Doctor-Patient Communication without Family Is Most Frequently Practiced in Patients with Malignant Tumors in Home Medical Care Settings

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Promotion of home medical care is absolutely necessary in Japan where is a rapidly aging society. In home medical care settings, triadic communications among the doctor, patient and the family are common. And "communications just between the doctor and the patient without the family" (doctor-patient communication without family, "DPC without family") is considered important for the patient to frankly communicate with the doctor without consideration for the family. However, the circumstances associated with DPC without family are unclear. Therefore, to identify the factors of the occurrence of DPC without family, we conducted a cross-sectional mail-in survey targeting 271 families of Japanese patients who had previously received home medical care. Among 227 respondents (83.8%), we eventually analyzed data from 143, excluding families of patients with severe hearing or cognitive impairment and severe verbal communication dysfunction. DPC without family occurred in 26.6% (n = 38) of the families analyzed. A multivariable logistic regression analysis was performed using a model including Primary disease, Daily activity, Duration of home medical care, Interval between doctor visits, Duration of doctor's stay, Existence of another room, and Spouse as primary caregiver. As a result, DPC without family was significantly associated with malignant tumor as primary disease (OR, 3.165; 95% CI, 1.180-8.486; P = 0.022). In conclusion, the visiting doctors should bear in mind that the background factor of the occurrence of DPC without family is patient's malignant tumors.

Introduction

Among all industrialized countries, Japan has the fastest rate of population aging and the highest life expectancy at birth (Ozawa and Nakayama 2005). Recently in Japan, there have been extensive discussions about the significance of home medical care, especially in the elderly (Ozawa and Nakayama 2005; Sasaki et al. 2008). At present, it is still a Japan-specific matter but the situation in Japan may easily become a reality in Europe and the United States in the near future.

During home medical care, visiting doctors are requested to engage in sufficient communication with the patient (Fukui et al. 2011). In home medical care settings, the family is usually present during the doctor's examination of the patient (Kimura et al. 2013b). This differs from outpatient settings, in which the elderly patient is accompanied by the family only when needed (Schilling et al. 2002; Ishikawa et al. 2005, 2006; Tanaka 2008; Wolff and Roter 2008). It also differs from inpatient bedside settings, in which the family is not present in principle (Tanaka 2008). In other words, the communication in home medical care settings is characterized by the fact that triadic communication among the patient, family, and doctor is common and routine (Kimura et al. 2013b).

In outpatient settings and inpatient bedside settings, patients occasionally experience difficulty in discussion with the doctor if the family is present. Thus, communication between only the doctor and patient without the family present (doctor-patient communication, hereinafter referred to as "DPC without family") is sometimes necessary (Maguire 2000; Tanaka 2008). Although DPC without family is necessary and sometimes practiced in home medical care settings, on which occasions DPC without family is carried out remains unclear not only in Japan, but also in Europe and the United States (Kimura et al. 2013a, b).

The present status of DPC without family during home medical care is characterized by the fact that in some cases, a doctor individually suggests to the patient or family that DPC without family is recommended based on his or her own clinical experience or, in some cases, a doctor practices DPC without family upon the request of the patient and/or family. Therefore, DPC without family is not performed when the doctor does not consider doing so or the when patient does not propose it out of consideration for the doctor or family. If the background behind the occurrence of DPC without family during home medical care is clarified, doctors will be encouraged to engage in DPC without family based on solid evidence, leading to much better doctor-patient communication. Thus, we conducted this study to investigate the background factors behind the occurrence of DPC without family during home medical care.

Methods

Sampling and enrollment criteria

A cross-sectional mail-in survey was conducted on the topic of communication during home medical care in June and July 2011. Among 323 families of patients for whom home medical care was carried out by physicians of Higashisaitama Hospital from May 2006 to April 2011, a total of 295 families that met the following three criteria were selected as potential participants: (1) those of patients who had received home medical care more than three times, excluding the deathbed visit; (2) those of patients who had been present at least once during home medical care; and (3) those of patients for whom more than 50 days had elapsed after death (out of respect for the bereaved family).

Ethical considerations

The present study was carried out with the approval of the ethics committee of Higashisaitama Hospital. The researchers explained to the potential families the purpose and contents of the study, the protection of their personal information, and the anonymity of the obtained data. 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 interpreted as proof of consent to participate in the study. 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 then obtained.

