

**Communication between patients and physicians
about terminal care**

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Summary

In order to assess whether physicians are correctly aware of the preferences of their patients regarding terminal care, I studied the accuracy of physicians' estimation (estimation accuracy, EA) by comparing their guesses with the patients' preferences concerning terminal care. Inquiries were made of inpatients and their attending physicians as regards the formers' attitudes toward 1) information about diagnosis and prognosis, 2) place of death, and 3) mode of therapy at terminal stage (life prolongation vs. pain control).

[Survey 1] Sixty-seven inpatients were interviewed. **Information:** Fifty-eight patients wished to have candid information at all events, while the physicians' guess was correct only for 24 (41%) cases. Furthermore, their guess was contrary to the patients' preferences in 9 (16%) cases (EA 42%). **Place of Death:** While 47 patients preferred to die at home, the physicians were correct in only 12 (26%) cases and confessed their ignorance regarding the other 34 (72%) cases (EA 21%). **Mode of Therapy:** Of 59 patients with stated preferences, 29 concurred with their physicians' estimation (EA 49%). The rate of failure in estimating the patient's preferences remained virtually the same regardless of the type of disease (malignancy vs. non-malignancy), the prognosis of the patient, the type of ward (medical vs. surgical), or the length of clinical experience of the physician (longer than 5 years vs. less).

[Survey 2] Sixty-eight inpatients were interviewed. **Information:** Fifty-three patients wished to have candid

information at all events, while the physicians' guess was correct only for 33 (62%) cases. Furthermore, their guess was contrary to the patients' preferences in 5 (9%) cases (EA 57%). **Place of Death:** While 50 patients preferred to die at home, the physicians were correct in only 23 (46%) cases and confessed their ignorance regarding the other 16 (32%) cases (EA 36%). **Mode of Therapy:** Of 65 patients with stated preferences, 32 concurred with their physicians' estimation (EA 49%).

[Survey 3] Sixty-six inpatients were interviewed. **Information:** Fifty-five patients wished to have candid information at all events, while the physicians' guess was correct only for 34 (62%) cases. Furthermore, their guess was contrary to the patients' preferences in 12 (22%) cases (EA 62%). **Place of Death:** While 42 patients preferred to die at home, the physicians were correct in only 19 (45%) cases and confessed their ignorance regarding the other 16 (38%) cases (EA 40%). **Mode of Therapy:** Of 58 patients with stated preferences, 37 concurred with their physicians' estimation (EA 64%).

The present findings indicate that in majority of cases physicians are either ignorant of or unsuccessful in correctly estimating the patients' preferences in the three hospitals studied. Since informed consent is considered rather alien to the cultural environment of Japan by its medical circle, I believe it is necessary to devise a more effective method of communication between a patient and his/her physician about terminal care preferences.

Introduction

Recent development of medical technology has enabled to extend life expectancy in many countries. However, the prolongation of life expectancy does not necessarily concur with that of active life expectancy as defined by Katz et al.¹ Vital statistics² and the National Health Survey³ of Japan indicate that there has been considerable prolongation of life expectancy for the morbid old.⁴ Clinically, this stage is such that expensive medical intervention is marginally beneficial and sometimes quite distressful. When therapeutic effectiveness is limited, patient's autonomous decisionmaking becomes important in health service. In western countries, communication between a patient and his/her physician is regarded indispensable in making therapeutic decisions during terminal stage.⁵⁻⁷

The terminal stage is usually undefinable antemortem with an exception of patients with cancer, for whom it begins with the termination of active antitumor treatment. Thus I defined it rather arbitrarily; about 3 month period immediately prior to death based on the following grounds: First, average duration of the terminal stage for the patient with cancer is reported to last 96 days.⁸ Second, my previous observation indicates that medical cost will rise in crescendo from around 3 months before death reaching the peak in the last month when the patient is hospitalized.⁹ Last, the length of "the terminal stage" was most frequently interpreted as "a few month period" by sampled individuals (Kai I, unpublished data).

