

# Factors Associated with Communication between Doctors and Patients' Families without Patient during Home Medical Care

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## ABSTRACT

### Background and Objective:

During home medical care, communications just between the doctor and the patient's family sometimes occur in the absence of the patient in some room of the patient's home (hereinafter referred to as "DFC without patient") but the characteristics and circumstances of DFC without patient in this context are unclear. The objective of this study is to investigate the background factors of the occurrence of DFC without patient.

### Methods:

In June and July 2011, we conducted a questionnaire survey targeting 295 families of patients who had previously received home medical care. Out of 271 families who consented to the survey, 227 (83.8%) responded to the questionnaire. Among the 227 respondents, we analyzed data from the 147 who experienced a patient death and consequent discontinuation of treatment. A logistic regression model was used to calculate adjusted odds ratios (ORs) and 95% confidence intervals (95% CIs) for the experience of communication between doctors and families (experienced=1 vs. not experienced=0).

### Results:

DFC without patient had taken place in 71.4% (n=105) of the families analyzed, and "existence of prescribed as-needed medications (OR: 3.571, 95% CI: 1.275-10.011)" was the background factor which was

significantly (p=0.015) related to the occurrence of such communication. In contrast, "the primary caregivers were spouses (OR: 0.369, 95% CI: 0.142 - 0.958)" was the background factor which was significantly (p=0.041) related to non-occurrence of DFC without patient.

### Conclusions:

The background factors that leads to the occurrence of DFC without patient during home medical care was revealed to be "existence of as-needed medications". In contrast, the background factor that results in non-occurrence of DFC without patient was revealed to be "the primary caregiver is the spouse of patient".

**Keywords:** home medical care, communication, family

## INTRODUCTION

Among all the industrialized countries, Japan has the fastest rate of population aging and the highest life expectancy at birth<sup>1)</sup>. In recent years, there have been extensive discussions in Japan on the value of home medical care<sup>2)</sup>. In this study communication is defined to be "any kinds of talks and dialogues exchanged in any room of the patient's home between the doctor and the patient and/or the patient's family". During home medical care, it is necessary for visiting physicians to satisfactorily communicate with the patient's family as well as the patient him-/herself<sup>3)</sup>. Usually, families who provide in-home care and assistance to patients have various concerns and questions<sup>3)</sup> and have been

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referred to as “second patients”<sup>4)</sup>. Good doctor-family communication is a key essential to ensuring successful in-home medical treatment<sup>3)</sup>.

Regarding good doctor-family communication at the outpatient clinic<sup>5)</sup> or in the patient room of the ward<sup>6)</sup>, it has been noted that “patients’ families sometimes find it difficult to tell the physician, or ask the physician, certain things, in the presence of the patient”<sup>5,6)</sup>. For this reason, communication between the doctor and the family members often occurs inevitably in the absence of the patient. In Japan, such communication typically occurs when lengthy explanations are given, for example, when discussing patients with a poor prognosis or a terminal condition<sup>6,7)</sup>.

Communication between the doctor and the family members in the absence of the patient occurs also during home medical care<sup>8,9)</sup>, but the background factors associated with the occurrence of such doctor-family communication in the absence of the patient in some room of the patient’s home during home medical care (hereinafter referred to as “DFC without patient”) are unclear both in Japan and in Europe and the United States.

Home medical care differs from outpatient- and inpatient care because, during home medical care, there is regular triadic communication among the doctor, patient and family<sup>10)</sup> and because in patient’s homes (unlike in medical institutions) there are no clearly defined places for doctors to explain the patient’s condition to the family<sup>8)</sup>. For these reasons, DFC without patient can not be the same as is done at the outpatient clinic or in an interview room of the ward.

At present, DFC without patient usually occurs by an initiative of individual doctors assessing the need (based on their clinical experience) or sometimes at the request of a patient’s family. Therefore, DFC without patient might not occur if the physician is not mindful of the need for communication or if family members are reserved and do not express their concerns and wishes.

A better understanding of the background factors of the occurrence of DFC without patient might provide physicians with useful clinical guidance for creating, maintaining and improving good DFC without patient. Thus, in this study we investigated the background factors of DFC without patient.

