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# Identification of Topics Explained by Home Doctors to Family Caregivers with Cancer Patients Died at Home: A Quantitative Text Analysis of Actual Speech in All Visits

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An important consideration in the quality of end-of-life care is whether the patient's place of death matches his or her hopes. We aimed to identify topics related to patients' home death by comparing the occurrence frequency of topics explained by doctors for family caregivers between the home death cases and the hospital death cases. The method of integrating qualitative and quantitative data was adopted in this study. Primary participants were 24 home doctors who specialized home medical care. Enrolled 18 patients received periodical medical care by cooperated doctors, understood their own health situation, and lived with family caregivers. Doctors recorded all their speech during every visit with voice-recorder until the patient died at home or was re-hospitalized. Doctors' speech was transcribed and converted to the number of occurrences based on number of visits. The occurrence frequency was compared with a $\chi 2$ test (Yates' correction). Speaking records of 227 visits to 18 patients by doctors were collected. Finally, 16 patients died at home and two died at hospital. We measured the occurrence frequency of topics during maximum 26 visits on 16 home death cases and maximum 13 visits on two hospital death cases. The topics of patients' death, helping daily burden using public insurance, and financial application were more frequently appeared with home death cases than hospital death cases. In conclusion, doctors should explain to family caregivers the topics of patients' death process and specific measures or procedures for reduction in care burden.

**Keywords:** explained topics by doctors; family caregivers; home medical care; occurrence frequency of topics; place of death
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## Introduction

An important consideration in the quality of end-of-life care is whether the patient's place of death matches his or her wishes. The results of large-scale surveys and previous studies have revealed that there is often a mismatch between where people want to die and where they actually die (Fukui et al. 2011; Broad et al. 2013). Particularly in Japan, many individuals die in a hospital rather than at home, despite a stated preference for dying at home (Broad et al. 2013).

Home hospice care is constantly increasing in Japan (Lee et al. 2010). However, there is a tendency to move patients to hospitals for treatment just before their death, a tendency greater in Japan than in other countries (Broad et al. 2013). Improving the match rate between the patient's desired place of death and his/her actual place of death requires control of the patient's symptoms, doctors' support, hospice care, and family support. Cases where patients express a wish to die at home and yet are taken to the hospital at the end of their life due to certain factors, such as difficulty in controlling their symptoms or a need for 24-hour nursing care, reduce the match rate between their desired and actual place of death (Bell et al. 2010). To prevent hospitalization or re-hospitalization of end-of-life cancer patients, it is necessary to integrate communication, educate patients and their families, adjust prescriptions, and have frequent follow-ups (Pinar et al. 2017). A patient's preference for a certain place of death is influenced by his or her awareness of care needs, past experiences, desire for dignity, and fear of being a burden on others (Chapple et al. 2011). In addition, the special support and involvement of

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palliative care influence a patient's preference for the place of death (Evans et al. 2014).

The patient's wishes are the most important, but in Japan, family caregivers' acceptance and desire for the patient to die at home also affect the patient's location at the time of death (Nakamura et al. 2010; Ishikawa et al. 2013). This may also be related to the actual death location. Very few studies have directly recorded and analyzed the contents of support given by the doctor to family caregivers and the actual place of death of the patient (i.e., the several cross-sectional studies that have been performed could not record doctors' actions or remarks in detail). A longitudinal examination of the conversations between doctors and family caregivers can provide important insights on the topics they discuss. Therefore, it is necessary for a new study to focus on topics that are explained by doctors to family caregivers with cancer patients, and to compare the occurrence frequency of each topic across visits on two death places: patients who died at home versus those who died at a hospital. Such a study will be able to identify which topics were presented in cases where there was a match between the place that patients preferred and actual place of death.

This study aims to identify the highest-frequency topic that was actually explained by doctors in case of home death patients. We also compared the occurrence frequency of topics on visits between the home death cases and the hospital death cases.

## Methods

*Design and enrollment criteria*

This study is exploratory sequential mixed-design-in-mixed-methods research (Teddlie and Tashakkori 2009; Creswell and Plano Clark 2010; Hesse-Biber and Johnson 2015). This is one of the methods of integrating qualitative data and quantitative data. This design's characteristics are that one study result influences the other data acquisition and analysis (Kakai and Narita 2016). The reason this design was adopted was the need to clarify topics of doctor speaking at first, and its result would influence the conversion of qualitative data into quantitative data in this study. Therefore, we conducted a basic qualitative study and categorized topics based on an expert doctor's explanation in a clinical setting (Chiba et al. 2014). As the hypothesis, we predicted that the topic of insurance system (e.g., the way of utilizing long-term care insurance) or that of attention about patients' death (e.g., not calling an ambulance) will be more frequent in the home death cases. Fig. 1 shows the diagram of this research design.

