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# Association Between Advance Care Planning Implementation and Home Deaths in Visiting Nurse Agencies

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## Abstract

# Objective

This secondary analysis of a nationwide survey examined the association between self-assessed advance care planning (ACP) implementation by visiting nurse agency (VNA) and home deaths among patients receiving end-of-life care.

# Results

Of 369 VNAs analyzed, VNAs were classified into two groups: Home Death Predominant VNAs (more patients died at home than in hospitals) and Hospital Death Predominant VNAs (more patients died in hospitals than at home). ACP implementation was evaluated using 10 self-assessment items, with total scores categorized as high or low. Home Death Predominant VNAs had a significantly higher proportion of high scores (92.9%) than Hospital Death Predominant VNAs (86.1%, $p = 0.04$). Among the 10 ACP self-assessment items, six were significantly more often practiced in Home Death Predominant VNAs: understanding individual's values and life goals ($p < 0.01$), understanding individual's wishes regarding medical treatment and care ($p = 0.03$), appropriate explanation by a physician or other healthcare provider ($p = 0.04$), discussion with the individual, family members, and the healthcare team ($p = 0.02$), record-keeping of discussions ($p = 0.03$), and repeatedly discussing changes in individual's wishes ($p = 0.04$). These findings suggest that higher self-assessed ACP implementation is associated with a greater predominance of home deaths at the agency level.

## Introduction

Advance care planning (ACP) involves an individual considering and engaging in discussions with those close to them, supported by trusted healthcare providers, to prepare for their future lifestyle, medical, and care preferences (1). Many studies have been conducted on ACP; its implementation has been associated with increased ACP documentation, improved end-of-life care, patient and family satisfaction, reduced depression, lower hospital readmission, and decreased life-sustaining treatment (2–6). However, most research has been conducted in Western countries and in acute care or community settings, with little focus on home medical care [7,8].

Worldwide, countries are experiencing growth in the size and proportion of older people in their population (7). Many people wish to die at home, and home deaths are said to be less expensive than hospital deaths in terms of costs of medical care (8). The place of death is frequently considered a crucial factor in the quality of end-of-life care, and there appears to be a significant gap between people's preferred and actual places of death. This discrepancy is significant in Japan because although 58.8% of Japanese people prefer home as the place of death (9), only 16.4% died at home (10). This is a much lower percentage than in other countries, and the majority of Japanese people die in hospitals (11).

Visiting nursing is essential for supporting home medical care in Japan, with approximately 1,100,000 people using it (12). In Japan, nurses can independently establish visiting nurse agencies (VNAs). This system began in 1992, and currently there are approximately 17,000 VNAs across Japan (13, 14). Nurses are the closest health professionals to patients and their families, and nurses have an important role in ACP (15–17). In home medical care, nurses can build trusting relationships with patients and their families as ACP facilitators (18). A randomized trial performed in 2016 demonstrated that ACP was significantly correlated with at-home deaths (19). Based on these results, we considered that the implementation of ACP by visiting nurses may be associated with achieving patients' wishes to die at home.

This study aimed to investigate whether the implementation of ACP, evaluated by the self-assessment of VNA managers, was associated with death at home for patients receiving end-of-life care in the VNA at the agency level.

## Methods

# Study design and participants

This study was a secondary analysis of data from the "Survey on the Promotion of End-of-Life Care at Home", a nationwide survey conducted as part of a project to promote health for older people under the Ministry of Health, Labour and Welfare's subsidy for promoting geriatric insurance projects in fiscal year 2019. The original survey was conducted by JMA Research Institute Inc. in collaboration with a taskforce of eight experts and professionals in home-based end-of-life care, who finalized the survey items and ACP definition between July and October 2019. In this survey, ACP was defined as "a process in which the patient repeatedly discusses the medical treatment and care in the end of life with family members and healthcare providers in advance"(1, 20).

The original survey targeted organizations involved in home-based end-of-life care, including home medical care clinics, VNAs, care management agencies, and care worker agencies. In November 2019, anonymous self-administered questionnaires were mailed to 1,500 VNAs randomly selected from VNAs nationwide in Japan. Nurse managers were selected as respondents because they were considered the most appropriate individuals to report agency-level ACP practices, service provision, and the annual number and place of deaths. The report of the original survey is publicly available (21).