In Japan, however, informed consent is not accepted as a

standard medical practice. My previous survey of the public attitude toward terminal care showed that the majority of the public (1) prefer to be fully informed about their current medical status at all events, (2) prefer home to hospital as the place of death, and (3) prefer pain control to life prolongation as the mode of therapy at terminal stage.¹⁰ However, previous survey showed that Japanese physicians seldom gave candid information to terminally ill patients.^{11,12} My survey¹⁰ also showed that the majority of physicians would not give a cancer patient candid information even if the patient asks them to do so. However, they are willing to respect patient's preferences for mode of therapy if the patient explicitly stated it. A frequently given reason for not telling the truth about the nature of the disease is the concern for possible psychological adverse effects. Many physicians expressed their conviction that even if prognosis of the patient is extremely poor, they believe it is inconsiderate to inform the bare truth and deprive him of any hope he might have.¹¹ The absence of direct communication between the patient and the physician may be justifiable if the physician correctly knows the patient's preferences. It is important to ascertain that the physician correctly estimates the patient's preferences during the terminal stage.

The primary purpose of my study was to estimate how correctly a physician knows the preferences of his patient about the following issues pertaining to terminal care: (1) preferences for candid information about diagnosis and

prognosis, (2) preferable place of death at terminal stage of illness, and (3) preferable mode of therapy (life prolongation vs. pain control).

The survey was conducted at three general hospitals in Japan: 2 in rural areas and 1 in an urban area. The three areas where the hospitals were located were distinct in the preferences of the residents and accessibility to medical care. The previous survey of mine in the same areas showed that preferences of the general public regarding terminal care were not significantly different among the rural and urban areas. However, the subjects in the urban area were more likely to prefer to have candid information and pain control during terminal stage, while the subjects in the rural areas were more likely to prefer home to hospital as the place of death. These results could be explained mainly by the difference of the age and educational background of the subjects in the three areas.¹⁰ As for accessibility to medical care, the urban area had advantage over the rural areas as described later in this paper.

It is of interest to compare the accuracy of physicians' estimation among the areas. The accuracy could be higher in an area where the preferences of subjects distribute more extremely because the physicians in such area are more likely to know the patients' preferences in general. For example, the physicians in rural areas can guess the patients' preference about the place of death more accurately because the rate of hospital death is lower, and greater proportion of people would like to die at home there. The comparison of the accuracy was another

purpose of my study.

[Survey 1]

Subject and Methods

The survey was conducted from July 28, 1985 through August 3, 1985 at the general hospital in a rural area of Japan.

The area is mainly agricultural. It is located in the central mountainous district of the Japanese Mainland. The area is divided into 127 small regions, and 540 volunteers called "regional health promoters" cooperate with health care section of the local government. The rate of hospital death in the area was lower than the national average (53.5% vs. 63.0% [1985]).² The accessibility to medical care was considerably low (1.2 physicians and 11.1 hospital beds per thousand population, and 1.8 hospital beds per square kilometer [1985]).¹³

The subjects were patients who were over 40 years of age and hospitalized in 2 medical wards and 1 surgical ward during the study period, and their attending physicians. Ninety-seven inpatients were initially selected, but 30 were subsequently excluded from the study because of apparent intellectual impairment (5), auditory impairment (4), motor aphasia (1), lethargy due to severe illness (18), and refusal to participate (2). Informed consent to participate in the survey was obtained prior to the interview.

Characteristics of the Patients

Of the 67 study patients, 34 were men and 33 women, 32 were cared in the medical wards and 35 in the surgical ward. Their mean age was 64 years (range 40-84). The mean length of stay in

the hospital was 38 days (range 1-314). The underlying diseases of the study population included malignant neoplasma (29) and other type of diseases (38). The severity of their illness was classified into three ranks by the attending physicians: (1) good (little or no probability of death during the current stay in the hospital), (2) fair (low probability of death, but eventual prognosis poor), and (3) grave (high probability of death during the current stay in the hospital). The number of patients in each category were 37, 23, and 7 respectively. The patients were asked of their preferences about terminal care. The interview was conducted in the wards by trained assistants who had took 3-day-course of role-playing of the structured interview according to written manual.

To determine whether dementia and/or depression was influencing the communication process and the patients' response, I tested their mental status using Hasegawa's Scale for Dementia (HS)¹⁴ which is widely used in Japan and in the countries in Far East and fairly similar to Mental Status Questionnaire proposed by Pfeiffer¹⁵, and modified Self-rating Depression Scale of Zung (SDS)^{16,17}. Intellectual impairment was defined as a score of 30.5 or less in HS (mild to severe dementia) while depression was defined operationally as a score of 40 (out of 80) or more in SDS.

