

## Medical explanations to family members in the foyer and hallway during home medical care visits

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**Objective:** To investigate the background of communications between doctors and family members in the foyer (i.e., the entrance hall at the front door) or in the hallway during medical care visits at a patient's home.

**Methods:** We conducted a cross-sectional mail survey of the families of Japanese patients who had previously received home medical care visits from doctors. Among 271 families who were mailed surveys, 227 responded (83.8%). The total analyzed subjects were 127 families of patients who died while receiving home medical care. The questionnaire asked whether or not the family had experienced medical communication between the patient's doctor and a family member or members in the foyer and/or hallway during home medical care visits, and multivariate logistic regression was performed using the following explanatory variables: "Malignant tumors as primary disease," "Experience of using home nursing services," "Frequency of doctors' home visits," "Length of doctors' home visits," "Having another room (i.e., other than the patient's room)," "Spouse as primary caregiver," and "Previously having received medical advice by phone."

**Results:** Communication between a doctor and a family member or members in the foyer and/or hallway occurred in 44.1% (n = 56) of families. Communication in the foyer and/or hallway was significantly associated with a malignant tumor as the patient's primary disease (odds ratio [OR], 3.212; 95% confidence interval [CI], 1.354–7.618; P = 0.008) and family members receiving medical advice by phone (OR, 2.797; 95% CI, 1.285–6.087; P = 0.01).

**Conclusion:** In home medical care settings, communications between a patient's doctor and a family member or members in the foyer and/or hallway frequently occur in the case of patients who have a malignant tumor as their primary disease, as well as the same occurring with those who had received medical advice from the patient's doctor by phone.

**Key words:** communication, doctor, family member, foyer, home medical care

### Introduction

Japan has the one of the fastest rates of population aging and one of the highest life expectancies at birth among the industrialized countries.<sup>1</sup> Women in Japan have the longest life expectancy in the world at 87 years, whereas men rank eighth at 80 years.<sup>2</sup> This has recently led to extensive discussions about the significance of home medical care, especially for older people. At present, this is quickly becoming not only a Japan-specific concern, but also has become an issue of concern in all countries worldwide.

One of the keys to success of home medical care is good communication between doctor, patient, and family.<sup>3-7</sup> In home settings, often the doctor, the patient, and a family member or members are all present in the patient's bedroom,<sup>3,5,6</sup> therefore, three-way communication between all of them in the patient's bedroom is normal in some home medical care settings.<sup>3,5,6,8,9</sup> Two-way communication between the doctor and the patient also takes place from time to time in the absence of the family members.<sup>6,10</sup> This is important to maintain the patient's autonomy. Formal communication between the doctor and the family members in the absence of the patient

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takes place only on an exceptional basis, after due consideration of patient confidentiality.<sup>3,10</sup> This type of communication is usually related to deathbed issues because those who are present at the deathbed are mostly the family members in home care settings.<sup>9</sup>

There is another type of communication specific to home medical care, where the family asks the doctor a question in the foyer (i.e., the entrance hall at the front door) and/or the hallway of the home in the absence of the patient.<sup>8,9</sup> This type of communication takes place when the family members do not want to take up much of the doctor's time or decline, in consideration of the patient's autonomy, to ask questions formally in another room in the patient's absence.<sup>9</sup> This concept is different in outpatient and inpatient settings. We refer to this type of communication as "doctor-family home care medical communications (DFHCC) without the patient in the foyer and/or hallway." Typically, such a situation may occur after the doctor has completed a medical examination and left the patient's bedroom. When the doctor and the family are passing through the hallway or saying goodbye in the foyer at the front door, one or more of the family members may ask a question or questions about the patient's condition saying, "By the way, Doctor, how is . . . (or) what about other symptoms and/or therapies (or) second opinions (or) trial programs (etc.)?" In a previous qualitative study, we showed that family members think that DFHCC can be useful to get brief, but important information on the patient's condition from the doctor.<sup>8</sup>

In outpatient settings, patients sometimes ask questions about a new subject immediately before leaving the examination room, which often encapsulates their real or true intentions or concerns.<sup>11,12</sup> Such behavior is commonly referred to as the "by-the-way syndrome" or "doorknob questioning," and we think that DFHCC is similar and, therefore, an important adjuvant clinical concept. In other words, during a doctor's home medical care visit, when a family member asks the doctor a question about a new topic or issue just before or after leaving the patient's bedroom, or before the doctor leaves the home, could encapsulate the family's actual concerns.

