusters, F(4, 788) = 5.3, p < .001. Scheffé's post hoc comparison showed a significant difference between the complete libertarians and the aid in dying advocates clusters (Table 3). The confidence in talent score, F(4, 806) = 2.0, ns, did not differ among the clusters. The persistence of will score showed a significant difference, F(4, 804) = 3.3, p < .05, but a post hoc comparison failed to demonstrate a significant difference between any two groups.

DISCUSSION

This investigation has found that the Japanese people vary in their opinion regarding respecting individuals' autonomous decisions in medical matters. The rate of response for respecting individual decisions was highest for death with dignity and euthanasia, followed by recognition of brain death and organ donation. It was the lowest for suicide and the civil commitment of people with severe mental disorders. Thus, although the Japanese may retain paternalistic sentiments in medical matters, this sentiment may be specific to individual medical situations. We think that the

TABLE 3
SIICS Subscale Scores by the Five Participant Groups Derived From Cluster Analysis

	SHCS Subscales							
	Assertion of Independence		Confidence in Talent		Persistence of Will			
Cluster	M	SD	M	SD	M	SD		
Protectors of the mentally ill	2.35	1.93	2.27	1.47	1.31	1.08		
Complete libertarians	2.90	2.23	2.38	1.53	1.26	1.12		
Questionables	1.73	1.99	1.67	1.44	1.74	1.23		
Aid in dying advocates	1.99	1.88	2.07	1.45	1.54	1.00		
Complete paternalists	1.17	2.25	1.97	1.38	1.76	0.99		
Scheffé's post hoc comparison	Complete libertarians > Aid in dying advocates		_		_			

Note. SIICS = Scale for Independent and Interdependent Construal of the Self (Kiuchi, 1995).

degree of respect for individual decisions (or for allowing paternalistic intervention) is determined both by personal and sociohistorical factors.

The hierarchy of libertarian attitudes in the national sentiment of the Japanese found in this study was also confirmed by a cluster analysis. The participants could be grouped into five clusters that could be ordered according to the magnitude of wanting to respect the decisions of patients. The majority (n = 577) of the participants belonged to the aid in dying advocates cluster. The people belonging to the complete paternalists cluster are a minority (n = 29). Therefore, the most popular national sentiment may be to allow patients to make their own decisions regarding death with dignity and euthanasia but not regarding brain death, organ donation, suicide, and psychiatric civil commitment.

In the questionnaire, we explained death with dignity as "withholding artificial treatment for patients" and euthanasia as "giving fatal treatment to terminally ill patients experiencing severe pain under the patient's desire." Promoting another person's death, even under his or her wish to abandon life, is not allowed by Japanese law; euthanasia is a criminal offense. On the other hand, death with dignity is withholding meaningless treatment and letting a patient die more naturally. Such cases have been regarded not as a legal matter but as something to be handled at the doctor's discretion. Killing a person and letting a person die are legally different. The finding that the issues of death with dignity and euthanasia do not produce discrete clusters may be interpreted as Japanese people viewing these two things as being essentially the same. The legal distinction between the two may not be shared by nonmedical, nonlegal people in Japan.

This interpretation may be reflected by the name change of the Japan Euthanasia Society to the Japan Society for Dying With Dignity in 1982. The Japan Euthanasia Society was established in 1976. The original purpose was "to promote the idea of

refusal of artificial treatment to terminally ill patients with no prospect of relief and vegetative patients" (Japan Euthanasia Society, 1976). The Japan Society for Dying With Dignity has recently laid stress on the movement for promoting living wills among the people. The group now has approximately 75,000 members.