Characteristics of the Physicians

The attending physicians were asked about the patients' preferences, independently of the interview of the patients.

Since a physician is frequently in charge of more than one patient (1-13 patients per physician), the responses represented opinions of 12 physicians (7 internists and 5 surgeons). Their clinical experience ranged from 1 to 30 years (mean 8 years).

Doctor-Patient Relationship

Doctor-patient relationship was assessed by two questions to the patients: the extent of patients' satisfaction with the amount of information which their attending physicians provided and the extent of patients' appreciation regarding their physicians' attentive attitude toward their complaints. Both questions were given three choices: "good", "fair", and "poor". The relationship was rated as "satisfactory" only when both items were reported as "good" and otherwise it was rated as "unsatisfactory".

Extent of the Communication

The extent of communication can be expressed by the estimation accuracy (EA) which is defined by the concordance rate between the patients' preferences and the physicians' estimation regarding; 1) information about diagnosis and prognosis, 2) place of death, and 3) mode of therapy at terminal stage (life prolongation vs. pain control). If the patient did not answer to a question, the case was excluded from the calculation of EA.

Group difference was assessed by the chi-square test. P values less than 0.01 were considered statistically significant.

Results

When the physicians were asked whether they discussed preferences about terminal care with the patients, they replied that they had never discussed this subject with patients (59/67,88%).

Preferences about Candid Information

Fifty-eight (87%) of the patients preferred to have candid information about diagnosis and prognosis at all events. The physicians correctly guessed the intention in only 24 of them and 9 patients were guessed by their physicians not to prefer candid talk while they wanted honest talk in reality. In case of 25 patients, the physicians replied that they did not know whether the patients wanted candid information or not. Thus, the overall estimation accuracy (EA) was 42% (Table 1).

Preferred Place of Death

Forty-seven (70%) patients replied that they preferred their home as a place of death, but only 12 of them were judged correctly by their physicians as preferring home. The physicians had not formed an opinion about preferred place of death for 34 patients. The EA was 21% in this respect (Table 2).

Preferable Mode of Therapy

As for the preferable mode of therapy in terminal care, of 59 patients with stated preferences, 29 corresponded with their

physicians' opinion, making the EA 49% (Table 3).

Effect of Patients' Characteristics on EA

The pattern of failure in estimating the patient's preferences about terminal care remained virtually the same when stratified by sex and age of the patients, whether the patients had malignant neoplasm or other type of disease, poor prognosis or favorable prognosis, whether patients' current stay in the hospital was longer than 30 days or not. The effects of intellectual impairment and depression were assessed by comparing the EA of those with intellectual impairment or depression and those who had neither. There was no significant difference of EA between the two groups.

The EA did not differ significantly whether the patient was in the medical ward or in the surgical ward, and whether the physician had longer than 5 years or less of clinical experience.

The doctor-patient relationship was rated as 'satisfactory' in 50 patients and 'unsatisfactory' in 14. The effect of the relationship on EA was also insignificant (Table 4).

[Survey 2]

Subject and Methods

The survey was conducted from May 25, 1986 through May 30, 1986 at the general hospital in a rural area of Japan.

The area is located in the most southern part of the Japanese Archipelago, where traditional culture is well preserved. One can still see large family system and ancestor worship (Toh-Toh-Meh) there.¹⁸ Shamans are active in some regions, where it is customary for them to participate in decisionmaking of the family where to care the terminally ill patient. The residents in a few regions believe that the deceased can not go to heaven unless they die at home. The rate of hospital death in the area had been low, but thanks to improved medical accessibility it was almost same as the national average in 1985 (64.4% vs. 63.0%).² However, the accessibility to medical care was still comparatively low (1.1 physicians and 11.9 hospital beds per thousand population, and 6.2 hospital beds per square kilometer [1985]).¹³

The subjects were patients who were over 40 years of age and hospitalized in 3 medical wards and 1 surgical ward during the study period, and their attending physicians. Seventy-five inpatients were initially selected, but 7 were subsequently excluded from the study because of motor aphasia (1), lethargy due to severe illness (1), and refusal to participate (5). Informed consent to participate in the survey was obtained prior to the interview.