However, the background of DFHCC is not clear in practice. In particular, when it actually occurs remains uncertain. DFHCC is, by definition, a concept specific to home medical care, and clarifying its background will lead to better overall home medical care practice. We, therefore, investigated the background of DFHCC in families who had experience with it.

## Materials and Methods

### *Sampling and enrolment criteria*

A cross-sectional postal questionnaire survey was conducted on the topic of doctor-family communications during home medical care visits in June and July of 2011. The questionnaire and the reply envelope were anonymous. Of 323 families of patients for whom home medical care was carried out by physicians of the Higashisaitama Hospital from May 2006 through April 2011, a total of 295 families meeting all three of the following criteria were selected as potential participants: (1) where patients had received home medical care visits more than three times, excluding the deathbed visit; (2) a family member or members had been present at least once during the home care visit; and (3) if the patient had died, more than 50 days had elapsed since their death (in respect for the bereaving family).

### *Ethical considerations*

The study was carried out with the approval of the ethics committee of the Higashisaitama Hospital. We explained the purpose and contents of the study, the protection of the patients' personal information, and the anonymity of the data obtained from the participating families. The questionnaires and an explanatory document were then mailed only to families who had given their consent to these conditions. Completion and return of the questionnaire by mail was taken as proof of consent. In cases in which home medical care was still ongoing during the survey period, the contents of the survey were also explained to the patient, from whom consent was also obtained.

### *Data sources*

The data sources for this study were medical records and completed questionnaires consisting of 53 questions, including some intended for other studies.<sup>5,6</sup> Information on basic patient characteristics was collected from the medical records, while that on patient background, family background, the caregiving situation, and DFHCC was extracted from the questionnaires. Selection of the questions and survey items was determined through discussions among the authors about the results of previous studies.<sup>7-12</sup>

### *Data collection*

#### 1. Basic patient characteristics

The following data were obtained: patient age at the initiation of home medical care, sex, primary disease, life status (alive, dead, or unknown), primary disease

duration (in months), duration of home medical care (in days), and frequency of doctors' home visits (per week).

## 2. Patient backgrounds

We obtained information on the level of care required for the patient at the initiation of home medical care using the guidelines of Japan's long-term care insurance program (i.e., requiring some assistance: care levels 1–5).<sup>1,13</sup> The questionnaire asked whether or not the patient had ever used home nursing services, it also asked the family member(s) at the initiation of home medical care whether or not they thought that the patient had a hearing impairment that hindered communication. The following five options were given as a possible answer: "Not at all," "I don't really think so," "I am not sure," "Yes, to some extent," or "Yes, very much so." The questionnaire also asked about the length of the doctor's visits (in minutes).

In addition, to check whether or not the patient's and family's privacy had been maintained in the patient's home at the initiation of home medical care, the questionnaire asked if there was another room in which the family could be apart from the patient. One of three possible answers was to be selected: "There is no other room," "There is another room, but the family could hear the doctor-patient conversation," or "There is another room, but the family could not hear the doctor-patient conversation."

## 3. Family backgrounds and caregiving situations

The following information was obtained: age and sex of the primary caregiver(s), familial relationship to the patient (spouse, parent, child, brother, sister, other), number of caregivers, and whether or not they had received advice from the patient's doctor by phone. The questionnaire also asked whether or not the family had questions and/or anxieties about the patient's symptoms at the beginning of the home medical care, and one of five possible answers was to be selected: "No, not at all," "No, not really," "Neither yes nor no," "Yes, to some extent," or "Yes, very much so."