## METHODS

### Study participants and items surveyed

In June and July 2011, we conducted a survey on communication during home medical care. During May 2006 to April 2011, 323 patients received home medical care from the Department of General Medicine, National Hospital Organization of Higashisaitama Hospital. The number of visiting doctors participated in the home medical care during this period was 15. Out of the 323, 28 families of patients with 1 or more of the following characteristics were excluded: those who had received only 1 or 2 home visits (not including the deathbed visit), those who had no family members present during home medical care, and those who had died during the 50 days before receipt of the questionnaire (out of consideration to the bereaved family). The remaining 295 families were regarded as potential survey subjects. The family member who was designated the primary caregiver was asked to complete the questionnaire. When there was more than 1 caregiver, the questionnaire indicated that the caregivers could discuss the questions each other before answering them.

### Ethical considerations

The present study was carried out with the approval of the ethics committees of the Toho University, Faculty of Medicine, and the National Hospital Organization of Higashisaitama Hospital. The researchers first explained the content of the survey to the families involved, either in person or over the telephone, and informed them of the purpose of the study, the protection of their personal information, and the anonymity of the obtained data. The questionnaires were mailed only to families who had given their consent to these conditions, and a document explaining the survey was also included in the envelope. Completing the questionnaire and returning it by mail was interpreted as proof of consent to participation in the study. Finally, in cases where home medical care was still ongoing during the survey period, the content of the survey was also explained to the patient, from whom consent was obtained. If the patient has impaired consciousness or lacks recognitional capacity, the consent was obtained from the family on behalf of the patient.

### Variables assessed

The data source of this study was medical records and completed questionnaires consisting of 53 questions in which questions intended for another study’s purpose were also included. The information on basic patient characteristics was collected from the medical records,

while the information on patient background, family background and caregiving situation was extracted from the questionnaires as well as the information for the principal subject of this study.

#### 1) Basic patient characteristics

Eleven survey items were extracted for basic patient characteristics (Appendix).

#### 2) Patient background

Respondents were asked about: the level of care (as specified in the Long-term Care Insurance program<sup>1)</sup>) required for the patient at the start of home medical care (ie, requiring some assistance or less, care levels 1, 2, 3, 4 and 5); other services they had used that were related to the home-care environment, excepting home medical care, eg, visiting nurse service, visiting pharmacist service, in-home dental treatment, home help service, visiting rehabilitation, visiting bath service, day-care service, and nursing-home respite stay. The questionnaires also asked the family member(s) to assess the patient's condition at the start of home medical care according to 7 questions, using a 5-point scale for each of the 7 questions (Appendix).

#### 3) Family background and caregiving situation

Family members were asked about the number, age and sex of the primary caregiver(s), the relationship to the patient (spouse, child, parent, other), number of caregivers, whether they had ever experienced an at-home death in the family, whether they had ever experienced home-care, whether there was anyone with whom the family members could consult regarding their caregiving and whether they had ever experienced any difficulty in talking to a doctor in the presence of the patient .

In addition, they were asked to rank their questions and concerns at the start of home medical care according to 6 questions, using a 5-point scale for each of the 6 questions (Appendix).

#### 4) Survey items for the principal subject of this study

As for the principal subject of this study —DFC without patient—, respondents were asked whether they have ever had an experience of exchange just between the doctor and you or your family members in the absence of the patient during home medical care, and they were asked to answer either “Yes, I have” or “No, I haven't”.

The above questions and survey items were determined through discussions by the authors based on the findings from previous studies<sup>11-15)</sup> and qualitative results obtained from our previous surveys on communication methods during home medical care<sup>7)8)</sup>.

## Methods of analysis

### 1) Survey items investigated and objects of analysis

Before conducting analysis, the primary disease was classified as “malignant tumor” or “other than malignant tumor”, and, in patients with multiple lesions, malignant tumor was preferentially adopted for classification.

The answers to the 7 questions about the patient condition assessed by the family were classified as follows: if respondents answered “I don't think so at all”, “I don't really think so” or “I can't say” such cases were classified as “NO group”, and if the answer was either “I think so” or “I very much think so”, such cases were classified as “YES group”.