Characteristics of the Patients

Of the 68 study patients, 38 were men and 30 women, 55 were cared in the medical wards and 13 in the surgical ward. Their mean age was 70 years (range 43-90). The underlying diseases of the study population included malignant neoplasma (10) and other type of diseases (56). The severity of their illness was classified into the three ranks described in the Survey 1: (1) good, (2) fair, and (3) grave. The number of patients in each category were 1, 62, and 2 respectively. The patients were asked of their preferences about terminal care. The interview was conducted in the wards by trained interviewers, who were proficient in the dialect of the area.

Characteristics of the Physicians

The attending physicians were asked about the patients' preferences, independently of the interview of the patients. Since a physician is frequently in charge of more than one patient (1-10 patients per physician), the responses represented opinions of 16 physicians (10 internists and 6 surgeons). Their clinical experience ranged from 3 to 17 years (mean 9 years).

Doctor-Patient Relationship

Doctor-patient relationship was assessed by the same method as employed in the Survey 1.

Extent of the Communication

The extent of communication was expressed by the estimation

accuracy (EA). If the patient did not answer to a question, the case was excluded from the calculation of EA.

Results

When the physicians were asked whether they discussed preferences about terminal care with the patients, they replied that they had never discussed this subject with patients (66/68,97%).

Preferences about Candid Information

Fifty-three (78%) of the patients preferred to have candid information about diagnosis and prognosis at all events. The physicians correctly guessed the intention in only 33 of them and 5 patients were guessed by their physicians not to prefer candid talk while they wanted honest talk in reality. In case of 15 patients, the physicians replied that they did not know whether the patients wanted candid information or not. Thus, the overall estimation accuracy (EA) was 57% (Table 5).

Preferred Place of Death

Fifty (74%) patients replied that they preferred their home as a place of death, but only 23 of them were judged correctly by their physicians as preferring home. The physicians had not formed an opinion about preferred place of death for 16 patients. The EA was 36% in this respect (Table 6).

Preferable Mode of Therapy

As for the preferable mode of therapy in terminal care, of 65 patients with stated preferences, 32 corresponded with their physicians' opinion, making the EA 49% (Table 7).

Effect of Patients' Characteristics on EA

The pattern of failure in estimating the patient's preferences about terminal care remained virtually the same when stratified by sex and age of the patients, whether the patients had malignant neoplasm or other type of disease, poor prognosis or favorable prognosis, whether the patients had educational background higher than primary school or not.

The EA did not differ significantly whether the patient was in the medical ward or in the surgical ward, and whether the physician had longer than 10 years or less of clinical experience.

The doctor-patient relationship was rated as 'satisfactory' in 62 patients and 'unsatisfactory' in 3. The effect of the relationship on EA was also insignificant (Table 8).

[Survey 3]

Subject and Methods

The survey was conducted from February 29, 1988 through March 4, 1988 at the general hospital in a metropolitan area of Japan.

The rate of hospital death in the area (77.0% [1985 data]) was higher than the national average.² The accessibility to medical care was among the highest of Japan (2.0 physicians and 11.2 hospital beds per thousand population, and 60.8 hospital beds per square kilometer [1985]).¹³

The subjects were patients who were over 40 years of age and hospitalized in 2 medical wards and 1 surgical ward during the study period, and their attending physicians. Sixty-nine inpatients were initially selected, but 3 were subsequently excluded from the study because of lethargy due to severe illness (2), and refusal to participate (1). Informed consent to participate in the survey was obtained prior to the interview.

Characteristics of the Patients

Of the 66 study patients, 31 were men and 35 women, 49 were cared in the medical wards and 17 in the surgical ward. Their mean age was 69 years (range 40-89). The mean length of stay in the hospital was 31 days (range 4-271). The underlying diseases of the study population included malignant neoplasma (13) and other type of diseases (53). The severity of their illness was classified into the three ranks described in the Survey 1: (1)

good, (2) fair, and (3) grave. The number of patients in each category were 38, 24, and 4 respectively. The patients were asked of their preferences about terminal care. The interview was conducted in the wards by interviewers who were trained by the same method as the Survey 1.