Questionnaires and other data source

The data sources of this study were medical records and completed questionnaires comprising 53 questions among which questions intended for the purpose of another study were also included (Kimura et al. 2013b). Information on basic patient characteristics was collected from the medical records, while information on patient background, family background, the caregiving situation, and DPC without family was extracted from the questionnaires. Inclusion of the above questions and survey items was determined based on the hypotheses formulated through discussions among the authors about the results of our previous qualitative studies in patients' families on the topic of communication methods in home medical care settings and other researchers' precursor studies (Schilling et al. 2002; Ishikawa et al. 2005, 2006; Wolff and Roter 2008; Kimura et al. 2009,

2013a). The questionnaire was pretested by three families in the presence of us by filing it in, to check whether or not some incomprehensible questions are included in it. Thus, it was confirmed in advance as much as possible that the patients' families well understand the researcher's questions and our intended assessment is feasible with the questionnaire.

Basic patient characteristics: For this study, the following data were obtained: patient age at the start of home medical care, sex, primary disease, life status (alive, dead, or unknown), duration of primary disease (in months), duration of home medical care (in days), and interval between doctor visits (in days).

In addition, the level of independence in activities in daily living (ADL) (eight levels) and the level of cognitive function (nine levels) assessed at the start of home medical care were described in accordance with the guidelines of Japan's long-term care insurance program, the attending physician's report, or the visiting nurse's directions (Ozawa and Nakayama 2005; Sasaki et al. 2008).

The verbal communication function was assessed based on the medical records by two researchers who had observed the patients during home medical care and was assigned to one of five levels (Normal, Slightly impaired, Comprehensible if repeatedly tried, Use of a communication tool, and Impossible). The judgment "Impossible" was applied only when the patient met all three components of "Inarticulate" on the Amyotrophic Lateral Sclerosis Function Rating Scale-Revised (ALSFRS-R), "Dialogue is almost incomprehensible" on the United Multiple System Atrophy Rating Scale (UMSARS), and "Unable to write" in the writing assessment (Cedarbaum and Stambler 1997; Wenning et al. 2004).

Patient background: For this study, we obtained information on the level of care required for the patient at the start of home medical care in accordance with the guidelines of Japan's long-term care insurance program (i.e., requiring some assistance or less; care levels 1, 2, 3, 4, and 5). The questionnaires asked the family member (s) whether they thought that the patient had a hearing impairment that hindered communication at the start of home medical care. One of five answers was given: "I don't think so at all," "I don't really think so," "I can't say which," "I think so," or "I think so very much." The questionnaire also asked about the duration of the doctor's stay (in minutes). In addition, to check whether the patient's privacy had been maintained in the patient's room at the start of home medical care, the questionnaire asked about the existence of another room in which the family stayed during DPC without family. One of three answers was given: "No other room existed," "Another room existed, but the family could listen to the doctor-patient dialogue," or "Another room existed, and the family could not hear the doctor-patient dialogue."

Family background and caregiving situation: For this study, the following information was obtained: age and sex of the primary caregiver (s), familial relationship to the patient (spouse, child, parent, brother, sister, other), number of caregivers, existence of caregiving advisors with whom the family could consult, and experience of the family member (s) with home care.

Survey items for the principal subject of this study: With respect to the principal subject of this study, namely DPC without family, respondents were asked, "Have you ever engaged in a dialogue only between the doctor and the patient in the absence of the family during home medical care?" The respondents were then asked to answer either "Yes, I have," or "No, I haven't."

Total number of potential families who met the criteria (*n* = 295)

→ Those who did not give consent (*n* = 17)
Those whose contact address was unknown (*n* = 7)

The number of families to whom the questionnaire was mailed (*n* = 271)

→ Non-respondents (*n* = 44)

Respondents (*n* = 227)

→ Non-respondents to specific questions on DPC without family (*n* = 22)

Experiencers of DPC without patient (*n* = 205)

→ Families of patients with severe hearing impairment (*n* = 28)

Families of patients with severe cognitive dysfunction (*n* = 3)