The primary participants were clinic doctors who fit the following criteria: they belonged to the Japan Network of Home Care Supporting Clinics, specialized in home medical care, and supported

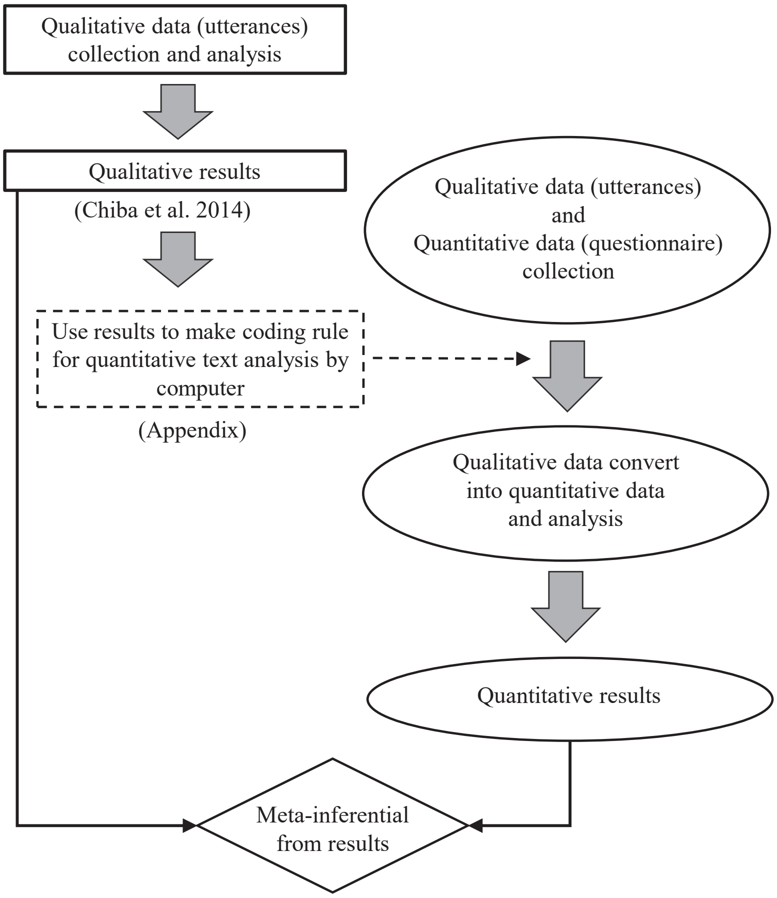


Fig. 1. Diagram of exploratory sequential design based on mixed-methods research in this study. Qualitative results in 2014 were integrated with this study at the time of analysis.

more than 10 end-of-life cancer patients per year until the patients died at home. The situations of the patients and their family caregivers were as follows. The patients were over 20 years old, were in the end-stage of cancer, had been informed of their end-stage and understood the situation, lived with one or more family caregivers, preferred home medical care rather than hospitalization, and desired palliative treatment.

### *Procedure and data acquisition*

Data were collected from December 2011 to December 2012. We requested, by telephone call, direct research collaboration with those doctors who conformed to our criteria using the yearbook (Wada 2008). Thirty-seven doctors at 20 clinics met the criteria and agreed to participate in the research. We explained procedures (i.e., how to use voice-recorder or distribution and collection of questionnaires) to all doctors and several staffs. After patients were referred to the clinic from the hospital where they had been hospitalized, clinic staffs selected patients and their families who met our candidate requirements. The family caregiver responded to the first questionnaire including sex, age, patient's care level, and patients' and family caregivers' preference before the doctor visited first. Next, the doctor recorded all their speech during medical examinations and conversations with family caregivers from the first visit until the patient's death or re-hospitalization. If the patient was re-hospitalized, the doctor confirmed the patient's death at the hospital. Finally, the family caregiver responded to the second questionnaire about patient's death place or caregiver's satisfaction for their doctor's explanation.

### *Ethical considerations*

This study is in accordance with the Declaration of Helsinki, and was approved by the Tohoku University School of Medicine Ethical Committee (2011-329). The corresponding author belonged to Tohoku University Graduate School of Medicine from 2008 to 2014; therefore, it was approved by this ethics committee. Other authors also have belonged to the same university. The roles of sharing this research were as follows: consideration of research design was the responsibility of Doctors Chiba, Ogata, Ito, and Kaneko; addressing to the ethical committee was the responsibility of Doctors Ito and Chiba; and data acquisition and analysis were the responsibilities of Doctors Chiba, Ogata, and Ito. Clinic staffs explained the purpose of the research to the patients and their family caregivers. We obtained written consent from all the participants. The patients' names or other identifying information were not linked to the research data. The doctors wore discreet pin microphones on their collar for the recordings in order to avoid any adverse effect that a large microphone might have on the interactions. The questionnaire response sheets of the family caregivers and USB flash-memory-saved doctors' voice data were safely stored in a keyed cabinet. We transcribed and analyzed only the doctors' speech, not the words of the patients and family caregivers. The study complies with the Personal Information Protection Law and Epidemiological Ethics Guidelines.

### *Analysis*

First, the words of the transcribed textual data were divided into parts of speech based on linguistics by using computer software KH-Coder version 2.0 (Higuchi 2004) and converted to numbers of occurrence. Only nouns, adjectives, and verbs were measured. Next, coding rules (see Appendix) were configured by applying the qualitative study result. This rule configured the word and word combination, which indicated doctors translated 15 sub-topics or three main topics (Chiba et al. 2014). It is applied to convert qualitative data into quantitative data using computer-assisted text mining. This procedure has the theoretical grounding of thematic text analysis (Roberts 1997; Popping 2000) with a dictionary-based approach (Osgood et al. 1957).

We measured the number of occurrences of the word and word combinations, on the basis of number of visits, by KH-Coder to conduct quantitative analysis of textual data. Quantitative analysis of textual data (Higuchi 2004, 2016, 2017) was developed using computer-based quantitative content analysis (Krippendorff 1980; Riffe et al. 2005).