## Measures

Evaluation of ACP implementation

Ten items were given to choose from for the question, “Do the visiting nurses at your facility practice the following to help the patient in the final stages of life reach the end of life that he/she desires?” The following 10 items are sub-items of the ACP definition created by a research team from the Ministry of Health, Labour, and Welfare based on previous studies and guidelines (1, 20)

Understanding patient’s values and life goal

Understanding patient’s wish to receive medical treatment and care

Understanding patient’s desired place to receive end-of-life care and death

Appropriate explanation by a physician or other healthcare provider

Identification of a person who can presume the patient’s wishes in case the patient loses decision-making capacity

Discussion with the patient, family members and other trusted persons, and the healthcare provider/medical team

Determining policies as a medical care team based on decisions chosen by the patient

Record-keeping each discussion

Information sharing within the medical care team

Repeatedly discussing changes in the patient’s wishes

Responses were rated on a four-point scale: “consistently practiced,” “mostly practiced,” “somewhat practiced,” and “not practiced,” scored as 4, 3, 2, and 1, respectively. Total scores ranged from 10 to 40 and were categorized as low (< 26) or high (≥ 26). For item-level analysis, “consistently practiced” and “mostly practiced” were defined as “practiced.”

Classification of VNA groups

The annual number of deaths and the place of death (home or hospital) between October 2018 and September 2019 were recorded. Based on the answers to these questions, VNAs were classified into two groups: “Home Death Predominant VNAs” if more patients died at home than in hospitals over the course of a year, and “Hospital Death Predominant VNAs” if more patients died in hospitals than at home over the course of a year. This classification was conducted by the researchers after data collection; respondents were not asked to classify their agencies when answering the survey. The data were collected before the major impact of the COVID-19 pandemic in Japan.

### Statistical analyses

Agency characteristics, number of patients, and annual number of deaths were compared between the two groups. Categorical variables were analyzed using the $\chi^2$ test or Fisher’s exact test, and continuous variables were analyzed using Student’s t-test or the Mann–Whitney U-test, as appropriate. Additionally, we used the $\chi^2$ test to compare the proportion of agencies in the high score group based on the total score of the 10 ACP self-assessment items and proportion of “practiced” responses for each item of the 10 ACP self-assessment items between the two groups. The significance level was set at 5% and two-tailed tests were used. VNAs with missing information on deaths or other key variables were excluded from analysis. SPSS for Windows version 25 (IBM Japan, Tokyo, Japan) was used for statistical analyses.

## Results

# Response rate and study sample

Of the 1,500 VNAs that received the questionnaires, 440 responded (response rate of 29.3%). Agencies that did not report the number of home and hospital deaths, reported no deaths, or reported deaths at places other than the hospital or home during the past year were excluded. The final subjects of the analysis were 369 agencies, of which 168 (46%) were Home Death Predominant VNAs and 201 (54%) were Hospital Death Predominant VNAs.

# Characteristics of VNAs

Table 1 presents agency-level characteristics obtained from the original Survey on the Promotion of End-of-Life Care at Home, including years since establishment, service provision, staffing, number of patients, and the annual number and place of deaths from October 2018 to September 2019. In terms of the characteristics of VNAs, the number of years since the establishment of the agency was significantly shorter in Home Death Predominant VNAs than in Hospital Death Predominant VNAs. The other characteristics were comparable between the two groups.

Table 1
The basic characteristics of the Visiting Nurse Agencies (VNAs), number of patients, and annual number of deaths

| Number of years since establishment of the agency | All (n = 369) | Home Death Predominant VNAs (n = 168) | Hospital Death Predominant VNAs (n = 201) | p value |
|---|---|---|---|---|
| | **7[3–20]** | **7[3–18]** | **9.5[4-20.25]** | **0.03*** |
| Having satellite offices | 31(8.4) | 16(9.6) | 15(7.6) | 0.5 |
| Providing 24-hour service | 317(87.3) | 148(89.7) | 169(85.4) | 0.2 |
| Number of hospitals or clinic that wrote instructions for visiting nurse (April 2019 to September 2019) | 23[10–38] | 23[10-40.75] | 22[10–38] | 0.7 |
| Number of nurses | | | | |
| full-time | 4[2–6] | 4[3–6] | 4[2–6] | 0.5 |
| part-time | 1[0–3] | 1[0–3] | 1[0–2] | 0.4 |
| Number of patients (October 2018 to September 2019) | 124[55–497] | 122[56–341] | 125[52–569] | 0.4 |
| with long-term care insurance | 80[29–327] | 75[26–210] | 82[31–392] | 0.08 |
| with medical insurance | 34[11–117] | 39[15–107] | 28[7-122] | 0.2 |
| Total number of deaths per year | 13[6–23] | 15[6–25] | 12[6–20] | 0.1 |
| Number of patients who died at home | 4[2–11] | 9[4–16] | 3[1–6] | < 0.01* |
| Number of patients who died at hospital | 6[2–11] | 3[1–8] | 7[4-13.5] | < 0.01* |