Characteristics of the Physicians

The attending physicians were asked about the patients' preferences, independently of the interview of the patients. Since a physician is frequently in charge of more than one patient (2-18 patients per physician), the responses represented opinions of 12 physicians (11 internists and 1 surgeon). Their clinical experience ranged from 1 to 20 years (mean 7 years).

Doctor-Patient Relationship

Doctor-patient relationship was assessed by the same method as employed in the Survey 1.

Extent of the Communication

The extent of communication was expressed by the estimation accuracy (EA). If the patient did not answer to a question, the case was excluded from the calculation of EA.

Results

When the physicians were asked whether they discussed preferences about terminal care with the patients, they replied that they had never discussed this subject with patients (63/66,95%).

Preferences about Candid Information

Fifty-five (83%) of the patients preferred to have candid information about diagnosis and prognosis at all events. The physicians correctly guessed the intention in only 34 of them and 12 patients were guessed by their physicians not to prefer candid talk while they wanted honest talk in reality. In case of 9 patients, the physicians replied that they did not know whether the patients wanted candid information or not. Thus, the overall estimation accuracy (EA) was 62% (Table 9).

Preferred Place of Death

Forty-two (64%) patients replied that they preferred their home as a place of death, but only 19 of them were judged correctly by their physicians as preferring home. The physicians had not formed an opinion about preferred place of death for 16 patients. The EA was 40% in this respect (Table 10).

Preferable Mode of Therapy

As for the preferable mode of therapy in terminal care, of 58 patients with stated preferences, 37 corresponded with their

physicians' opinion, making the EA 64% (Table 11).

Effect of Patients' Characteristics on EA

The pattern of failure in estimating the patient's preferences about terminal care remained virtually the same when stratified by sex and age of the patients, whether the patients had malignant neoplasm or other type of disease, poor prognosis or favorable prognosis, whether patients' current stay in the hospital was longer than 30 days or not, whether the patients had educational background higher than junior high school or not.

The EA did not differ significantly whether the patient was in the medical ward or in the surgical ward, and whether the physician had longer than 10 years or less of clinical experience.

The doctor-patient relationship was rated as 'satisfactory' in 45 patients and 'unsatisfactory' in 19. The effect of the relationship on EA was also insignificant (Table 12).

Discussion

The absence of direct communication between the patient and the physician may be justifiable if the physician correctly knows the patient's preferences. From this point of view, it is important to ascertain that the physician correctly estimates the patient's preferences during the terminal stage. The present findings indicate that communication between a patient and his physician is far from satisfactory in the studied population. The EA in Survey 1, Survey 2 and Survey 3 was 42%, 57% and 62% for candid information, 21%, 36% and 40% for the place of death, and 49%, 49% and 64% for the mode of therapy, respectively.

The accuracy did not differ significantly among the three hospitals. However, the EA for the three questions was somewhat higher in the Survey 3 compared with the other areas. There are possible explanations for the high EA: (1) the urban people with their inclination to the individualism and high educational background are more likely to state their preferences explicitly to their attending physicians, or (2) the attitudes of Japanese physicians had changed over the time between the studies. Another survey to confirm reproducibility in an urban area is now under way.

There are several potential sources of bias in my study. First of all, the patients I had interviewed were not randomly sampled. Although I intended to interview all the patients in each ward, those who were too sick were excluded from the study for obvious reasons. However, EA of the patients with grave

prognosis was more or less similar to the patients with good and fair prognosis. Secondly, in a situation where a single physician is in charge of more than one patient, bias from clustering may occur: if physicians' skill markedly varied in estimating their patients' preferences, it would be expected that EA differs between subgroups stratified by physician's characteristics. The fact that EA did not vary significantly between physicians with long and short clinical experiences nor between internists and surgeons suggests that the bias of clustering would not have been serious, even if present. For instance, one may assume that a physician with longer clinical experience may be more skillful in fathoming his patient's preferences about terminal care, but that was not the case. Thirdly, the pattern of the stated preferences of patients may change according to the course of an illness, especially in patients with good prognosis who may feel it unnecessary to do decisionmaking about terminal care; their preferences may not be based upon careful deliberation. In this regard, continuous information sharing and periodical confirmation of patients' preferences are recommended in USA.¹⁹ Fourthly, physicians' "no answer" to the questionnaire might reduce the EA. Some of the physicians seemed to think it undesirable to ask the patients when they were not at risk for terminal illness. However, the EA did not vary according to the severity of the patients' illness in this survey. On the other hand, it is understandable that the question regarding the preferable place of death got especially high rate of "no answer". The ability to give care

to the terminally ill patients at home has considerably reduced because of increased participation of women in labor market and change in family structure in Japan.²⁰ Consequently, the rate of hospital death has been increasing steadily, while majority of the patients hope to die at home. "No answer" of the attending physicians seems to reflect this discrepancy. Finally, relatively small size of the study population would make it rather difficult to generalize the present findings.