With regard to the relationship of the patient to the primary caregiver(s), the family member was classified as “spouse” or “non-spouse”.

In response to the 6 questions regarding the family situation, if the answer was “none at all” or “almost none”, such cases were classified as “NO group”. However, if the answer was “a few”, “quite a few” or “very much”, such cases were classified as “YES group”.

As for the principal subject of this study, the following 13 survey items were set up by formulating a predictor hypothesis on DFC without patient, based on discussions by the researchers referring to the results of our previous qualitative study on the communication method during home medical care<sup>7)8)</sup>: basic patient characteristics (age, sex, disease classification, level of care required), patient background (understanding of doctor's explanations, hearing loss, existence of as-needed medications, meaning medicines to be taken as needed eg, antipyretics), family background and caregiving situation (age and sex of the primary caregiver(s), relationship(s) between the patient and the primary caregiver(s), whether the family had experience with at-home care, whether the family had questions or concerns and experience of a telephone explanation from doctor). Then, to allow investigation of the entire course of treatment, we restricted our analysis to families (1) in which a patient had died and the home medical care had finished and (2) who had provided answers to all the above 13 survey items and the question “Have you ever had an experience of exchange just between the doctor and you or your family members in the absence of the patient during home medical care?”.

## Statistical analysis

First, to identify the background factors associated

with the occurrence of DFC without patient, we investigated the relation of each of the above 13 items to the occurrence of DFC without patient. The chi-square test was used to evaluate nominal variables, the Wilcoxon signed rank sum test was used for ordinal variables, and the t-test was used for continuous variables.

Next, a logistic regression model was constructed, using the dependent variable DFC without patient (experienced = 1 vs. not experienced = 0), and adjusted odds ratios (ORs) and 95% confidence intervals (95% CIs) were calculated.

The analysis was conducted by selecting “experience of DFC without patient” and “significantly-associated explanatory variables at the level of  $p < 0.1$  in univariate analysis” were selected, and the forced entry method was used. For analysis, the statistics package SPSS Version 19 for Windows was used, and the significance level of 5% was employed. When a multivariable model was constructed, fitting was also analyzed using Hosmer Lemeshow test.

## RESULTS

Of the potential 295 families, 17 did not give their consent and 7 could not be contacted. Thus, 271 questionnaires were sent out. A total of 227 were returned (response rate: 83.8%). Of these, 147 families met the inclusion criteria for analysis. Table 1 shows the characteristics of the patients, and Table 2 shows the characteristics of the analyzed families.

In response to the survey item which is the principal subject of this study “Have you ever had an experience of exchange just between the doctor and you or your family members in the absence of the patient during home medical care?”, 71.4% ( $n=105$ ) answered “Yes” and the remaining 28.6% ( $n=42$ ) answered “No”.

### Patient characteristics and Results of univariate analyses of DFC without patient

Table 3 shows the patient characteristics and the results of univariate analyses of DFC without patient. For patients in whom the primary disease was a malignant tumor, there was significantly more ( $p=0.010$ ) DFC without patient than for those whose primary disease was not malignant. In addition, there was significantly more ( $p=0.003$ ) DFC without patient for patients with existence of as-needed medications than for those not having such medicines. The level of care required (median) tended ( $p=0.085$ ) to be lower in the group that

experienced DFC without patient than the group that did not experienced it.

### Family characteristics and Results of univariate analyses of DFC without patient

Table 4 shows the family characteristics and the results of univariate analyses of DFC without patient. Among family members reporting that they experienced DFC without patient, the age of the primary caregiver(s) was significantly ( $p=0.032$ ) younger than those who had not. When the primary caregiver was a spouse, the rate of DFC without patient was 63.9%, versus 76.7% for non-spouses ( $p=0.099$ ).

Finally, there was no statistically significant association of DFC without patient with patient age or sex, the extent to which family members understood the doctor’s explanations, presence of hearing loss, sex of primary caregiver(s), experience with previous home care, presence of questions or concerns regarding the patient’s medical condition, or experience of telephone explanations.