Families of patients with severe verbal communication dysfunction (*n* = 31)
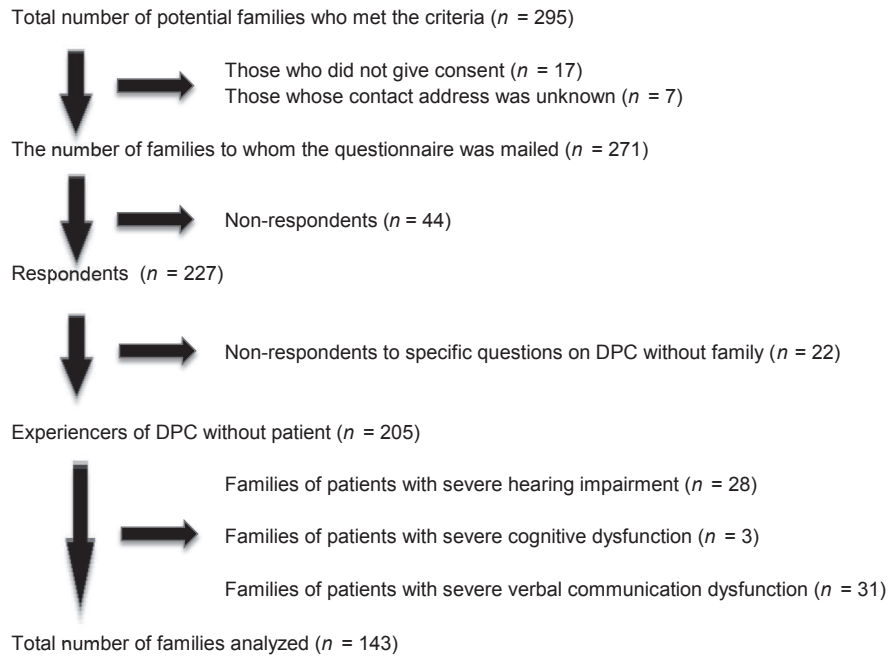
Total number of families analyzed (*n* = 143)

Fig. 1. Population-flow diagram of subjects.
Of the 227 respondents, excluded were 22 who skipped the answers about DPC without family, 28 families of patients with hearing impairment, 3 with cognitive impairment, and 31 with verbal communication dysfunction. Analyses were conducted on the remaining 143 families.

Data analysis

Analysis: Of the potential 295 families who met the criteria, 17 did not give their consent and 7 could not be contacted. Thus, 271 questionnaires were sent out. A total of 227 (83.8%) were returned.

Of these 227, the analysis was first restricted to 205 families who had responded to the specific questions for the principal subject of this study, DPC without family, after exclusion of 22 non-respondents to such specific questions. Next, to exclude patients with severe hearing impairment, 28 families who answered "I think so" or "I think so very much" to the question about the patient's hearing impairment were excluded. In addition, to exclude patients with severe cognitive impairment, three families of patients assessed as having the worst of the eight cognitive function levels in Japan's long-term care insurance program were excluded. Finally, to exclude patients with severe verbal communication dysfunction, 31 families of patients assessed as "Impossible to verbally communicate" were excluded. As a result, the remaining 143 families were analyzed. Fig. 1 shows a population flow diagram of this study.

Model for DPC without family in this study: We constructed a multivariable logistic regression analysis model for DPC without family through discussion among the authors with reference to previous studies. The model included the following considerations:

(1) We formulated a hypothesis that a malignant tumor as the primary disease is associated with the occurrence of DPC without family (Morishima 2009). Before conducting the analysis, the primary disease was classified as either malignant tumor or disease other than malignant tumor. In patients with multiple lesions, malignant tumor was preferentially adopted for classification.

(2) When the ADL level is low, patients must frequently be chaperoned by the family. Therefore, we formulated a hypothesis for inclusion in the model stating that the lower the ADL level, the less frequent the occurrence of DPC without family (Schilling et al. 2002;

Ishikawa et al. 2005, 2006; Wolff and Roter 2008).

(3) Considering the fact that the doctor-patient relationship is associated with the occurrence of DPC without family, we formulated a hypothesis for inclusion in the model stating that DPC without family occurs more frequently when the duration of the home medical care is longer, the doctor's visits are more frequent, and the doctor's duration of stay is longer (Maguire 2000; Tanaka 2008; Kimura et al. 2013a).

(4) We considered that the model should include the factor on whether patient's privacy had been maintained during DPC without family in terms of the layout of the house (Kimura et al. 2009). For this factor, if the answer to the question regarding the existence of another room was "Another room existed, and the family could not hear the doctor-patient dialogue," such cases were assigned to the "YES group." However, if the answer was "No other room existed" or "Another room existed, but the family could listen to the doctor-patient dialogue," such cases were assigned to the "NO group." Incidentally, even if there is no other room, DPC without family is theoretically possible when family members withdraw from the patient's bed room. However, if the family members stop outside the door and listen to the doctor-patient dialogue, patient's privacy is not maintained and the significance of DPC without family is spoiled. Therefore, the present study focused only on the existence of another room to investigate the association with the occurrence of DPC without family.