In addition to the physicians' characteristics, effects of several characteristics of patients on EA were also assessed in this study. The analysis showed that these factors did not influence EA strongly. Generally, intellectual impairment and/or depression of the patient is expected to influence the communication process and the response pattern to the questionnaire concerning terminal care.²¹⁻²³ In the present study, however, I found no significant difference between EA of the patients who had intellectual impairment and/or depression and EA of those who had not. Likewise, it is quite conceivable that doctor-patient relationship may affect EA. I assessed the relationship by asking the patients whether they were satisfied with the amount of information their physician provided and whether their physician heartily listened to their complaints. However, EA was not improved by the better doctor-patient relationship thus defined. It is of course possible that the patients, confined in the hospital, tend to rate their relationship with physician better than real.

As regards a questionnaire survey, a misgiving always arises

whether respondents are giving their genuinely personal view or simply an answer they are expected to give in principle. If there is discrepancy between the two, the response of the elderly and the patients with grave prognosis who have the prospect of diminishing life expectancy are more reliable because they can think about the issues relating to terminal care in less abstract terms. However, in my previous survey majority of the patients and the general public favored to be fully informed about their medical status, to go home during terminal stage, and to have pain control over life prolongation regardless of the age and the prognosis.¹⁰ I believe the foregoing observations strongly suggest that they expressed their genuinely personal view.

Problems related to the lack of patient-physician communication are becoming increasingly serious. Many Japanese physicians who treat terminally ill patients realize that the lack of candid communication with the patients often makes it difficult to select adequate treatment. The previous survey of mine indicated that majority of the residents in the three areas wanted to go home if they became terminally ill.¹⁰ However, the rate of hospital death has steadily increased during the past three decades, resulting in inundation of the hospitals with the patients for whom therapeutic effectiveness is marginal to say the least. Thus, the lack of direct communication between a patient and his physician causes extended hospital stay and unnecessary treatment of terminally ill patient. Its economic implication is also grave, since the sampled cases of terminal

patients indicated that incurred cost was more than tenfold greater with hospital death than home death.⁹

Why informed consent has not gained popularity in Japanese medical circle merits some comments. Firstly, traditional doctor-patient relationship in Japan is not based upon a contract between a patient and his physician which permits mutual participation²⁴ in therapeutic decisionmaking, but upon a tacit consent between the two parties. A Japanese cultural feature seems to underlie this relationship. It has been pointed out that one of the most prominent features of Japanese human relationship is mutual dependence: a desirable relationship is such that unless one person explicitly ask a favor from the other person, the other should infer his intention and act accordingly.^{25,26} The fact that majority of Japanese physicians seldom give candid information about terminal illness may at least in part be explained on this basis. Recently, the public seem to demand more participation in decisionmaking concerning health care. Interest in hospice movement and "comfortable hospital" where more attention should be devoted to patient utility is on the rise, however this trend remains quantitatively negligible (there are only 2 hospices in Japan).

Secondly, decisionmaking process in Japan is generally group-oriented.²⁷ In the setting of health care, principal family members other than the patient often participate in the decisionmaking process even if the patient is not given candid information. Namihira pointed out that the intervention by the

family members was prominent feature in Japanese health care system.²⁸ It is partly because the Japanese family is likely to take grave illness of its member as that of the whole family. The health care providers in Japan believe the participation of the family members is essential in terminal care.²⁹ The active participation of family members can be observed in western countries. Bedell et al reported that 86% of the family members of patients who were designated do-not-resuscitate were involved in the decision, while only 22% of patients were actually involved.³⁰ Thus, further study is necessary to analyse the extent of communication between the patients, family members, and physicians.