In contrast to the high numbers of those who favor aid in dying, recognition of brain death and organ donation from brain-dead bodies are not widely accepted. Commentators have suggested various cultural reasons for the reluctance among Japanese to embrace the ideas of recognizing brain death and of organ transplantation (Leflar, 1996). They have asserted that the Japanese believe the body must remain intact not only in life but also after death; that Japan lacks a tradition of altruistic giving to unknown others; that viewing a warm, breathing body as dead is more unnatural to Japanese than Westerners; and that family members in Japan tend to be more involved in terminal care at the bedside. These explanations correspond with the report that family caregivers of demented elderly persons believe that they can (and should) continue caregiving despite various difficulties of care (Yamamoto & Wallhagen, 1997).

The newly legislated Organ Transplantation Act regulates organ donation only when both the patient and the family members desire it. However, there has been no organ transplantation from a brain-dead body since the law's enactment in 1997. A recent large (n = 2,229; response rate = 74%) opinion survey on organ donation conducted by a Japanese newspaper company ("Organ Donation Still Halfway Through," 1998) showed that 38% of participants preferred recognition of only cardiac death, 61% preferred cautious implementation of the act, and 63% knew that a prefilled donor card was a prerequisite for donation but only 3% had the donor card. As an explanation for why no cases of organ donation had occurred, about 45% of the participants listed "society has not yet accepted it." Moreover, 25% of them answered that they would not agree to organ donation from a family member of theirs even if he or she showed clear will of donation. This and our study suggest that in the domain of brain death and organ donation, the Japanese are still reluctant to respect a patient's own advance directives.

Suicide and involuntary admission of the mentally ill are the areas where all the participants took a paternalistic attitude other than the complete libertarians and questionables. If one respects self-determination in suicide, it probably means that self-determination in all other medical areas will also be respected. Research in Western countries has demonstrated lay people's opposition to suicide and approval of suicide prevention (Beswick, 1970; Boldt, 1982; Domino, Gibson, Poling, & Westlake, 1980; Eskin, 1992; Ginsburg, 1971; Kalish, Reynolds, & Farberow, 1974). The paternalistic attitude toward suicide may be explained by the participants' attribution of suicidal attempts to a "cry for help" (Stein, Witztum, & Kaplan, 1989). Participants belonging to each cluster in our study had similar attitudes toward suicide and civil commitments of the mentally ill. This may mean that our participants viewed suicide as a sign of ill mental health. This should be further examined in a future study.

Until this century, several Western countries, including England and Italy, punished people who attempted or committed suicide. However, suicide has always been considered an honorable way to die in Japan. Harakiri was practiced until the Edo period in the 19th century and was regarded as the most honorable way to die. The current criminal law in Japan punishes those who participate in suicide but does not punish those who attempt or commit suicide. People still sympathize with those individuals who are involved in suicide rather than criticize them. Often, people choose suicide as a means to "take responsibility" (Inseki-jisatsu; Takahashi & Berger, 1996). Parents kill their children before committing suicide to "save" the child from misfortune (Shinjuu). These anecdotes are often referred to as evidence of the national acceptance of suicide as a societal norm. However, in this study, the majority of the Japanese approved the prevention of suicide. This may be due to the current very paternalistic national sentiment (i.e., suicidal people should be saved) or the change of the social view of suicide from the honorable means to save one's "face" to a treatable psychiatric condition. Whichever explanation may be feasible, the attitude toward suicide in Japan may have changed.

Two thirds of our participants believed that autonomy should be restricted in the case of involuntary admission of individuals with mental illness. The Japanese Mental Health Welfare Law provides two means of civilly committing individuals with mental disorders. The mentally ill may be involuntarily admitted when (a) they are dangerous to self or others or (b) they need treatment and care (Kitamura et al., 1998). The law does not refer to necessary assessment of a patient's incompetence before involuntary admission. Therefore, in theory, competent patients may be admitted without consent if both of two psychiatrists agree that treatment is necessary. This paternalistic mental health legislation in Japan seems to be supported by the results of our investigation.