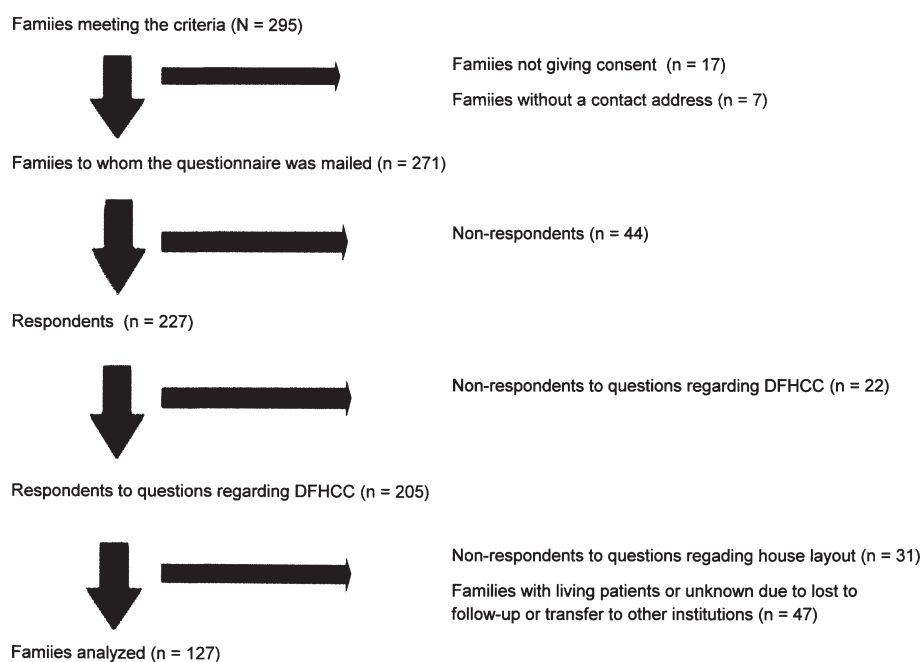
## 4. Survey items for the principal subjects

The questionnaire asked two questions about DFHCC. "Have you ever discussed the patient's symptoms and/or conditions with the patient's doctor in the foyer?" And "Have you ever discussed the patient's symptoms and/or conditions with the patient's doctor in the hallway?" The respondents were asked to answer either, "Yes, I have" or "No, I haven't" to both questions.

## Data analyses

### 1. Analysis objective

Of the 295 families who met the criteria, 17 did not give their consent, and 7 could not be contacted; therefore, 271 questionnaires were mailed to the families, and 227 (83.8%) were returned. The analysis was restricted to the 205 families who had responded



**Figure 1.** Population flow diagram of the subjects

to the two specific questions for the principal objective of this study, i.e., whether or not a family member or members had discussed the patient's symptoms with the patient's doctor in either the foyer or the hallway. Another 31 families were excluded who did not answer the question about having another room, and 47 other families were excluded where the patient was still alive or not known to be alive or dead because he or she was lost to follow-up due to having been transferred to another institution. We limited the analyses to families where the patient had died in order to study the entire course of home medical care, including the terminal stage of the disease when communications between the doctor and the family become more frequent. This methodology, therefore, left 127 families for the analyses. Figure 1 shows a population flow diagram of all the subjects in the present study.

## 2. The DFHCC model

We constructed a multivariable logistic regression analysis model for DFHCC through discussions among the authors with reference to previous studies.<sup>6,10</sup> The model included the following considerations.

### (1) Items regarding patient factors

The analytical model included whether or not the patient had a malignant tumor as the primary disease. The symptoms of malignant tumors are apt to change more frequently than those of other diseases, therefore, family members are more likely to want to ask questions about the patient's condition. Due to the necessity to emphasize self-determination in cancer patients, at least as much as in patients with other terminal or debilitating diseases, the occurrence of doctor-patient communications between the doctor and the patient, in the absence of the family, could become more frequent, because the family respects the patient's autonomy.<sup>6,10</sup> We, therefore, formulated a hypothesis that DFHCC (which enables family members to ask doctors brief questions) occurs more frequently in families of patients with malignant tumors and, therefore, included this in the analysis model. In patients with multiple lesions, that of "malignant tumor" was preferentially adopted for the purpose of this classification.

This model also included whether or not the family had used home nursing services. We formulated a hypothesis that DFHCC becomes less frequent in users of home nursing services because those nurses can give the family additional information about the patient's condition.

### (2) Items regarding communications during home medical care visits

The analytical model included the frequency of the doctors' home visits. We hypothesized that frequent visits would increase the opportunity for the family members to ask questions, therefore, DFHCC would become less frequent than it would with fewer visits. Therefore, the model also included the length of the doctors' visits, because we hypothesized that a longer stay would increase the opportunity for the family members to ask the doctors questions so that DFHCC would most likely occur less frequently.