In this analysis, the counting unit is not the number of persons (i.e., doctors, patients, or family caregivers) but the number of doctor visits. If doctors explained about the topic several times at the same time of visit through all cases by death places, we counted it as one per one visit. According to this measurement, the number of occurrences of topics does not exceed the maximum number of visits, the occurrence frequency was calculated that maximum number of visit in each death place were divided by the number of visit with explanation in each death place. We then compared the occurrence frequency of topics across visits on two death places (death at home and at the hospital) using Yates' correction, a chi-square test.

## Results

### *Summary of participants' data*

The participants were 24 home doctors (Table 1), 18 cancer patients (Table 2), and their family caregivers (Table 3). Twenty-four doctors cooperated in eight clinics from the Tohoku to Shikoku areas (Table 1). No cooperation was obtained from doctors in the Kyushu-Okinawa area. The average number of doctors per clinic was 3.0 (SD 4.1). Table 2 shows patients at terminal stage of cancer (16 men and two women), whose average age was 71.9 years (SD 12.4). The nursing care levels were as follows: four patients at Level I or II (22.2%), five at Level III to V (27.8%), two in the application process for a certification (11.1%), and seven with no application (38.9%). The family caregivers, shown in Table 3, comprised 1 man and 17 women whose average age was 61.9 years (SD 12.9). Thirteen caregivers had the support of other caregivers in the family but five did not. Regarding the caregivers' relations with the patients, 14 were marital partners and four were the patients' adult children.

We showed the number of doctors' visits and occurrence of explained topics (Table 4). Doctors visited 18 patients a total of 227 times, with 12.6 (SD 6.5) visits on average per patient. They visited home death patients at most 26 times and hospital death patients at most 13 times. The average number of doctors' visits per patient was 12.9 (SD 6.7) in the home death cases and 10.0 (SD 4.2) in the hospital death cases. Days until next visit were 3.5 (SD 2.5) in the home death cases and 3.1 (SD 0.5) in the hospital death cases. Visit time length was 358.6 minutes (SD 195.4) in the home death cases and 327.0 minutes (SD 128.7) in the hospital death cases. Time length per visit was 28.4 minutes (SD 6.8) in the home death cases and

Table 1. Characteristics of home doctors who participated in this research.

| | Home doctors | |
|---|---|---|
| | N | % |
| Number of doctors | 24 | 100.0 |
| Sex | | |
| Males | 20 | 83.3 |
| Females | 4 | 16.7 |
| Clinical years of experience, mean (SD) | 18.4 ( 8.5 ) | |
| Clinical years of home care experience, mean (SD) | 5.5 ( 4.6 ) | |
| Number of doctors per clinic, mean (SD) | 3.0 ( 4.1 ) | |
| Locations | | |
| Hokkaido･Tohoku area | 14 | 58.3 |
| Kanto･Shinetsu area | 4 | 16.7 |
| Tokai･Hokuriku area | 2 | 8.3 |
| Kinki area | 3 | 12.5 |
| Tyugoku ･Shikoku area | 1 | 4.2 |
| Kyusyu･Okinawa area | 0 | 0.0 |

Participated doctors belonged to the Japan Network of Home Care Supporting Clinics, specialized in home medical care, and supported more than 10 end-of-life cancer patients per year until the patients died at home which based on data of Yearbook of Home Care Doctors (Wada 2008).

Table 2. Characteristics of cancer patients who had been visited by doctors.

| | Cancer patients | |
|---|---|---|
| | N | % |
| Sex | | |
| Males | 16 | 88.9 |
| Females | 2 | 11.1 |
| Age, mean (SD) | 71.9 (12.4) | |
| Long-term care insurance | | |
| first insured person (over 65 years old) | 12 | 66.7 |
| second insured person (over 40 but under 65 years old) | 6 | 33.3 |
| Certification for long-term care people | | |
| authorization | 9 | 50.0 |
| no authorization | 9 | 50.0 |
| Level of nursing care | | |
| Level Ⅰ | 1 | 5.6 |
| Level Ⅱ | 3 | 16.7 |
| Level Ⅲ | 1 | 5.6 |
| Level Ⅳ | 3 | 16.7 |
| Level Ⅴ | 1 | 5.6 |
| Applied | 2 | 11.1 |
| Not Applied | 7 | 38.9 |
| Nursing care survice | | |
| Using | 10 | 55.6 |
| Not Using | 4 | 22.2 |
| Uncertain | 4 | 22.2 |
| Primary site | | |
| Pancreas | 4 | 22.2 |
| Stomach | 3 | 16.7 |
| Lung | 3 | 16.7 |
| Bowel | 2 | 11.1 |
| Liver | 2 | 11.1 |
| Esophagus | 1 | 5.6 |
| Gallbladder | 1 | 5.6 |
| Tongue | 1 | 5.6 |
| Unclear | 1 | 5.6 |

Cancer patient's attribute data were obtained with questionnaire before home doctor's initial visit. "Unclear" was squamous cell carcinoma, but primary site didn't indentified from answer by family caregiver.

