

## Coordination Issues for Incurable Patients between Home Care Physicians and Acute Care Physicians

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(Accepted October 27, 2005)

We conducted a survey to clarify issues related to a smooth transition from a hospital which providing medical treatment at an acute stage (abbreviated as "acute care") to a home care setting (abbreviated as "community") when a cancer patient at a terminal stage selects his/her home as the place of medical treatment. The items included in the questionnaires were ① demographic data, ② informed consent, ③ anxiety of a patient/family, and ④ coordination. We compared with the situations of home care setting and acute care hospitals. Questionnaires of 185 were distributed and 123 (35 from acute doctors, 88 from community doctors) were returned. The response rate was 67%. The acute care doctors of 43% responded that "they will go along with the family's wish" with regard to the issue of informing, and 85% responded that "the patient/family understands the medical condition". On the other hand, 58% of the community doctors responded that "the patient/family understands the medical condition", and only about 50% of the community doctors responded that "the description of the medical condition provided by the acute doctor and the level of understanding of the medical condition by the patient's family is consistent". Both the acute care and community doctors experienced difficulty dealing with a patient/family because they did not inform the patient about their life expectancy and because the patient's family did not understand enough about the medical condition. Acute care doctors need to assure a sense of security for patients allow both a smooth transition to a home care setting from a hospital. These issues include informing the patient/family, explaining the medical condition, and cooperating with the community doctors' at the time of transition to home care. For that purpose, acute doctors need to acquire the necessary communication skill so that they can properly provide informed consent, can cooperate with the community doctors and can lead group activities in a medical team.

**Key words:** terminal stage cancer patients, home care medicine, informed consent, questionnaires

### Background

What kind of care or death does a patient hope for when facing a terminal disease? In Japan, about 19,000 cancer patients die at home annually in the year 2003<sup>1)</sup>. This is equivalent to only 6% of the total number of cancer deaths. Most cancer patients remained in the medical institutions at their final stage. Even so, a high ratio of patients received treatments at "their own home", during their termi-

nal stage of disease<sup>2)~4)</sup>.

Kawagoe<sup>5)</sup> explained that home care for terminal cancer patients is not widespread because of ① reasons within medical institutions (hospitals, home care service), ② lack of awareness of the patient or family, ③ lack of information for the patient, ④ poor administrative systems, and ⑤ other reasons. These reasons indicate a need for acute care hospitals and home care medical institutions to acknowl-

**Table 1** Demographic data of subjects (n = 123)

	Acute	Community
n	35	88
Age (year)	45.7 ± 9.2	47.2 ± 8.9
Experience in profession <sup>a</sup> (year)	18.7 ± 9.0	20.9 ± 9.2
transition <sup>b</sup> (%)	88.6	
home care <sup>c</sup> (%)	77.1	93.2
patients' deaths at home <sup>d</sup> (%)	71.4	93.2

<sup>a</sup>: experience as a medical doctor, <sup>b</sup>: doctors who had experience in helping patients with home care transition, <sup>c</sup>: doctors who had experience in caring for patients at home, <sup>d</sup>: doctors who had experience in attending patients' death at home.

edge their respective roles and work together.

We tried to clarify some of the coordination issues and discuss the roles of both acute care and community doctors caring for terminal cancer patients.

### Subjects and Methods

Acute care doctors are those doctors who work in acute care hospitals and community doctors are doctors who work in local, small, primary care hospitals or clinics.

Acute care and community doctors who participated in The Japanese Academy of Home Care Physicians, 2005 were asked to participate in the survey. On the day of the meeting, two types of questionnaires were distributed, one for acute care doctors and one for community doctors. Questionnaires were later collected in the assembly hall.

The items in the questionnaires included: ① demographic information, ② issues related to explaining a medical condition to a patient or a family and informing them about the life expectancy, ③ issues relating to anxiety of a patient or his family, and ④ coordination between acute care hospital and community hospital. One of four responses from questions ② thru ④ was selected for evaluation.

The scores of each questionnaire was totaled and Chi-squared test to determine the difference in trends between groups.