### Adjusted odds ratios of factors for DFC without patient in the multivariable model

Table 5 shows adjusted odds ratios of factors for DFC without patient in the multivariable model. Based on the results of univariate analyses, a multivariable model was constructed, which consists of variables such as “Existence of as-needed medications”, “Existence of malignant tumor as primary disease”, “Level of care required (median)”, “Primary caregiver is spouse” and “Age of primary caregiver(s)”. As the fitting was not rejected in Hosmer Lemeshow test, this model was employed and enforced entry was implemented ( $p=0.365$ ).

DFC without patient was significantly associated with existence of as-needed medications (OR: 3.571, 95%CI: 1.275 -10.011,  $P=0.015$ ). The factor that the primary disease is malignant (OR: 2.155, 95% CI: 0.877-5.294) showed a tendency ( $p=0.094$ ) of association with DFC without patient (Table 5). In contrast, the factor that the primary caregivers were spouses had significantly less likelihood of DFC without patient (OR: 0.369, 95% CI: 0.142 - 0.958,  $p=0.041$ ).

## DISCUSSION

The results of the present study reveal important background factors regarding DFC without patient.

### Items positively associated with DFC without patient

First, with regard to the positive association between existence of as-needed medications and DFC without patient, it is possible that explanations by physician regarding administration of such as-needed medications which are frequently used in relation to home medical care would be given in the form of DFC without patient. It will be also necessary to clarify the association between use of opioids and DFC without patient, although the present study did not investigate it.

Next, the finding that patient's malignant tumor as primary disease tended to associate with DFC without patient could possibly be related to the social atmosphere in Japan that the patient's family frequently asks the doctor not to tell the patient about the cancer he/she has. A survey on healthy adults done in Japan revealed that the percentage of those who wish notice of cancer and explanation of prognosis was lower in case one assumes that his/her family member has a cancer than in case one assumes that he/she has a cancer<sup>16)</sup>. Further study is necessary also about what contents the patient's family desires as DFC without patient.

### Items inversely associated with DFC without patient

There was a significant inverse association with DFC without patient when the primary caregiver(s) was the spouse of a patient. A study of the desire to be informed of a cancer diagnosis among healthy Japanese adults (>70% of whom were married) found that one reason given for wanting to be informed was that participants "didn't want it to be kept secret from family members"<sup>17)</sup>, which suggests that healthy adults do not desire DFC without patient. In addition, also in a US study on patients with a digestive system cancer and their spouses, it was suggested that keeping a secret leads to emotional distress<sup>18)</sup>. More research is needed also on the form and content of explanations given during home medical care and family's preference for DFC without patient.

Although not investigated in the present study, there is a possibility that the family members other than the patient's spouse such as child(ren), parent(s), brother(s) and sister(s) have different desires from each other about DFC without patient, and this point should also be further studied.

### Study limitations

First, we did not investigate patients' desires regarding DFC without patient. Second, because we sought to investigate DFC without patient over the duration of treatment (including the terminal stage) and thus only studied families of patients who had died, selection bias is a concern. Third, there is a possibility of recall bias due to the fact that the survey was done after completion of all home medical care. A prospective survey focusing on this point is expected in future. Fourth, there is a possibility that the definition and understanding of DFC without patient differ from respondent to respondent and this issue remains still to be solved. Fifth, because of the cross-sectional study, we cannot infer the direction of causality between DFC without patient and its associated factors. Sixth, there might be other factors associated with DFC without patient that were not investigated in this study. Finally, although there was a relatively high response rate of 83.8%, all our data were obtained from only a single facility despite a multi-center study is desirable, which indicates that the present results might not be generalizable to other such facilities.

### Conclusion

The items positively associated with the occurrence of DFC without patient were existence of as-needed medications. In contrast, DFC without patient was significantly less frequent in case the primary caregiver is the spouse of patient.