Table 3. Characteristics of Primary family caregivers of cancer patients.

| | Family caregivers N | Family caregivers % |
|---|---|---|
| Sex | | |
| Males | 1 | 5.6 |
| Females | 17 | 94.4 |
| Age, mean (SD) | 61.9 ( 12.9 ) | |
| Relationship | | |
| Partner | 14 | 77.8 |
| Child | 4 | 22.2 |
| Presence of other caregivers | | |
| Yes | 13 | 72.2 |
| No | 5 | 27.8 |
| Work : employment | | |
| Employed | 7 | 38.9 |
| Not employed | 11 | 61.1 |

Family caregiver's attribute data were obtained with questionnaire before home doctor's initial visit.

Table 4. The number of visits by doctors and textual data from doctors' utterances.

| | | Total | Visits to hospital death cases | Visits to home death cases |
|---|---|---|---|---|
| Number of visits | total | 227 | 20 | 207 |
| | max | 26 | 13 | 26 |
| | min | 3 | 7 | 3 |
| Number of visits, mean (SD) | | 12.6 (6.5) | 10.0 (4.2) | 12.9 (6.7) |
| Days until next visit, mean (SD) | | 3.4 (2.3) | 3.1 (0.5) | 3.5 (2.5) |
| Time length of all visits, mean (SD) | | 355.1 (186.5) | 327.0 (128.7) | 358.6 (195.4) |
| Time length per visit, mean (SD) | | 28.9 (6.6) | 32.9 (1.1) | 28.4 (6.8) |
| Doctors' utterances: textual data | | | | |
| | total characters | 424,103 | 33,284 | 392,547 |
| | analyzed characters | 92,554 | 7,348 | 84,924 |
| | analyzed words | 5,415 | 1,154 | 5,139 |

Unit of time length of all visits and time length per visit were minutes. Analyzed characters and words were only nouns, adjectives, and verbs, other part of speech were excluded.

32.9 minutes (SD 1.1) in the hospital death cases. Altogether, 424,103 characters were transcribed. Excluding some parts of speech, 92,554 characters (5,415 words) were analyzed in total. There were 5,242 words in the home death cases and 1,184 words in the hospital death cases, with duplication of some terms for both death places.

*Preference with patients and their family caregivers*

Table 5 shows preference of patients and family caregivers as well as patients' actual death place. A majority of patients (11 patients, 61.1%) and nine family caregivers (50%) preferred death at home. On the other hand, two patients (11.1%) and five caregivers (27.8%) preferred hospital death. Patients lived an average of 44.1 days (SD 47.5). Finally, 16 patients died at home and two died at a hospital. All patients with family caregivers who desire to die at home died at home. On the other hand, at the start of home medical care, not all patients whose families felt better for the patient to die at the hospital actually died at the hospital. Patients who died at the hospital did not clearly state a preferred place of death at the start of home medical care, and their family caregivers were also unclear. About patients' death places, 83.3% of family caregivers felt "fulfilled" and 11.1% felt "inevitable about different death place". No one answered "regret" and 5.6% left the question unanswered.

*Comparison of topics explained by doctors*

We set the number of maximum visits (26 times in the home death cases and 13 times in the hospital death cases) as the denominator in calculation of the occurrence frequency. We counted it as one per one visit, even if doctors

Table 5. Preferred place of death and patients' actual place of death.

| | Total | | Hospital death cases | | Home death cases | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| Patient's preferred place of death | | | | | | |
| home | 11 | 61.1 | 0 | 0.0 | 11 | 100.0 |
| hospital | 2 | 11.1 | 0 | 0.0 | 2 | 100.0 |
| don't know | 3 | 16.7 | 2 | 66.7 | 1 | 33.3 |
| no answer | 2 | 11.1 | 0 | 0.0 | 2 | 100.0 |
| Family's preferred place of patient's death | | | | | | |
| home | 9 | 50.0 | 0 | 0.0 | 9 | 100.0 |
| hospital | 5 | 27.8 | 0 | 0.0 | 5 | 100.0 |
| don't know | 2 | 11.1 | 1 | 50.0 | 1 | 50.0 |
| no answer | 2 | 11.1 | 1 | 50.0 | 1 | 50.0 |
| Days of home care living, mean (SD) | 44.1 ( 47.5 ) | | 30.0 ( 8.5 ) | | 45.8 ( 50.3 ) | |
| Actual place of patient's death | 18 | 100.0 | 2 | 11.1 | 16 | 88.9 |
| Family's satisfaction for patient's place of death | | | | | | |
| fulfilled | 15 | 83.3 | 1 | 6.7 | 14 | 93.3 |
| inevitable | 2 | 11.1 | 1 | 50.0 | 1 | 50.0 |
| regret | 0 | 0.0 | 0 | 0.0 | 0 | 0.0 |
| don't know | 0 | 0.0 | 0 | 0.0 | 0 | 0.1 |
| no answer | 1 | 5.6 | 0 | 0.0 | 1 | 100.0 |

Data for patient's preferred place of death and family's preferred place of patient's death were obtained with questionnaire before home doctor's initial visit. Data for actual death place of patient and family's satisfaction were got with questionnaire which conducted after patient's death.