### Results

#### 1. Demographic data of subjects (Table 1)

A total of 248 doctors were registered in meeting.

Questionnaires were distributed to 185 doctors and 123 (35 acute care doctors and 88 community doctors) responded giving a response rate of 66.5%. Most doctors were males (80.0% and 88.6% for acute care and community doctors respectively). The demographic information of the subject is shown in Table 1.

#### 2. Response by acute care doctor (Table 2)

Over 80% of the doctors set the treatment target at admission to be inclusive after discharge. Over 90% of doctors responded that the patient and the family understood the treatment target. On the question asking how a doctor inform a patient about a diagnosis or a bad prognosis, 2.9% responded that "the diagnosis is not informed", 25.7% responded that "the bad prognosis is not informed", 28.6% responded that "the diagnosis and the bad prognosis are informed", and 42.9% "will go along with the family's wish", indicating that they respect the interest of the family over that of the patient.

A total of 85% responded that patients and their families understood their medical condition at the time of discharge. Over 74% of doctors have had difficulty dealing with a patient or a family due to their lack of understanding of their condition. About half of the doctor have had difficulty dealing with a patient or a family because they have not informed them on a bad prognosis. More acute care doctors have had difficulty gaining understanding from a patient or a family when explaining a medical condition and informing the patient on the bad prognosis before starting home care.

#### 3. Community doctors (Table 3)

Responses to the question "Do you consider that the content of the description of the medical condition provided by the acute care doctor and the patient's level of understanding is consistent?", 5.7% responded "consistent", 42% responded "consistent for the most part", and roughly one-half responded "not consistent".

To the question "What issues do the patient/family feel anxious about after the patient's discharge?", 72.7% responded "medical support at night", 68.2% responded "the support system of the hospital at a time of emergency" and 46.6% re-

**Table 2** Questions for acute care doctors and their responses

Questions	Answers	Frequency (%)
What is the treatment goal at the time of admission?	Improve the current medical condition	3 ( 8.6)
	Improve the medical condition while in hospital	1 ( 2.9)
	Include treatment after discharge	30 (85.7)
	No response	1 ( 2.9)
Have you explained the goal of treatment discharge to the patient/family and gained their understanding?	They understand	9 (25.7)
	They understand for the most part	23 (65.7)
	They do not understand much	3 ( 8.6)
	They do not understand	0
How do you inform a patient about a bad prognosis?	The diagnosis is not informed	1 ( 2.9)
	The bad prognosis is not informed	9 (25.7)
	The diagnosis and the bad prognosis are informed	10 (28.6)
	Will go along with the family's wish	15 (42.9)
Does a patient's family understand the medical condition at the time of the patient's discharge?	They understand	3 ( 8.6)
	They understand for the most part	27 (77.1)
	They do not understand much	5 (14.3)
	They do not understand	0
Have you had difficulty dealing with a patient/family because of their lack of understanding of the medical condition?	Often	2 ( 5.7)
	Sometimes	26 (74.3)
	Hardly ever	6 (17.1)
	None	0
	No response	1 ( 2.9)
Have you had difficulty dealing with the patient/family because you have not informed them on the bad prognosis?	Often	6 (17.1)
	Sometimes	19 (54.3)
	Hardly ever	7 (20.0)
	None	2 ( 5.7)
	No response	1 ( 2.9)

sponded "Is adequate medical care available?". These responses seem to indicate that the anxiety level is quite high among the patient/family with regard to medical support.

Responses to the question "Does the patient/family understand the medical condition at the time of the patient's discharge", 4.5% responded they "understand", 53.4% responded they "understand for the most part", indicating that roughly 60% mostly understand. In response to a question asking if they have had difficulty dealing with the patient/family due to their lack of understanding of the medical condition, 31.8% responded "often", and 51.1% responded "sometimes", a total of 82.9% have had such difficulty.