Thirdly, medico-legal situations are quite different from western countries. Malpractice lawsuits are far less frequent than in USA though increasing recently.³¹ The judicial precedents in Japan allow physicians much liberty not to give candid information to the patients.³²

Finally, medical education in Japan has not much dealt with skills of establishing effective communication between the patient and physician nor with ethical aspects of terminal care.^{11,33} Thus, a prevailing trend in medical circle favors paternalistic attitudes toward the patient in the matters of disclosure of prognosis and therapeutic decisionmaking.

There remains much uncertainty whether or not informed consent will be accepted in the near future. Certainly, there is some possibility to establish guidelines for effective communication for the application of life-sustaining technology.

My previous survey showed that a considerable fraction of physicians thought it desirable to check patients' preferences about having candid information (42%) or to take no heroic measure for life prolongation in terminal stage (36%) through the documented intention of the patients.¹⁰ However, Bedell et al reported that it is difficult to establish effective communication between a patient and his physician even when the physician is clearly aware of general guideline for the application of cardio-pulmonary resuscitation (CPR): out of 15 patients who had desired CPR, 12 were correctly guessed by the house officers while only 1 of 8 patients who had not desired CPR was correctly guessed.³⁴ The effectiveness of making such guidelines will apparently depend upon willingness of the physicians to ascertain the intention of the patients.

A cross-sectional survey by Hukui showed that the proportion of patients who would like to have opportunity of participating in the decisionmaking regarding therapeutic measures decreased stepwise according to the age of the patients. Eighty-two percent of the younger patients (aged 21 to 44) replied that they would like to participate in the decisionmaking, while only 32% of the elderly patients (aged 75 and over) did so.³⁵ The results can be explained either by the cultural difference among age groups (the younger generation are likely to be more highly educated and individualistic than the elderly) or by the advancement of age itself. If the former hypothesis is true, patients' participation in the decisionmaking process will inevitably increase in the future.

In conclusion, communication between the patient and the physician was far from satisfactory in this study population. The absence of effective communication and practice of informed consent may put Japanese physicians in a more vulnerable position in the future, as their practice during terminal stage is noted to be frequently at variance from the patients' intention. Moreover, as effectiveness of medical intervention is limited in terminal care, such practice may lead to overtreatment and inappropriate use of scarce medical resources. I believe that there is a practical necessity to devise effective way of communication between a patient and his physician about terminal care preferences.

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Table 1 Estimation Accuracy on Preference
about Candid Information in Survey 1

Patients' preference	Physicians' estimation		
	Candid information	No information desired	Do not know
Candid information at all events	24	9	25
Candid information if treatable	3	-	3
No information desired	1	-	-
No answer	2	-	-

Estimation Accuracy = 42%

Table 2 Estimation Accuracy on Preferable Place of Death
in Survey 1

Patients' preference	Physicians' estimation		
	Home	Hospital	Do not know
Home	12	1	34
Hospital	3	1	8
Other institutions	1	-	2
No answer	3	-	2

Estimation Accuracy = 21%

Table 3 Estimation Accuracy on Preferable Mode of Therapy
in Survey 1

Patients' preference	Physicians' estimation		
	Life prolongation	Pain control	Do not know
Life prolongation	3	12	4
Pain control	9	26	5
No answer	4	3	1

Estimation Accuracy = 49%

Table 4 Estimation Accuracy and Patients' Characteristics in Survey 1

Patients' characteristics(n)		Patients' preferences		
		Candid information	Place of death	Mode of therapy
Sex	Male(34)	42	16	33*
	Female(33)	41	26	66
Age	40s and 50s(24)	61*	23	50
	60 and over(43)	31	20	49
Malignancy	Malignancy (+) (29)	45	27	38
	Malignancy (-) (38)	39	17	57
Prognosis	Good(37)	43	11	49
	Fair(23)	43	33	53
	Grave(7)	29	33	40
Mental status	Normal(37)	43	15	55
	Deteriorated(30)	39	29	42
Current length of stay	Less than 30 days(44)	47	16	54
	30 days and over(23)	32	32	40
Ward	Medical(32)	33	23	57
	Surgical(35)	49	19	42
Physicians' clinical experience	Less than 5 years(32)	27*	30	56
	5 years and over(35)	54	13	44
Doctor-patient relationship	Satisfactory(50)	40	19	53
	Unsatisfactory(14)	43	33	36
TOTAL (67)		42	21	49