had explained one topic more than once at same time of visit through all cases (16 home death cases or 2 hospital death cases) in each death place. A comparison of the occurrence frequency of each sub-topic that doctors explained revealed that eight sub-topics occurred significantly more in the home death cases (Table 6). "Visiting 24 hours and 365 days" occurred 20 vs. 3 (76.9% vs. 23.1% chi-square value = 8.280, $p < 0.01$), "Predicted sudden deterioration pattern" 22 vs. 2 (84.6% vs. 15.4% chi-square value = 14.747, $p < 0.01$), "Ease of contacting or consulting with doctors" 23 vs. 5 (88.5% vs. 38.5% chi-square value = 8.373, $p < 0.01$), "Current life expectancy" 12 vs. 1 (46.2% vs. 7.7% chi-square value = 4.168, $p < 0.05$), "Decay and death caused by aging" 20 vs. 1 (76.9% vs. 7.7% chi-square value = 14.045, $p < 0.01$), "Calling home care doctors instead of an ambulance" 16 vs. 2 (61.5% vs. 15.4% chi-square value = 5.688, $p < 0.05$), "Home care service based on a long-term care insurance system" 20 vs. 5 (76.9% vs. 38.5% chi-square value = 4.025, $p < 0.05$), and "Medical insurance system and payment" 16 vs. 2 (61.5% vs. 15.4% chi-square value = 5.688, $p < 0.05$). For easy comparison, the data, shown in Table 6, are also presented as Fig. 2.

Among the three main topics, doctors explained "Medical treatment and control of painful symptoms" with all visits in both places. "Available insurance systems and financial information" occurred with 23 visits in the home death cases and 6 in the hospital death cases. "Meaning of death at home and its process" occurred with 23 visits in the home death cases and 3 in the hospital death cases (Table 7). "Meaning of death at home and its process" (88.5% vs. 23.1% chi-square value = 13.861, $p < 0.01$) and "Available insurance systems and financial information" (88.5% vs. 46.2% chi-squared values = 6.069, $p < 0.05$) were mentioned by doctors more frequently in the home death cases compared with the hospital. On the other hand, there was no difference in the occurrence frequency of the topic "Medical treatment and control of painful symptoms" across visits on two death places. For easy comparison, the data are also presented as Fig. 3.

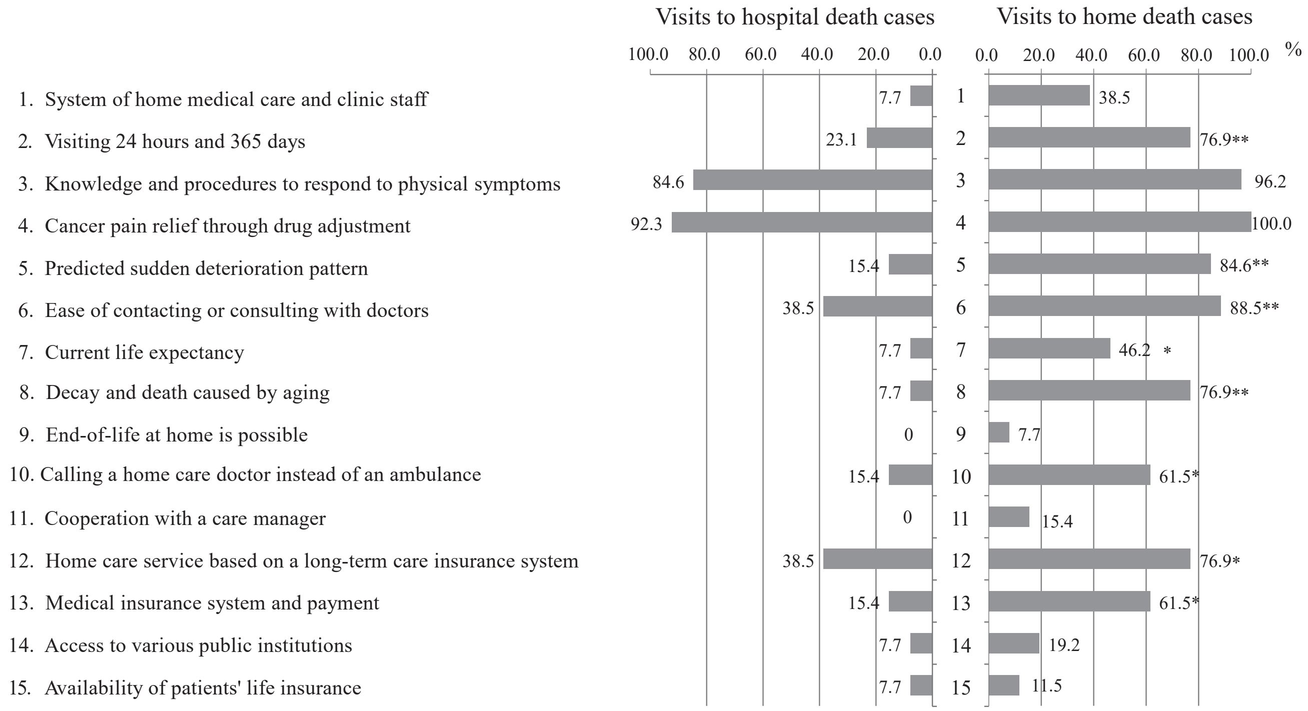
## Discussion

We show the difference in the occurrence frequency of topics that had been explained by doctors to family caregivers according to the patients' places of death. The present findings indicate that doctors should explain and focus on psychosocial and supportive life topics besides medical information about treatments to family caregivers with patients who hope to die at home. Few studies have pointed out the concrete topics that doctors explain better with actual direct speech to patients and caregivers. Previous studies on end-of-life care realization have indicated the importance of provision of information about pain or symptom control in medical treatments to patients and reduction of care burden on family caregivers. For family caregivers actively involved in end-of-life care, it is important to supply and confirm information about the status of the patient with their doctors, along with information about the desired place of death and whether or not to prolong survival