Also, in response to a question asking if they have had difficulty dealing with the patient/family because they have not informed them about their life expectancies. Community doctor of 26.1% responded "often" and 51.1% responded "sometimes", indicating that a total of 77% doctors have had diffi-

culty dealing with the patient and/or the patient's family.

#### 4. Comparison between acute care and community doctors (Table 4)

The four levels of evaluation in Tables 2 and 3 were summarized into "yes" and "no" and a chi-squared test was performed, the results of which are shown in Table 4. On the question "Does a patient's family understand the medical condition at the time of the patient's discharge?", 85.7% of acute care doctors and 58.0% of community doctors responded "yes", showing a significant difference ( $p < 0.01$ ). Also, the frequency of experiencing difficulty was high for both the acute care and community doctors on the question "Have you had difficulty dealing with the patient/family because of their lack of understanding of a medical condition?". However, as shown in Table 3, the extent of difficulty was greater for the community doctor.

With regard to the question of whether or not to inform a patient on life expectancy, 51.4% of acute

**Table 3** Questions and responses by community doctors

Questions	Answers	Frequency (%)
Do you consider the description of a medical condition provided by an acute care doctor and a patient's level of understanding is consistent?	Consistent	5 ( 5.7)
	Consistent for the most part	37 (42.0)
	Not much consistency	39 (44.3)
	Not consistent	5 ( 5.7)
	No response	2 ( 2.3)
What issues do the patient/family feel most anxious about after the patient's discharge?	Support system of hospital at emergency	60 (68.2)
	Medical support at night	63 (71.6)
	Is adequate medical care available?	41 (46.6)
	Not confident about medical treatment	19 (21.6)
	Medical support of local medical institution	22 (25.0)
	Finance	22 (25.0)
	Medical condition	24 (27.3)
	Emotional support for patient	22 (25.0)
Does a patient's family understand the medical condition at the time of the patient's discharge?	Understand	4 ( 4.5)
	Understand for the most part	47 (53.4)
	Do not understand much	35 (39.8)
	Do not understand	1 ( 1.1)
	No response	1 ( 1.1)
Have you had difficulty dealing with a patient/family because of their lack of understanding of the medical condition?	Often	28 (31.8)
	Sometimes	45 (51.1)
	Hardly ever	13 (14.8)
	None	1 ( 1.1)
	No response	1 ( 1.1)
Have you had difficulty dealing with the patient/family because you have not informed them on a bad prognosis?	Often	23 (26.1)
	Sometimes	45 (51.1)
	Hardly ever	16 (18.2)
	None	2 ( 2.3)
	No response	2 ( 2.3)

**Table 4** Comparison of acute care and community doctors responses

Questions	Response	Acute n = 35	Community n = 88	p-Value
Does a patient/family understand the medical condition at the time of patient's discharge?	Yes	30 (85.7)	51 (58.0)	0.01
	No	5 (14.3)	36 (40.9)	
Have you had difficulty dealing with the patient/family because of their lack of understanding of the medical condition?	Yes	28 (80.0)	73 (83.0)	NS
	No	6 (17.1)	14 (15.9)	
Have you had difficulty dealing with the patient/family because you have not informed them on the bad prognosis?	Yes	25 (71.4)	68 (77.3)	NS
	No	9 (25.7)	18 (20.5)	

NS: non-significant.

care doctors communicate the information to community doctor however, roughly one-half of the acute care doctors do not inform their patients, indicating that they do not see the need. On the other hand, 70.5% of the community doctors prefer giving the information and saw the information as important.

### 5. The extent of understanding of a medical condition by a patient/family and the difficulty dealing with the patient/family by community doctors (Table 5)

Table 5 shows the responses to the questions "Have you had difficulty dealing with the patient/family because of their lack of understanding of the medical condition?" and "Do you consider that the

**Table 5** The extent of understanding of a medical condition by a patient/family and the difficulty dealing with the patient/family by community doctors

Do you consider the description of a medical condition provided by the acute care doctor and the patient's level of understanding consistent?	Have you had difficulty dealing with the patient/family because of their lack of understanding of the medical condition?		
	Yes	No	Total
Yes	28 (66.7)	14 (33.3)	42 (100)
No	44 (100)	0	44 (100)
Total	72 (83.7)	14 (16.3)	86 (100)

Chi-squared test  $p < 0.01$ .