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## REFERENCES

- 1) Ozawa MN, Nakayama S: Long-term care insurance in Japan. *JASP*17:61-84, 2005
- 2) Tsuji T: Community design in aging society. *Igaku No Ayumi*239: 590-596, 2011(Japanese)
- 3) Wada T: Communication skills with patients and family members. *Nippon Ishikai Zasshi*139:58-61, 2010 (Japanese)
- 4) Lederberg BD: The family of the patient with cancer. Holland JC. In Rowland JH(ed): *Handbook of Psycho-oncology* Oxford University Press, p.585-597, 1989
- 5) Maguire, P: Communication skills for the Doctors. Arnold, 2000(Wakabayashi Y. Ishi no tame no communication gijyutu, Seiwa shoten, 2009)
- 6) Tanaka T. Interviewing the Elderly, Outpatient, Inpatient and Home Care Settings. In the Japanese Geriatrics Society(ed): *textbook of geriatric medicine*, 3rd Edition, Medical View, p.44 – 47, 2008(Japanese)
- 7) Colclough, Y.Y.; Young, H.M. Decision making at end of life among Japanese American families. *Journal of family nursing*13, 201-225, 2007
- 8) Kimura, T.; Imanaga, T.; Aoki M.; et al. Case report of home-care patient, difficulty in finding a place for communication between doctors and patients' families. Annual meeting program of Japanese Primary Care Society 32,91, 2009(Japanese)
- 9) Kawai, M.; Kimura, T.; Imanaga, T.; et al. Qualitative research of Communication during home care with families of patients with terminal nerve disease. – Research on improvement of Quality of Life (QOL) in patients with specified diseases (Tokuteisikkan) – Nanjiseisikkan kokufuku kenkyu jigyou by the Ministry of Health, Labour and Welfare in Japan), General Overview and Research Report 2010, 87-92, 2011 (Japanese)
- 10) Kawagoe, S.; Takaya, Y. A day of group visiting team. *Nippon Ishikai Zasshi* 139:10-12, 2010(Japanese)
- 11) Brown, J.B.; Brett, P.; Stewart, M. et al. Roles and influence of people who accompany patients on visits to the doctor. *Can Fam Physician*44:1644-1650, 1998
- 12) Schilling, L.M.; Scatena, L.; Steiner, J. et al. The third person in the room, frequency, role, and influence of companions during primary care medical encounters. *J Fam Pract*51:685-690, 2002
- 13) Wolff, J.L.; Roter, D.L. Hidden in plain sight, medical visit companions as a resource for vulnerable older adults. *Arch Intern Med*168:1409-1415, 2008
- 14) Ishikawa, H.; Roter, D.L.; Yamazaki, Y. et al. Physician-elderly patient-companion communication and roles of companions in Japanese geriatric encounters. *Soc Sci Med*60:2307-2320, 2005
- 15) Ishikawa, H.; Roter, D.L.; Yamazaki, Y. et al. Patients' perceptions of visit companions' helpfulness during Japanese geriatric medical visits. *Patient Educ Couns*61:80-86, 2006
- 16) Akamine, Y.; Akamine K. A Survey on Awareness of the Terminal Stage of Cancer Notification in Outpatients at a clinic. *Jpn J Prim Care*25:19-28, 2002(Japanese)
- 17) Kamezaki, A.; Muramoto, C.; Maeda, Y.; et al. Factors Affecting People's Attitudes Concerning Being told of a Diagnosis of Cancer, A Survey of Healthy Adults. *Bulletin of Kumamoto University, School of Health Sciences*4:35-51, 2008(Japanese)
- 18) Porter LS, Keefe FJ, Hurwitz H. Disclosure between patients with gastrointestinal cancer and their spouses. *Psychooncology*14:1030-42, 2005