Table 6. Comparison of the occurrence frequency of 15 sub-topics.

| | 15 sub-topics | Total | | Visits to hospital death cases | | Visits to home death cases | | |
|---|---|---|---|---|---|---|---|---|
| | | N | % | N | % | N | % | |
| 1 | System of home medical care and clinic staff | 11 | 28.2 | 1 | 7.7 | 10 | 38.5 | n.s. |
| 2 | Visiting 24 hours and 365 days | 23 | 59.0 | 3 | 23.1 | 20 | 76.9 | ** |
| 3 | Knowledge and procedures to respond to physical symptoms | 36 | 92.3 | 11 | 84.6 | 25 | 96.2 | n.s. |
| 4 | Cancer pain relief through drug adjustment | 38 | 97.4 | 12 | 92.3 | 26 | 100.0 | n.s. |
| 5 | Predicted sudden deterioration pattern | 24 | 61.5 | 2 | 15.4 | 22 | 84.6 | ** |
| 6 | Ease of contacting or consulting with doctors | 28 | 71.8 | 5 | 38.5 | 23 | 88.5 | ** |
| 7 | Current life expectancy | 13 | 33.3 | 1 | 7.7 | 12 | 46.2 | * |
| 8 | Decay and death caused by aging | 21 | 53.9 | 1 | 7.7 | 20 | 76.9 | ** |
| 9 | End-of-life at home is possible | 2 | 5.1 | 0 | 0.0 | 2 | 7.7 | n.s. |
| 10 | Calling a home care doctor instead of an ambulance | 18 | 46.2 | 2 | 15.4 | 16 | 61.5 | * |
| 11 | Cooperation with a care manager | 4 | 10.3 | 0 | 0.0 | 4 | 15.4 | n.s. |
| 12 | Home care service based on a long-term care insurance system | 25 | 64.1 | 5 | 38.5 | 20 | 76.9 | * |
| 13 | Medical insurance system and payment | 18 | 46.2 | 2 | 15.4 | 16 | 61.5 | * |
| 14 | Access to various public institutions | 6 | 15.4 | 1 | 7.7 | 5 | 19.2 | n.s. |
| 15 | Availability of patients' life insurance | 4 | 10.3 | 1 | 7.7 | 3 | 11.5 | n.s. |
| | Total | 39 | | 13 | | 26 | | |

Chi-square test *p < 0.05, **p < 0.01; n.s., not significant.
N, number of occurrences of topics explained by doctors.



Chi-square test *p < 0.05, **p < 0.01

Fig. 2. Comparison of the occurrence frequency of 15 sub-topics which home doctors explained to families by cancer patients' death places.
The occurrence frequency were calculated the total number of visit divided by the number of visit with topics explanation.

(Heyland et al. 2010). Further, bereaved families of cancer patients who died at home have evaluated the support by a 24-hour care team, support for family caregivers, and support for decision making (Okamoto et al. 2015). In particular, as it is important to reduce the burden of caregiving on family caregivers (Ishii et al. 2012), decreasing the caregiv-

Table 7. Comparison of the occurrence frequency of the three main topics.

| | Three main topics | Total | | Visits to hospital death cases | | Visits to home death cases | | |
|---|---|---|---|---|---|---|---|---|
| | | N | % | N | % | N | % | |
| Ⅰ | Medical treatment and control of painful symptoms | 39 | 100.0 | 13 | 100.0 | 26 | 100.0 | n.s. |
| Ⅱ | Meaning of death at home and its process | 26 | 66.7 | 3 | 23.1 | 23 | 88.5 | ** |
| Ⅲ | Available insurance systems and financial information | 29 | 74.4 | 6 | 46.2 | 23 | 88.5 | * |
| | Total | 39 | | 13 | | 26 | | |

Chi-square test *p < 0.05, **p < 0.01; n.s., not significant.
N, number of occurrences of topics explained by doctor.