**Table 6** House call experience by acute care doctors and their methods of informing the patient

Experience in house calls	Informing patient and family by acute care doctors			Total n (%)
	Will not inform on the bad prognosis	Will inform	Go along with family's wish	
Yes	4 (14.8)	9 (33.3)	14 (51.9)	27 (100)
No	6 (75.0)	1 (12.5)	1 (12.5)	8 (100)
Total	10 (28.6)	10 (28.6)	15 (42.9)	35 (100)

Chi-squared test  $p < 0.05$ .

content of the description of the medical condition provided by the acute doctor and the patient's level of understanding consistent?". All doctors who responded that the description and the understanding of the medical condition by the patient was not consistent indicated difficulty in dealing with the patient/family because of their lack of understanding of the medical condition.

Furthermore, 66.7% of doctors who responded that the description provided by the acute care doctor and the understanding of the medical condition by the patient/family was consistent experienced difficulty in dealing with the patient/family ( $p < 0.01$ ). It clarifies the fact that many community doctors feel it is difficult to deal with a patient/family due to inconsistency in the description of the medical condition provided by the acute doctor and a lack of understanding of the patient's medical condition.

#### 6. House call experience by acute care doctors and the method of informing the patient (Table 6)

Acute care doctors who have no house call experience (75%) and those who have house call experience (14.8%) indicated that they do not inform the

patients on life expectancies showing a significant difference between the two groups ( $p < 0.05$ ). The house call experience seems to make them feel it is necessary to inform the patients about expectancies.

#### Discussion

Although the number of acute doctors ( $n = 35$ ) was small, there was no significant difference in age, number of years as clinical practitioners, and ratio of male/female when compared with community doctors ( $n = 88$ ). Acute care doctors of 89% had experience in caring for patient at home, and 70% had experience home care and attending the patient's death at home. As the survey was conducted among doctors who participated in the Japanese Academy of Home Care Physicians, both the acute care and community doctors have had some involvement in home care medicine, and as a result the doctors were highly aware of the subject matter. The community doctors of 24% belong to clinics specialized in home medical care, and 93% have experience in visiting for home and attending the patient's death at his/her home.

### 1. Explaining the medical condition to patient/family

Acute doctors of 80% included “beyond discharge” in their treatment plan at the time of admission. Based on that, 90% of acute doctors responded that they explain the medical condition to the patient/family and gain their understanding (Table 2). From these facts, acute doctors seem to believe that they have communicated well with the patient/family and that the patient/family is not anxious when they face the patient’s discharge.

On the other hand, community doctors responded that the understanding of the medical condition by the patient/family was significantly ( $p < 0.01$ ) inadequate (Table 4), and that roughly one-half of them felt that the description of the medical condition provided by the acute doctor was not consistent with the patient’s understanding (Table 3). In addition, 27% of community doctors responded that the patient/family was anxious about the patient’s medical condition. With regard to the patient in palliative care introduced by the acute hospital, Yoshizawa<sup>6)</sup> reported that: ① the preparatory period for starting home care is short, communication with the patient’s family is inadequate, and a trusting relationship has not been developed, ② the content of information provided to patients varied, and there are cases where they have not been informed, ③ the explanation provided to the family is inadequate; and pointed out the inadequacy of information and explanation of the medical condition provided at the acute hospital.

The difference was observed by the awareness between acute care doctors and community doctors with regard to an understanding of, and anxiety about, the medical condition at the time of discharge. While in the hospital, some of the problematic issues should be anticipated before being transferred to home care settings and an adequate explanation of the medical condition to the patient’s family by the acute care doctor is desirable.