Additionally, the model included whether or not there was another room in the house suitable for communication in the patient's absence. We hypothesized that DFHCC occurs more frequently if there is no other room available.<sup>8,9</sup> If the answer to the question regarding whether or not there was another room was, "There is another room, and the family members could not hear the doctor-patient conversations," such cases were assigned to the "YES" group. However, if the answer was, "There is no other room" or "There is another room, but the family members could hear the doctor-patient conversations," such cases were assigned to the "NO" group.

### (3) Items regarding family factors

The analytical model included whether or not the primary caregiver was the patient's spouse. Previous studies have suggested that when the caregiver is the patient's spouse, the patient and the spouse tend not to keep secrets from each other.<sup>14,15</sup> We, therefore, hypothesized that DFHCC occurs less frequently if the caregiver is the spouse.

The model also included whether or not the family had received medical advice by phone. We hypothesized that if the family had been advised over the phone, this complemented at-home explanations and, therefore, reduced the occurrence of DFHCC.<sup>16</sup>

## *Statistical analyses*

Those who responded to the question about receiving medical information from the doctor in the foyer and/or the hallway were divided into two different groups: the "DFHCC group," which had received such information and the "non-DFHCC group," which had not received that information. Differences in DFHCC experience by patient and family characteristics were tested using the *t*-test for continuous variables, the Wilcoxon rank-sum test for the ordinal rating scale, and the  $\chi^2$  test for

categorical variables.

Non-family factors associated with DFHCC were assessed using multivariable logistic regression analysis (experienced = 1 vs. not experienced = 0). Adjusted odds ratios (ORs) and their 95% confidence intervals (95% CIs) were also calculated. For the multivariable model, a forced entry model was constructed to include the following items, through discussions among the authors referring to the previous studies:<sup>6,8-10,14-16</sup> "Malignant tumors as primary disease," "Experience of using home nursing services," "Frequency of doctors' home-visits," "Length of doctors' visits," "Having another room," "Spouse as primary caregiver," and "Previously receiving medical advice by phone." The statistical package SPSS, version 22 for Windows (SPSS Inc., Chicago, IL, USA) was used for the statistical analyses. All P values were two-sided, and values of <0.05 were considered statistically significant. When the logistic regression model was constructed, goodness of fit was also analyzed using the Hosmer-Lemeshow test.

## Results

There were 31 families (24.4%) who answered "Yes" to having received medical information from the doctor in

the hallway, and 51 (40.2%) who answered "Yes" about having received medical information from the doctor in the foyer, and as many as 56 families (44.1%) who had experienced both.

### *Differences in patient characteristics*

Table 1 shows the patient characteristics by DFHCC experience. DFHCC occurred significantly more often in the families of patients with malignant tumors (P = 0.012). Where a high level of care was required, the proportion of families reporting that they experienced DFHCC was significantly lower (P < 0.047). There was no statistically significant association between the occurrence of DFHCC and patient age, sex, primary disease duration, duration of home medical care, frequency of doctors' home visits, experience of home nursing services, having a hearing loss, length of doctors' visits, or having another room.

### *Differences in family characteristics*

Table 2 shows the family characteristics by DFHCC experience. Where family members reported that they experienced DFHCC, the proportion of families reporting that they had received medical advice by phone was greater (P < 0.008). There was no statistically significant