**Table 1. Patient characteristics (n=147)**

|  |                     |
|--|---------------------|
| Age, yrs (mean $\pm$ SD)   | 77 $\pm$ 13.5       |
| Sex  |                     |
| Male, n(%)   | 76(51.7)            |
| Female, n(%)   | 71(48.3)            |
| Disease classification   |                     |
| Malignant, n(%)  | 67(45.6)            |
| Non-malignant, n(%)  | 80(54.4)            |
| Existence of as-needed medications                                 |                     |
| Yes, n(%)  | 121(82.3)           |
| No, n(%)   | 26(17.7)            |
| Independency in daily activity (median[1st Quartile,3rd Quartile]) | B2 [ A2,C2 ]        |
| Cognitive function (median[1st Quartile,3rd Quartile])             | I [Independent,IV ] |
| Primary disease duration (months) (mean $\pm$ SD)                  | 48 $\pm$ 62.8       |
| Duration of home medical care (days) (mean $\pm$ SD)               | 210 $\pm$ 317.2     |
| Total number of doctor visits (times) (mean $\pm$ SD)              | 22 $\pm$ 25.5       |
| Interval of doctor visits (days) (mean $\pm$ SD)                   | 8 $\pm$ 7.1         |
| Level of care required (median[1st Quartile,3rd Quartile])         | 3 [ 2,5 ]           |
| Use of visiting nurse service                                      |                     |
| Yes, n(%)  | 98(70.5)            |
| No, n(%)   | 41(29.5)            |
| Understanding of doctor's explanations                             |                     |
| YES group, n(%)  | 107(72.8)           |
| NO group, n(%)   | 40(27.2)            |
| Understanding of family's talk                                     |                     |
| YES group, n(%)  | 119(81.5)           |
| NO group, n(%)   | 27(18.5)            |
| Hearing loss   |                     |
| YES group, n(%)  | 21(14.5)            |
| NO group, n(%)   | 124(85.5)           |
| Expression of wishes to doctor                                     |                     |
| YES group, n(%)  | 33(22.6)            |
| NO group, n(%)   | 113(77.4)           |
| Understanding of disease name                                      |                     |
| YES group, n(%)  | 92(63.9)            |
| NO group, n(%)   | 52(36.1)            |
| Understanding of prognosis   |                     |
| YES group, n(%)  | 61(42.1)            |
| NO group, n(%)   | 84(58.0)            |
| Wishes to know all about disease                                   |                     |
| YES group, n(%)  | 57(39.9)            |
| NO group, n(%)   | 86(60.1)            |

In case missing values exist in each item, the total number is less than the number of respondents "n=147".

**Table 2. Characteristics of analyzed families (n=147)**

|   |               |
|---|---------------|
| Age of primary caregiver(s) (mean $\pm$ SD)                         | 63 $\pm$ 11.0 |
| Sex of primary caregiver(s)   |               |
| Male, n(%)  | 41(27.9)      |
| Female, n(%)  | 106(72.1)     |
| Number of caregivers (mean $\pm$ SD)                                | 2 $\pm$ 1.1   |
| Primary caregiver(s)'s relationship to patient                      |               |
| Spouse, n(%)  | 61(41.5)      |
| Non-spouse, n(%)  | 86(58.5)      |
| Primary caregiver(s) has experience with home care                  |               |
| Yes, n(%)   | 49(33.3)      |
| No, n(%)  | 98(66.7)      |
| Experienced of at-home death in the family                          |               |
| Yes, n(%)   | 45(30.6)      |
| No, n(%)  | 102(69.4)     |
| Existence of caregiving advisors                                    |               |
| Yes, n(%)   | 111(76.5)     |
| No, n(%)  | 34(23.5)      |
| Experienced difficulty in telling in presence of patient            |               |
| Yes, n(%)   | 57(58.1)      |
| No, n(%)  | 79(41.9)      |
| Primary caregiver's experience of telephone explanation from doctor |               |
| Yes, n(%)   | 78(54.2)      |
| No, n(%)  | 66(45.8)      |
| Primary caregiver(s) has questions or concerns                      |               |
| YES group, n(%)   | 66(44.9)      |
| NO group, n(%)  | 81(55.1)      |
| Existence of questions/concerns on patient's prognosis              |               |
| YES group, n(%)   | 80(54.4)      |
| NO group, n(%)  | 67(45.6)      |
| Concerns on what to do in case of patient's sudden worsening        |               |
| YES group, n(%)   | 77(52.4)      |
| NO group, n(%)  | 70(47.6)      |
| Concerns on patient's medicine                                      |               |
| YES group, n(%)   | 22(85.0)      |
| NO group, n(%)  | 125(15.0)     |
| Wishes to tell patient everything including unpleasant information  |               |
| YES group, n(%)   | 34(23.4)      |
| NO group, n(%)  | 111(76.6)     |
| Consultation opportunity with care manager                          |               |
| YES group, n(%)   | 126(86.3)     |
| NO group, n(%)  | 20(13.7)      |

Footnote: Non-spouses consist of 44 children, 12 parents, 12 brothers/sisters and 22 others.