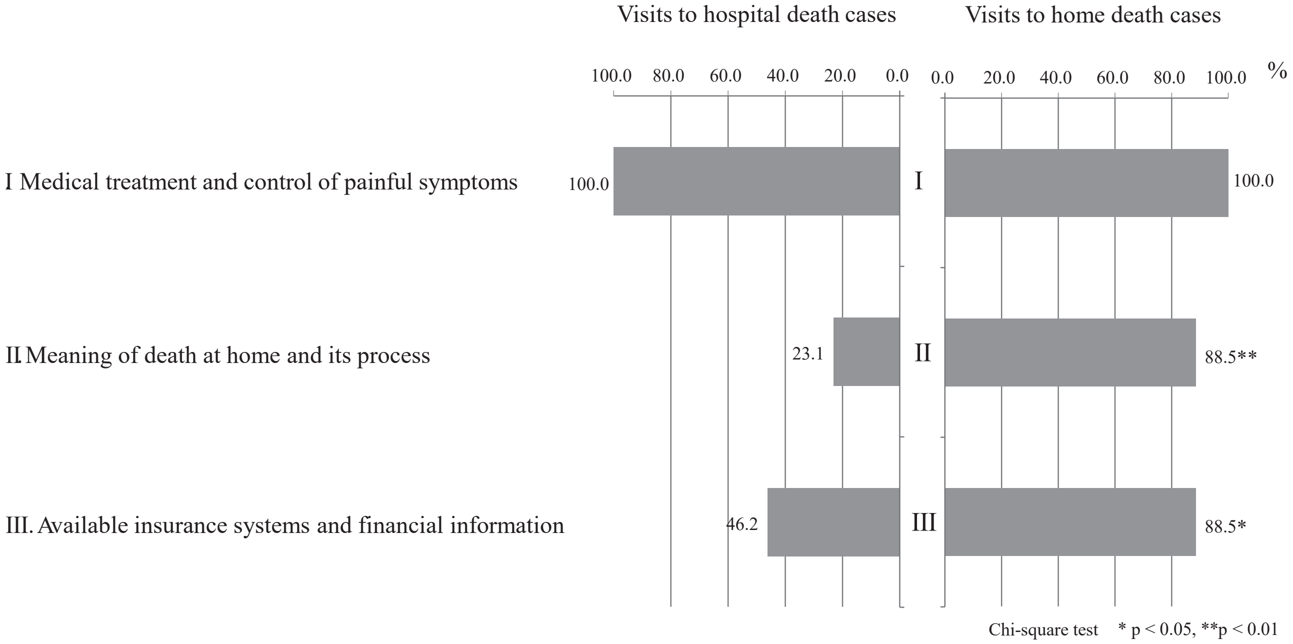


Fig. 3. Comparison of the occurrence frequency of three main topics which home doctors explained to families by cancer patients' death places.
The occurrence frequency were calculated the total number of visit divided by the number of visit with topics explanation.

ers' burden is one factor that supports a sense of ease in daily life (Igarashi et al. 2016). In this way, past studies have suggested factors related to home death but have not shown how doctors act or what they explain to patients and family caregivers.

We pointed out specific topics related to home death. The caregivers should be told to call the doctor directly and not an ambulance when they observe that the patient has died. Patients and their families do not hope for resuscitation at the hospital, but family caregivers sometimes panic and call an ambulance. If caregivers call an ambulance after patients die at home, the patients are not taken to the hospital by emergency personnel but are instead delivered to the police, who are responsible for conducting the autopsies. Such families' unintended situation may be caused by home medical professionals misunderstanding the law or may be due to insufficient explanation to caregivers (Sakamoto 2014). Therefore, doctors have to explain patients' ending process to family caregivers clearly and timely in end-of-life care at home (Yang and McNabney 2017).

Furthermore, we suggest that the doctor should explain the way of utilization of long-term care insurance and medical insurance systems with the family caregivers. By using public insurance, patients and their families can borrow welfare equipment and use helper services and bathing services at little expense. This explained topic by doctors will contribute toward reducing caregivers' burden. By reducing the burden of nursing care on the family, the experience of end-of-life care and satisfaction improves (Naoki et al. 2018). Ishikawa et al. (2013) showed that the family's preference affects the place of patients' death and suggested the importance of supporting family caregivers in order to achieve the true patients' wishes for home death. Therefore, five patients whose families hoped the patients would die in hospital might have died at the hospital in the questionnaire survey at the start of home medical care in our study. However, the five patients died at home, and their families also did not express regret about the death location change in the questionnaire survey after the patients died. Although we cannot prove a causal relationship in this study, this could possibly increase home care and home death of cancer patients by home doctors' supplying and explaining topics to family caregivers.

The utilization of this study results will be its application to practical training for doctors new to home medical care or medical students during clinical training. It is a practical strategy for improvement of doctors' productive communication ability and effective use of time (Dugdale et al. 1999). It will lead to more constructive discussions between doctors and caregivers. Moreover, it may contribute to better quality of life for the patients. These are also consistent with the ethics guidelines to optimize relationships among caregivers, patients, and doctors (Mitnick et al. 2010).

In Japan, the estimated number of outpatients who receive home medical care has been increasing since 2008. In particular, the number of patients receiving home visit consultations has increased rapidly (Ministry of Health, Labour and Welfare 2014). In total, 111,000 people (31.2% of cancer deaths) wish to die at home (Morita et al. 2012). Doctors can utilize the results of this study to select and supply appropriate information with family caregivers with end-of-life cancer patients in cases where the patient wishes to die at home.

In both the places where deaths occurred, the data of doctors' speech, which we have collected, were detailed to the extent that they could be compared. Moreover, the data were collected from multiple regions. However, this research has some limitations. The number of cases was small and the death cases in a hospital were quite few when compared with those that occurred in a patient's home. Therefore, it is necessary to collect and analyze more data in the future. The reason behind the small number of cases is that the data collection takes a long time and involves collecting conversations from busy clinical settings. To collect more data, it will be necessary to request cooperation from many doctors who provide home care as a multicenter study. Moreover, it is important to prepare an environment in which it is easy to record doctors' conversations, and the technology needs to be updated for making the transliteration easier.

Psychological considerations (e.g., anxiety and spirituality) are necessary as the study involves patients in end-of-life stage (Bovero et al. 2016) or fulfilling the caregivers' emotional needs (Lee et al. 2014; Burge et al. 2015). Therefore, for future studies, it is necessary to consider patients' or caregivers' psychological aspects. Furthermore, future studies also need to analyze the explanations that were supplied by a few other professionals (e.g., visiting nurse, care manager, pharmacist, etc.) in home medical care with caregivers.