Estimation Accuracy (%)
* P < 0.05

Table 5 Estimation Accuracy on Preference
about Candid Information in Survey 2

Patients' preference	Physicians' estimation		
	Candid information	No information desired	Do not know
Candid information at all events	33	5	15
Candid information if treatable	4	-	1
No information desired	4	1	4
No answer	1	-	-

Estimation Accuracy = 57%

Table 6 Estimation Accuracy on Preferable Place of Death
in Survey 2

Patients' preference	Physicians' estimation		
	Home	Hospital	Do not know
Home	23	11	16
Hospital	6	1	6
Other institutions	1	-	3
No answer	-	-	1

Estimation Accuracy = 36%

Table 7 Estimation Accuracy on Preferable Mode of Therapy
in Survey 2

Patients' preference	Physicians' estimation		
	Life prolongation	Pain control	Do not know
Life prolongation	8	12	7
Pain control	11	24	3
No answer	-	3	-

Estimation Accuracy = 49%

Table 8 Estimation Accuracy and Patients' Characteristics in Survey 2

Patients' characteristics(n)		Patients' preferences		
		Candid information	Place of death	Mode of therapy
Sex	Male(38)	66	39	53
	Female(30)	45	31	44
Age	40s,50s,60s(31)	68	45	48
	70 and over(35)	47	29	50
Malignancy	Malignancy (+) (10)	50	40	40
	Malignancy (-) (56)	58	36	51
Prognosis	Good(1)	0	100	100
	Fair(62)	59	36	49
	Grave(2)	50	50	50
Education	Longer than 6 years(35)	68	37	49
	6 years and less(30)	47	38	48
Ward	Medical(55)	59	43	48
	Surgical(13)	46	8	54
Physicians' clinical experience	Less than 10 years(35)	57	37	56
	10 years and over(33)	56	34	42
Doctor-patient relationship	Satisfactory(62)	59	34	49
	Unsatisfactory(3)	33	67	50
TOTAL (68)		57	36	49

Estimation Accuracy (%)

Table 9 Estimation Accuracy on Preference
about Candid Information in Survey 3

Patients' preference	Physicians' estimation		
	Candid information	No information desired	Do not know
Candid information at all events	34	12	9
Candid information if treatable	3	1	-
No information desired	1	1	-
No answer	2	-	3

Estimation Accuracy = 62%

Table 10 Estimation Accuracy on Preferable Place of Death
in Survey 3

Patients' preference	Physicians' estimation		
	Home	Hospital	Do not know
Home	19	7	16
Hospital	5	4	5
Other institutions	1	1	-
No answer	5	1	2

Estimation Accuracy = 40%

Table 11 Estimation Accuracy on Preferable Mode
of Therapy in Survey 3

Patients' preference	Physicians' estimation	
	Life prolongation	Pain control
Life prolongation	1	7
Pain control	14	36
No answer	2	6

Estimation Accuracy = 64%

Table 12 Estimation Accuracy and Patients' Characteristics in Survey 3

Patients' characteristics(n)		Patients' preferences		
		Candid information	Place of death	Mode of therapy
Sex	Male(31)	77*	37	50*
	Female(35)	48	42	77
Age	40s,50s,60s(31)	67	23*	57
	70 and over(35)	58	53	70
Malignancy	Malignancy (+) (13)	38*	25	82
	Malignancy (-) (53)	69	43	60
Prognosis	Good(38)	69	44	74
	Fair(24)	50	38	45
	Grave(4)	75	0	67
Education	Longer than 8 years(50)	60	39	62
	8 years and less(14)	69	36	70
Current length of stay	Less than 30 days(44)	65	46	70
	30 days and over(21)	57	26	50
Ward	Medical(49)	71*	37	63
	Surgical(17)	38	47	65
Physicians' clinical experience	Less than 10 years(50)	60	40	63
	10 years and over(16)	71	40	67
Doctor-patient relationship	Satisfactory(45)	63	33	74*
	Unsatisfactory(19)	59	50	39
TOTAL (66)		62	40	64

Estimation Accuracy (%)
* P < 0.05