In case missing values exist in each item, the total number is less than the number of respondents "n=147".



Table 3. Results of univariate analyses of patient characteristics (n=147)

|  | No experience of<br>Doctor Family<br>Communication<br>without patien †<br>(n=42) | Experience of<br>Doctor Family<br>Communication<br>without patien †<br>(n=105) | p value   |
|--|--|--|-----------|
| Age, yrs (mean ± SD)                   | 77 ± 15  | 77 ± 13  | 0.966 †   |
| Sex                                    |  |  | 0.274 ††  |
| Male, n(%)                             | 25(32.9)   | 51(67.1)   |           |
| Female, n(%)                           | 17(23.9)   | 54(76.1)   |           |
| Disease classification                 |  |  | 0.010 ††  |
| Malignant, n(%)                        | 12(17.9)   | 55(82.1)   |           |
| Non-malignant, n(%)                    | 30(37.5)   | 50(62.5)   |           |
| Level of care required (median)        | 4  | 3  | 0.085 ††† |
| Understanding of doctor's explanations |  |  | 0.543 ††  |
| YES group, n(%)                        | 29(27.1)   | 78(72.9)   |           |
| NO group, n(%)                         | 13(32.5)   | 27(67.5)   |           |
| Hearing loss                           |  |  | 0.608 ††  |
| YES group, n(%)                        | 7(33.3)  | 14(66.7)   |           |
| NO group, n(%)                         | 35(27.8)   | 91(72.2)   |           |
| Existence of as-needed medications     |  |  | 0.003 ††  |
| Yes, n(%)                              | 28(23.1)   | 93(76.9)   |           |
| No, n(%)                               | 14(53.8)   | 12(46.2)   |           |

† t-test

†† chi-square test

††† Wilcoxon signed rank sum test

**Table 4. Results of univariate analyses of family characteristics (n=147)**

|   | No Experience of<br>Doctor Family<br>Communication<br>without patient †<br>(n=42) | Experience of<br>Doctor Family<br>Communication<br>without patient †<br>(n=105) | p value  |
|---|---|---|----------|
| Age of primary caregiver(s) (mean ± SD)                         | 66 ± 8  | 61 ± 12   | 0.032 †  |
| Sex of primary caregiver(s)                                     |   |   | 0.685 †† |
| Male, n(%)  | 13(31.7)  | 28(68.3)  |          |
| Female, n(%)  | 29(27.4)  | 77(72.6)  |          |
| Primary caregiver(s)'s relationship to patient                  |   |   | 0.099 †† |
| Spouse, n(%)  | 22(36.1)  | 39(63.9)  |          |
| Non-spouse, n(%)  | 20(23.3)  | 66(76.7)  |          |
| Primary caregiver(s) has experience with home care              |   |   | 0.252 †† |
| YES group, n(%)   | 17(34.7)  | 32(65.3)  |          |
| NO group, n(%)  | 25(25.5)  | 73(74.5)  |          |
| Primary caregiver(s) has questions or concerns                  |   |   | 0.833 †† |
| Yes, n(%)   | 31(27.9)  | 80(72.1)  |          |
| No, n(%)  | 11(30.6)  | 25(69.4)  |          |
| Primary caregiver(s) received telephone explanation from doctor |   |   | 0.363 †† |
| Yes, n(%)   | 25(32.1)  | 53(67.9)  |          |
| No, n(%)  | 17(24.6)  | 52(75.4)  |          |

† t-test

†† chi-square test

**Table 5. Adjusted odds ratios (ORs) of Doctor Family Communication without patient (n=147)**

|   | OR    | 95% CI         | p value |
|---|-------|----------------|---------|
| Existence of prescribed as-needed medications | 3.571 | 1.275 - 10.011 | 0.015   |
| Malignant tumor as primary disease            | 2.155 | 0.877 - 5.294  | 0.094   |
| Level of care required (median)               | 0.894 | 0.705 - 1.128  | 0.342   |
| Primary caregiver is spouse                   | 0.369 | 0.142 - 0.958  | 0.041   |
| Age of primary caregiver(s)                   | 0.987 | 0.944 - 1.032  | 0.563   |

An OR ≥ 1 indicates more doctor-family communication.