Traditionally, patients and families have been expected to follow doctors' decisions without questioning or little, if any, knowledge about the diagnosis and prognosis; nor did they have much access to information about the suggested treatment. They are rarely requested to take an active role in medical decision making. Doctors decide almost everything, often without formal enquiry into patients' desire. They seldom tell the patient the true diagnosis if it has poor prospects (e.g., cancer). Doctors fear that it would make the patients depressive, cause them to give up hope, and even cause them to commit suicide. In medical schools, education is generally concentrated in medical technology, with little emphasis on the patient–physician relationship. The fact that such paternalistic sentiment in medical care has existed for such a long time may also be due to the historical fact that, in Japan, doctors having skills and knowledge are highly respected in the society. Leflar (1996) pointed out that the lack of autonomous decision making by the Japanese patient is due to the fact that, as elaborated by cultural anthropologists, "personhood" in Japanese culture is a more group-dependent concept than the au-

tonomous individuality celebrated in Western culture and postulated at the core of Western liberal philosophical theory.

It is much more paternalistic in psychiatry. Japanese psychiatrists hardly tell the true diagnosis of schizophrenia to patients (McDonald-Scott, Machizawa, & Satoh, 1992). This may be enhanced by the still strong prejudice against schizophrenia and shortage of professional staff (Koizumi & Harris, 1992). Thus, psychiatric patients find it difficult to express their disagreement with the psychiatrists. Although the Mental Health Law opens the door for those appealing their admission to the Prefectural Governor, who informs the Psychiatric Review Board of the patient's request, only 3.2% of the cases filed for discharge were accepted by the board (Yamazaki et al., 1997). Habeas corpus has rarely been used as a means to be discharged from undue admission.

Recently, however, informed consent has become more widely known in Japan. In 1990, the Medical Ethics Committee of the Japan Medical Association issued a report on informed consent. It said that doctors should give medical information including laboratory results, diagnosis, prognosis, and treatment in easy-to-understand terms to patients (Medical Ethics Committee of the Japan Medical Association, 1990). In accordance with this, the majority of patients in medical settings wish to learn about diagnosis and treatment (Health Insurance Societies, 1998). Medical complaints have been filed more frequently and have involved the lack of explanation to patients about the nature of the disease or the risks of the procedure, although it is difficult to obtain the needed evidence and knowledge in medicine. A draft regarding patient's rights to access medical records has been discussed by the Japanese government, but no conclusion has been reached. These observations may be in concordance with this study showing that the Japanese are more interested in respecting patients' autonomous decision making than they used to be.

Before starting this questionnaire survey, we hypothesized that the paternalistic national sentiment in Japan, derived from the feudalistic social system in the Edo period, has resulted in the development of a personality trait in people such that they determine private matters not by following their own ideas and goals in life but rather by relying on what others think and how others see them. This interdependent trait may, in turn, lead to paying less attention to the self-determination of others. The SIICS data showed that the complete libertarians scored the highest in the assertion of independence score. This is in line with our hypothesis. Although they still belong to a minority group, people of the complete libertarians cluster make up more than 10% of all the participants. This may mean that respect of autonomous decision making in medical matters is gaining in popularity.

Our study has shown that male participants are generally libertarians, whereas female participants are generally paternalists. In Japan, women are brought up from childhood not to be too independent. They have been told to follow their parents, teachers, and husbands and are used to doing so in general. Inoue and Ehara

(1995) reported that the majority of Japanese women agreed with the notion of the husband as a breadwinner and wife as a homemaker.

This study has shown that (a) nonmedical people in Japan show different attitudes toward "difficult" medical situations, (b) these attitudes may be used to categorize people into five groups, (c) the people in these groups range from complete paternalists to complete libertarians, and (d) their libertarian attitude may be explained by their trait of assertion of independence. This may mean that the Japanese are not as universally paternalistic as might be expected based on their historical background (Leflar, 1996) and that they are possibly in the midst of a gradual transition in national sentiment toward self-determination in medical matters.

ACKNOWLEDGMENTS

Since we finished this article, there have been three cases of organ transplantation from a brain-dead body in Japan.

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