(5) Previous studies have suggested that when the caregiver is a spouse, the patient and the spouse are prone to not keep secrets from each other (Porter et al. 2005; Kamezaki et al. 2008). Therefore, the model included the factor on whether the caregiver is a spouse. For this factor, the primary caregiver was classified as being either a "spouse" or "non-spouse."

Table 1 shows the characteristics of the patients, and Table 2

Table 1. Patient characteristics (*n* = 143).

Age, yrs (mean ± S.D.)	75 ± 14.1
Sex	
Male, *n* (%)	74 (51.7)
Female, *n* (%)	69 (48.3)
Disease classification	
Malignant, *n* (%)	59 (41.3)
Non-malignant, *n* (%)	84 (58.7)
Alive or dead	
Alive, *n* (%)	38 (28.6)
Dead, *n* (%)	95 (71.4)
Level of care required (median [1st Quartile, 3rd Quartile])	4 [3, 5]
Independency in daily activity (median [1st Quartile, 3rd Quartile])	B1 [A1, C1]
Primary disease duration (months) (mean ± S.D.)	53 ± 75.4
Duration of home medical care (days) (mean ± S.D.)	287 ± 377.7
Interval between doctor visits (days) (mean ± S.D.)	11 ± 10.0
Doctor's staying time duration (minutes) (mean ± S.D.)	34 ± 19.4
Existence of another room by which patient's privacy is maintained	
Yes, *n* (%)	113 (79.0)
No, *n* (%)	30 (20.1)

The alive or dead of 10 patients is unknown due to referral to another institution, thus, the total number of cases is less than 143.

Table 2. Characteristics of analyzed families (*n* = 143).

Age of primary caregiver(s) (mean ±S.D.)	63 ± 10.3
Sex of primary caregiver	
Male, *n* (%)	38 (26.6)
Female, *n* (%)	105 (73.4)
Primary caregiver's relationship to patient	
Spouse, *n* (%)	69 (48.3)
Non-spouse, *n* (%)	74 (51.7)
Number of caregivers (mean ± S.D.)	2 ± 1.2
Existence of caregiving advisors	
Yes, *n* (%)	105 (73.4)
No, *n* (%)	38 (26.6)
Primary caregiver(s) has experience with home care	
YES group, *n* (%)	46 (32.2)
NO group, *n* (%)	97 (67.8)

shows the characteristics of the analyzed families.

Statistical analysis: Factors associated with DPC without family 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. The factors included were "Malignant tumor as the primary disease," "Independence in daily activity," "Duration of home medical care," "Interval between doctor visits" "Doctor's duration of stay," "Existence of another room in which the patient's privacy was maintained," and "Spouse as primary caregiver."

The statistical package SPSS, version 19 for Windows (SPSS, Chicago, IL, USA) was used for statistical analysis. All *P* values were two-sided, and those of < 0.05 were considered statistically significant. When the logistic regression model was constructed, fit was also analyzed using the Hosmer-Lemeshow test.

Results

In response to the survey item regarding the principal subject of this study, DPC without family, 26.6% (*n* = 38) of the families answered, "Yes," and the remaining 73.4% (*n* = 105) answered, "No."

ORs of factors for DPC without family in the multivariable logistic regression analysis

Table 3 shows the ORs and 95% CIs of factors for DPC without family in the multivariable model. DPC without family was significantly associated with "Malignant tumor as the primary disease" (OR, 3.165; 95% CI, 1.180-8.486; *P* = 0.022). "Independence in daily activity" tended to be associated with DPC without family (OR, 1.150; 95% CI, 0.998-1.326; *P* = 0.053). No association with DPC without family was observed for "Duration of home medical care", "Interval between doctor visits", "Doctor's duration of stay", "Existence of another room in which patient's privacy was maintained" and "Spouse as primary caregiver."

Because the fit was not rejected in the Hosmer-Lemeshow test (*P* = 0.800), the present model was employed. Our model used for a study on a home death was not considered to not fit the present study.

Discussion

The results of the present study revealed important background factors regarding DPC without family. First, the factor "Malignant tumor as the primary disease" was

Table 3. Factors associated with patient-doctor communication without family in the multivariate logistic regression analysis (*n* = 143).

	Adjusted OR	95% CI	*p* value
Malignant as primary disease	3.165	1.180 - 8.486	0.022
Independency in daily activity	1.150	0.998 - 1.326	0.053
Duration of home medical care	1.001	1.000 - 1.002	0.152
Interval between doctor visits	0.991	0.939 - 1.046	0.744
Doctor's staying time duration	1.006	0.987 - 1.027	0.532
Existence of another room	0.856	0.322 - 2.275	0.755
Primary caregiver is spouse	0.849	0.388 - 1.855	0.681

OR, odds ratio; CI, confidence interval.