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## Conflict of Interest

The authors declare no conflict of interest.

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## Appendix

We measured that the occurrence frequency of the explanation was presented once when the following specified words appeared within 10 words, in multiple combinations using the software program KH-Coder. "near" is a program rule indicating that words appear within 10 words. "-" is a program rule indicating "and," "\|" is those of "or."

| Three main topics | 15 sub-topics | | Coding rules (Software program rules) |
|---|---|---|---|
| **I "Medical treatment and control of painful symptoms"** | 1 | "System of home medical care and clinic staff" | near ((doctor \| full-time medical doctor \| full-time medical physician \| regular doctor) - (part-time doctor \| part-time medical doctor \| locum doctor) - (nurse \| visiting nurse \| domiciliary nurse)) \| near (number of - doctors) \| near (number of - physicians) \| near ((scheduled \| visit) - doctor's visit) \| near (meeting - shared) \| brochure |
| | 2 | "Visiting 24 hours and 365 days" | near ((24 hours \| 365 days \| even when \| by night \| midnight \| by all means) - (house call \| correspondence \| going)) |
| | 3 | "Knowledge and procedures to respond to physical symptoms" | near ((breeding \| tired \| crash \| hard \| sleep \| appetite \| calorie \| nausea \| heartburn \| constipation \| dream \| hallucination \| auditory hallucination) - (intravenous feeding \| heparin \| injection \| drawing blood \| X-rays \| the liquid enteral nutrition formula Racol \| the liquid enteral nutrition formula Ensure \| oxygen \| liter \| saturation \| percentage \| blood pressure)) |
| | 4 | "Cancer pain relief through drug adjustment" | near ((painful \| breeding \| tired \| crash \| hard) - (Durotep \| Fentos \| Levotomin \| Horizon \| Oxynorm \| Anpec \| Rinderon \| Sandstatin \| Calonal \| Depas \| Oxycontin \| Adefro \| Loxonin \| Loxoprofen \| Opso \| Risperdal \| Lexapro \| Nervone \| Myslee \| Rozerem \| Gabapen \| Depakene \| Takepron \| Teprenone \| Pantoprazole \| Mucosta \| Omeproton \| Omerap \| Omepral \| Omeprazon \| Maalox \| Cytotec \| Anchusan \| Predonine \| Rinderon \| Eksalb \| Solanax \| Novamin \| Magmitt \| Morphine \| narcotics \| OneDuro \| Pursennid \| Magnesium oxide \| Imuran \| Omepral \| Tramacet \| Gran \| Laxoberon \| Urief \| Ropion \| Alloyd \| Gasmotin \| Lecicarbon \| Naixan) - (anodyne \| basal agent \| medicine for maintenance \| rescue agent \| base \| rescue \| single use \| potion \| suppository \| medicinal drink \| medical patch \| liquid medicine \| patch \| tape \| quantity \| milligram \| pack \| tablet)) |
| | 5 | "Predicted sudden deterioration pattern" | near (sudden change - (bleeding \| hematemesis \| cerebral infarction \| breathing \| stop \| possibility \| pattern)) |
| | 6 | "Ease of contacting or consulting with doctors" | near ((state \| health condition \| state of mind \| uneasiness) - (midnight \| by night \| anytime) - (contacting \| cell phone \| telephone)) |
| **II "Meaning of death at home and its process"** | 7 | "Current life expectancy" | near (the rest - time) \| near (come through - (month \| week \| day)) |
| | 8 | "Decay and death caused by aging" | near (aging - (phenomenon \| physical strength \| decrease strength \| last time \| latter end)) \| near (physical function - (decline \| decrease strength \| decrease strength))) + (death \| death bed \| lay down life's burden \| to be beautified) |
| | 9 | "End-of-life at home is possible" | near (living place - death bed - feasible) \| near (home - death bed - feasible) \| near (living place - latter end - climax) \| near (home - latter end - climax) \| near (sleeping - latter end) |
| | 10 | "Calling a home care doctor instead of an ambulance" | near (ambulance - (resuscitation \| prolongation of patient's life \| heart \| cardiac massage \| costa)) + near (hospital - (die \| death bed \| lay down life's burden) |
| **III "Available insurance systems and financial information"** | 11 | "Cooperation with a care manager" | near (Care manager - medical care) \| near (Care manager - proffer) \| near (information - visiting medical management in home) \| near (information - proffer) |
| | 12 | "Home care service based on a long-term care insurance system" | near (long-term care insurance - (home helper \| primary doctor \| primary doctor judgment on long-term care \| visiting bathing care \| mattress \| air mattress \| portable \| portable toilet \| balneum bath \| bathtub)) |
| | 13 | "Medical insurance system and payment" | near (medical insurance - (yen \| burden \| percent \| upper limit \| amount of money)) |
| | 14 | "Access to various public institutions" | near (disability - certificate) \| near (physical disabilities - certificate) \| persons with physical disabilities \| certificate \| support for independence |
| | 15 | "Availability of patients' life insurance" | near (severe disablement - (insurance payment \| life insurance \| a life insurance company \| an insurance carrier \| mutual aid \| loan)) |