**Table 1.** Characteristics of patients (N = 127)

Variable	DFHCC families (n = 56)	No DFHCC families (n = 71)	P value
Age, years (mean ± SD)	74 ± 14	77 ± 13	0.159*
Sex			0.860**
Male, n (%)	27 (48.2)	33 (46.5)	
Female, n (%)	29 (51.8)	38 (53.5)	
Disease classification			0.012**
Malignant tumors, n (%)	37 (66.1)	30 (42.3)	
Other, n (%)	19 (33.9)	41 (57.7)	
Primary disease duration (months) (mean ± SD)	38 ± 50.3	50 ± 71.8	0.269*
Duration of home medical care (days) (mean ± SD)	185 ± 324.5	176 ± 270.1	0.871*
Frequency of doctors' home visits (/week) (mean ± SD)	2.2 ± 1.8	2.1 ± 1.9	0.738*
Level of care required (median [1st, 3rd quartiles])	3 ([2,4])	3 [2,5]	0.047***
Experience of home nursing services			0.351*
Yes, n (%)	40 (71.4)	45 (63.4)	
No, n (%)	16 (28.6)	26 (36.6)	
Hearing loss (median [1st, 3rd quartiles])	2 ([1,2])	2 [1,3]	0.211***
Length of doctors' visits (mean ± SD)	35 ± 19.9	39 ± 20.7	0.330*
Having another room			0.461*
Yes, n (%)	33 (59.9)	47(66.2)	
No, n (%)	23 (41.1)	24 (33.8)	

\*t-test

\*\* $\chi^2$  test

\*\*\*Wilcoxon signed-rank sum test

association between the occurrence of DFHCC and the primary caregiver's age or sex, whether the primary caregiver was a spouse, number of caregivers, existence of family's anxieties and/or questions about the patient's symptoms.

*Adjusted odds ratios of factors for DFHCC in the multivariate model*

Table 3 shows adjusted ORs of factors for DFHCC in the multivariate model. DFHCC was significantly associated with "Malignant tumor as the primary disease" (OR, 3.212; 95% CI, 1.354–7.618; P = 0.008) and "Previous experience of receiving medical advice by phone" (OR, 2.797; 95% CI, 1.285–6.087; P = 0.01). No association with DFHCC was observed for "Experience of using home nursing services," "Frequency of doctors' home visits," "Length of doctors' home visits," "Having another room," or "Spouse as primary caregiver." Because

goodness of fit was not rejected in the Hosmer-Lemeshow test, the model was considered to fit this study and was, therefore, used (P = 0.656).

**Discussion**

Our results revealed some background factors linked to the occurrence of DFHCC. First, when the patient's primary disease was a malignant tumor, there was a positive association between a malignant tumor as the primary disease and the occurrence of DFHCC. DFHCC is a kind of doctor-family communication without the patient, which could be problematic in terms of the patient's autonomy and confidentiality, although this concern is not confined to patients with malignant tumors. It has already been reported that, in inpatient settings in Japan, doctors' explanations to the family members about

**Table 2.** Characteristics of families (N = 127)

Variable	DFHCC families (n = 56)	No DFHCC families (n = 71)	P value
Age of primary caregiver(s) (mean ± SD)	60 ± 14	63 ± 10	0.081*
Sex of primary caregiver(s)			0.844**
Male, n (%)	16 (28.6)	19 (26.8)	
Female, n (%)	40 (71.4)	52 (73.2)	
Primary caregiver			0.858**
Spouse, n (%)	25 (44.6)	30 (42.3)	
Non-spouse, n (%)	31 (55.4)	41 (57.7)	
Number of caregivers (mean ± SD)	1.9 ± 1.1	2.0 ± 1.2	0.656*
Experience of receiving medical advice by phone			0.008**
Yes, n (%)	35 (62.5)	27 (38.0)	
No, n (%)	21 (37.5)	44 (62.0)	
Family anxieties and/or questions (median [1st, 3rd quartiles])	3 [3,4]	3 [3,4]	0.929***

\*t-test

\*\*χ<sup>2</sup> test

\*\*\*Wilcoxon signed-rank sum test

**Table 3.** Adjusted odds ratios of DFHCC (N = 127)

Variable	Adjusted OR	95% CI	P value
Malignant tumors as primary disease	3.212*	1.354–7.618	0.008
Experience of home nursing services	1.179*	0.508–2.738	0.702
Frequency of doctors' home visits	0.906	0.723–1.135	0.39
Length of doctors' home visits	0.991	0.972–1.011	0.37
Having another room	0.823	0.373–1.816	0.629
Spouse as primary caregiver	1.026*	0.465–2.265	0.95
Previously receiving medical advice by phone	2.797*	1.285–6.087	0.01

OR, odds ratios; CI, confidence interval

\*OR ≥ 1 indicates DFHCC are more frequent.

the poor prognosis or impossibility of cure of malignant tumors tends to be carried out in the absence of the patient.<sup>17</sup> The family is apt to be involved in a large part of the patient's decision-making in inpatient settings.<sup>18</sup> Such behavior could impair a patient's right to know, which is an important and Japan-specific clinical issue.