An OR <1 indicates less doctor-family communication.

## Appendix

### 1. Basic patient characteristics

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- 1) Patient age at start of home care
  - 2) Patient sex
  - 3) Primary disease of patient
  - 4) Existence or absence of as-needed medications<sup>a</sup>
  - 5) Level of independence in activities of daily living (9 levels)<sup>b</sup>
  - 6) Cognitive function (8 levels)
  - 7) Duration of primary disease (months)
  - 8) Total number of doctor visits (times)
  - 9) Duration of home medical care (days)
  - 10) Interval of doctor visits (days)<sup>c</sup>
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<sup>a</sup>As-needed medications mean medicines to be taken as needed e.g. antipyretics, which are prescribed by the physician in advance for some anticipated symptom(s), kept in the patient's home and given to the patient by the family in accordance with physician's pre-instruction when the symptom(s) appeared.

<sup>b</sup>Please assess the patient's condition at start of home medical care, in 9 levels, in accordance with the guidance contained in the Long-term Care Insurance program, Attending Physician's Report or Visiting Nurse Service Directions.

<sup>c</sup>The interval of doctor visits (days) was calculated using a math formula "Total number of doctor visits (times)/Duration of home medical care (days).

### 2. Family's assessment of patient comprehension and condition at start of home medical care

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- 1) Do you think the patient understood what the doctor says?
  - 2) Do you think the patient understood what you (the family) say?
  - 3) Do you think the patient had hearing loss that hinders communication?
  - 4) Do you think it was possible for the patient to express his/her wishes to the doctor?
  - 5) Do you think the patient understood the name of his/her disease?
  - 6) Do you think the patient understood the probable future course of his/her disease?
  - 7) Do you think the patient wanted to know everything about his/her disease, including unpleasant information?
- 

Five response levels: I don't think so at all, I don't really think so, I can't say which, I think so, I think so very much

### 3. Family's situation at start of home medical care

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- 1) Family's questions and concerns regarding the patient's condition
  - 2) Family's questions and concerns regarding the patient's prognosis
  - 3) Family's concerns regarding their response to a sudden worsening of the patient's condition
  - 4) Family's questions and concerns regarding the patient's medicine
  - 5) Did you plan to tell the patient everything, including unpleasant information?
  - 6) How many times they had consulted with a care manager
- 

Five response levels: none at all, almost none, a few, quite a few, very many

Translated by Takuma Kimura, Katufumi Sawamura and David Kipler.

在宅医療において、患者を除いた家族と医師のみのコミュニケーションが実施される背景因子に関する検討

抄録

**背景と目的：**

在宅医療の際、患者を含まない医師と家族のみのコミュニケーションを、患者宅の部屋で行うこと(以下、「患者を除いたDFC」と略す)がしばしばあるが、その特徴や状況は明らかではない。本研究の目的は、在宅医療で「患者を除いたDFC」が実施される背景を検討することである。

**方法：**

2011年6月、および7月、在宅医療の実施歴がある患者の家族295名を対象に質問紙票で調査を行った。調査の承諾が得られた家族271名のうち、227名から回答を得た(83.8%)。227名分のうち、患者が永眠し診療が終了している147名分を解析した。「患者を除いたDFC」実施のオッズ比(OR)と95%信頼区間(95%CI)をロジスティック回帰モデル(実施=1 vs. 非実施=0)で算出した。

**結果：**

「患者を除いたDFC」は71.4%(n=105)で実施され、頓服薬があること(OR3.571, 95%CI: 1.275-10.011)は、実施されることと有意に関連がある背景因子であった(p=0.015)。一方、主介護者が配偶者であること(OR: 0.369, 95% CI: 0.142 - 0.958)は、「患者を除いたDFC」が実施されないことと有意に関連がある背景因子であった(p=0.041)。

**結論：**

訪問診療で「患者を除いたDFC」が実施される背景として、「頓服薬があること」が明らかになった。一方、実施されない背景として、「主介護者が配偶者であること」が明らかになった。

**Key words：**在宅医療, コミュニケーション, 家族

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