OR ≥ 1 indicates that patient-doctor communication without family is more frequent.

significantly associated with DPC without family. In Japan, the family of patients with malignant tumors plays a leading role in decision-making settings and, therefore, patient autonomy is hardly reflected in such settings unlike in United States (Ruhnke et al. 2000). However, the patients with malignant tumors who received home medical care had chosen the home medical care on their own free will (Gomes and Higginson 2006). In a Japanese study on factors that enable a home death of patients with malignant tumors, the authors pointed out the importance of confirming the patient's preference for a home death (Suzuki and Suzuki 2005). When a doctor confirms the patient's preference for a home death, it is necessary to have DPC without family, taking into consideration the possibility that patients may experience difficulty in discussing their wishes if the family is present. Therefore, the doctors are requested to pay special attention to this point in cases of home medical care of patients with malignant tumors as the primary disease.

Second, the lower the patient's ADL level, the more frequently DPC without family tended to occur. This is because the patients were more frequently chaperoned by the family if the patient's ADL level was low, and this differed from the outpatient setting, in which the occurrence of DPC without family is lower (Schilling et al. 2002; Ishikawa et al. 2005, 2006; Wolff and Roter 2008). In home medical care settings in which triadic communication among the patient, family, and doctor is common, i.e. the case of patients whose ADL level is low, DPC without family is most likely to occur when the family withdraws from the patient's bedroom. In such cases, there is no opportunity for patient-doctor communication unless the family leaves the patient's bedroom. Therefore, the visiting doctor should consider a specific setup for DPC without family in cases in which the patient's ADL level is low despite some maintenance of cognitive, language, and hearing functions/abilities. The visiting doctor should keep this in mind. With respect to the issues related to DPC without family that were not resolved in this study, further research is necessary to clarify, in particular, topics suitable for setting up DPC without family.

In the present study, no association was observed between the occurrence of DPC without family and the existence of another room in which the family stayed during the doctor-patient dialogue. Thus, DPC without family in patients whose ADL level is low is set up by withdrawal of the family from the patient's bedroom. In Japan, however, a relatively high number of houses are still small, and no other appropriate room exists even though the family wants to move to such a room to wait there. In such a situation, the family might stop outside the door or in the passage during the doctor-patient dialogue. The influence of such situations on patient's privacy and the significance of DPC without family will have to be further investigated.

Third, considering the basic patient characteristics and patient backgrounds, it is interesting that "Duration of home medical care", "Total number of doctor visits" and "Interval between doctor visits" were not associated with DPC without family, among other survey items for measuring the doctor-patient relationship. We previously formulated a hypothesis that the longer the doctor's stay duration is and the more frequent the doctor's visits are, the more solid the patient-doctor relationship becomes. The hypothesis also included that these factors are associated with the occurrence of DPC without family. However, the results of the present study do not support this hypothesis. So, the measurements of the present study could possibly not reflect the doctor-patient relationship in home medical care settings. It is necessary to further study the association between the doctor-patient relationship and the occurrence of DPC without family.

Fourth, the factor "spouse" or "non-spouse" as the primary caregiver was not associated with DPC without family. Previous studies have suggested that the patients and their spouses do not want to keep secrets from each other (Porter et al. 2005; Kamezaki et al. 2008). And we thus formulated the hypothesis that DPC without family occurs less frequently when the primary caregiver is a spouse in the home medical care setting. However, the results of the present study do not support this hypothesis.

The present study has some limitations. First, we did not investigate patients' desires regarding DPC without

family. Second, this study focused on verbal communication only, although communication intrinsically includes both verbal and nonverbal communication. Third, there is a possibility that some recall bias occurred because the survey was conducted after completion of all home medical care. Fourth, because of the cross-sectional nature of this study, we cannot infer the direction of causality between DPC without family and its associated factors. Fifth, the questionnaire used for the present study is considered to have a limitation in its validity. And there may be other factors associated with DPC without family that were not investigated in this study. Finally, although there was a relatively high response rate (83.8%), all of our data were obtained from only a single medical facility. This indicates that the present results might not be generalizable to other such facilities, and a multicenter study is desirable.

The results of the present study revealed that the factor most positively associated with the occurrence of DPC without family during home medical care was the presence of a malignant tumor as the primary disease. In conclusion, the visiting doctors should bear in mind that the background factor of the occurrence of DPC without family is patient's malignant tumors.

Acknowledgements

Conflict of Interest

The authors declare no conflict of interest.

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