Our previous study revealed that communication in another room between the doctor and the family members in the absence of the patient was not significantly more frequent in patients with malignant tumors than for those with other diseases.<sup>5</sup> Doctor-patient communications in the absence of the family, however, was significantly more frequent during home medical care visits for patients with malignant tumors.<sup>5</sup> From these findings, we consider that the principle of the patient's autonomy and confidentiality is better respected in home medical care settings than in inpatient settings. It has, however, already been reported that families consider DFHCC useful, especially where they hesitate to ask an important question in the presence of the patient.<sup>9</sup> It is possible that DFHCC is carried out only after the family's due consideration of the patient's autonomy and confidentiality. From our results, it is clear that DFHCC is more frequent where the patient's primary disease is a malignant tumor, which supports our hypothesis. Although not investigated here, it would be helpful to further elucidate, by checking what is specifically discussed in the foyer or the hallway, and whether or not DFHCC is really advisable, taking into consideration the patient's autonomy and confidentiality and the family's circumstances.

The experience of receiving medical advice by phone was also positively associated with DFHCC. It is possible that telephone explanations can be useful to complement communications in home medical care settings.<sup>18</sup> In our previous qualitative study on communication methods in home medical settings, it was demonstrated that patient's families consider telephone explanations useful to obtain answers to questions that could not be asked the doctor during the home medical care visits.<sup>9</sup> However, the effect of telephone explanations on DFHCC could differ from when the family called the doctor compared with when the doctor called the family. This point remains unclear and, therefore, warrants future investigations.

Our study demonstrated that neither frequency nor length of doctors' home visits are associated with the occurrence of DFHCC. More frequent home medical care visits and longer stays are considered to promote communications between doctors and family members, but that does not necessarily lead to reduction in the frequency of DFHCC, suggesting that DFHCC is regulated by factors other than the amount of

communication. This is similar to the phenomenon that, in outpatient settings, the frequency of the "by-the-way syndrome" is not reduced even if the medical examinations last longer.<sup>11,12</sup>

No association was observed between DFHCC and having another room in the home. Generally, Japanese houses are relatively small and the foyer (i.e., the entrance to the home) and/or the hallway is used for various doctor-family member communications.<sup>19</sup> We, therefore, hypothesized that DFHCC occurs because no other room is available for medical conversations. However, our results did not support this hypothesis. This suggests the possibility that DFHCC is regulated by something other than the physical factor of having a suitable place for such conversations. We suggest that this concept is associated with psychological factors in the family members themselves because, in our previous qualitative study, most of them considered DFHCC useful when they wanted to briefly ask the patient's doctor a question or questions that were not appropriate for the patient to hear, such as how to act at the patient's deathbed and/or what to say to the patient in his or her deathbed.<sup>9</sup>

#### *Study limitations*

This study has several limitations. First, because we sought to investigate DFHCC without the patient over the entire course of home medical care period (including the terminal stage) and, therefore, only studied families of patients who had died, selection bias is a concern. Because the study involved patients in the terminal stage and, therefore, families with more anxiety and questions, the study results might have been influenced by such phenomena. Recall bias might also have occurred because the survey was carried out after the completion of all home medical care.

Second, there are other confounding factors that were not taken into consideration. For example, the patients' levels of consciousness were not comparable and the doctors' characters and communication skills were different in such a medical system as this group practice by multiple physicians. These factors most likely skewed the results.

It is also possible that the definition and understanding of DFHCC in the patients' absence differs from respondent to respondent, which remains an issue. Because we carried out a cross-sectional study, we cannot infer the direction of causality between DFHCC and its associated factors. We plan to conduct a future prospective survey focusing on this point.

Finally, although there was a relatively high response rate of 83.8%, all our data were obtained from a single

facility. For these types of investigations and data, a multi-center study would be desirable because these results may not be generalizable in other facilities.

## Conclusions

The items positively associated with the occurrence of DFHCC were a malignant tumor as the patient's primary disease and a family member or members having received medical advice by phone. When making home medical care visits, doctors should be aware that DFHCC during those visits can be valuable to the patients' families.

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