### 2. Regarding informing patient

With regard to informing the patient of a disease, which is the starting point for cancer treatment and care, the awareness study conducted by the Minis-

try of Health and Welfare in 1998<sup>7)</sup> reported that 72.6% of patients responded that when they have an illness that is incurable they wanted to know about the length of treatment and their life expectancies, directly from the doctor. On the other hand, only 3.4% of doctors responded that they would inform the patient of the disease, but 58.8% reported that they would provide an explanation to the patient’s family. In our study, 43% doctors indicated that they would inform the name of the disease and the medical condition of the patient to the family before explaining it to the patient, a result which is similar to the study conducted by the ministry.

Also, based on the fact that 71% of acute care doctors and 77% of community doctors had difficulty dealing with the patient because they had not informed them on life expectancy it seems that informing the patient about their remainder of life and the manner of informing require sufficient discussion.

### 3. Coordination and understanding home care

Half of acute doctors responded that the information on informing the remainder of life is sent to community doctors. While 70% of community doctors responded that they would like to receive the information (data unshown). Also, the awareness related to informing the patient seems to be significantly lower ( $p < 0.05$ ) among acute care doctors who have no experience in house calls as compared with those doctors who have such experience (Table 6).

In order to start and continue home care for patients at the terminal stage without anxiety, it is necessary for acute doctors to understand the uniqueness of home care and to provide the necessary information to community doctors, properly, and in a timely manner.

### 4. Future issues

“The Manual for Cancer Palliative Care” by the Ministry of Health Welfare and Labor indicates that “decision making by the patient, informed consent, and a second opinion are considered important, and that in order to practice medicine by adopting these concepts it is essential to truthfully inform the patient about his/her disease”. Also, for home care to

succeed, as essential factors in helping patients at the terminal stage, Ashino<sup>8)</sup> stated that a doctor needs to acquire the technique to gain informed consent directly from the patient and to convey the bad news.

Therefore, an explanation of the medical condition to the patient and his/her family and their understanding of the medical condition are imperative for effective treatment and care and can be the starting point for medical treatment. When explaining, the medical team needs to proceed step-by-step while confirming the extent of understanding by the patient's family. Furthermore, acute care and community doctors are expected to learn the qualitative difference in the medical service they can offer, and the transition should be preceded by considering each other's views.

This study clarified that community doctors as well as acute care doctors have experienced difficulty in dealing with cancer patients who have not been informed, or a patient's family that does not understand the medical condition however, it is the role of the acute care doctor to coordinate and resolve issues before transferring a patient to home care. The important issues for acute care doctors are informing the patient at an early stage, explain-

ing the medical condition, preparation for home care, and timely exchange of accurate information with the community doctor.

Important things for doctors are improving communication skills, acquiring home care and exercising leadership.

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### 在宅療養移行時の病診連携と急性期病院医師の課題

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終末期患者が療養の場所として自宅を選択する場合に、急性期病院（急性期）から地域医療機関（地域）医師へのスムーズな移行のために、どのような課題があるかを明らかにし、今後の急性期と地域医師連携に役立てるために、医師対象のアンケート調査を行った。アンケート項目は①属性、②患者家族への病状説明、告知の問題、③患者家族の不安について、④病診連携等、などであり、アンケート配布数 185、回答数は 123（急性期医師 35、地域医師は 88）で回収率は 67% であった。アンケート結果は、急性期医師の 43% が告知に関して「家族の希望に沿う」と回答し、85% は「患者家族の病状理解ができています」と回答している。一方、地域医師の「患者家族の病状理解ができています」は 58% で、「急性期からの申し送り内容と患者家族の病状理解が一致している」と回答した地域医師は約 50% にすぎなかった。そして、急性期、地域医師たちの多くは患者へ余命告知がされていないこと、患者家族の病状理解が不十分であることに起因する対応困難を感じていた。安心な在宅医療、療養生活のために、急性期医師が整理すべき重要な課題として、患者家族に対しての告知、病状説明や在宅医療へ移行時の医療連携があげられる。具体的には、①急性期医師がコミュニケーションスキルを獲得すること、②患者にとっては生活の場である在宅での医療の視点で連携ができること、さらに③院内外のお他職種とのチーム医療をリードできることが必要と考えられる。