Data are expressed as number (%) or median [IQR]

Comparisons were conducted using the $\chi^2$ test or Fisher's exact test for categorical variables, and Student's t-test or Mann–Whitney U-test for continuous variables, depending on whether the data followed a normal distribution. *p < 0.05

## Proportion of high and low total score group of the 10 ACP self-assessment items

The total scores for the 10 ACP self-assessment items were categorized into high and low score groups. Overall, 329 VNAs (89.2%) were classified into the high score group, and 40 VNAs (10.8%) were classified into the low score group. In the Home Death Predominant VNAs the proportion of the high score group (92.9%) was significantly higher than in the Hospital Death Predominant VNAs (86.1%) (p = 0.04). (Table 2)

Figure 1 shows the proportion of "practiced" responses for each of the 10 ACP self-assessment items by VNA group. Six items were significantly more often practiced in Home Death Predominant VNAs: understanding patients' values and life goals, understanding patients' wishes for medical treatment and care, appropriate explanation by physicians or other healthcare providers, discussion with patients, family members, trusted persons, and healthcare providers, record-keeping of discussions, and repeated discussion of changes in patients' wishes.

Table 2
Proportion of agencies in the high-score group based on the total score of the 10 ACP self-assessment items: Comparison between Home Death Predominant VNAs and Hospital Death Predominant VNAs

| Proportion of 2 total score group of the 10 ACP self-assessment items | | | |
|---|---|---|---|
| | **High score n(%)** | **Low score n(%)** | **p value** |
| Home Death Predominant VNAs (n = 168) | 156(92.9) | 12(7.1) | 0.04* |
| Hospital Death Predominant VNAs (n = 201) | 173(86.1) | 28(13.9) | |

Comparisons were conducted using the $\chi^2$ test *p < 0.05

## Discussion

In a nationwide questionnaire survey of VNAs, Home Death Predominant VNAs had a significantly higher proportion of high scores on the 10 ACP self-assessment items than Hospital Death Predominant VNAs. This finding suggests an agency-level association between higher self-assessed ACP implementation and home death predominance among VNA patients. However, because this was a cross-sectional study using agency-level self-reported data, the findings should be interpreted as an association rather than evidence of a causal relationship between ACP implementation and death at home.

Significant differences were observed in items related to patients' values, wishes for treatment and care, explanations by healthcare providers, discussions with patients and families, documentation, and repeated discussions. Consistent with previous ACP definitions, these findings emphasize the importance of the discussion process and repeated discussions about patients' values and wishes [1,20]. However, not all ACP items showed statistically significant differences between the two groups. Items related to understanding the desired place of end-of-life care and death, identifying a surrogate decision-maker, determining care policies as a medical care team, and sharing information within the medical care team did not differ significantly. These findings may reflect that some practices were already commonly implemented in both groups or that the self-assessment items were not sufficiently sensitive to capture qualitative differences in multidisciplinary collaboration and ACP discussions. Therefore, the non-significant findings should not be interpreted as indicating that these elements are unimportant.

Visiting nurses may play an important role in home-based end-of-life care by maintaining close involvement with patients and families, helping them express their values and wishes (22, 23). Patients are more likely to die in their desired place if visiting nurses repeatedly confirm the chosen place of death until close to the end of life and explain the influence of disease prognosis on daily life, with updates based on changes in symptoms (24). Repeated ACP discussions may help patients and families prepare for home death when caregiving burden or symptom management becomes challenging (25).

The findings should also be interpreted considering the complexity of home deaths. Death at home does not necessarily indicate that ACP was implemented or that the patient's preferred place of death was achieved. Place of death can be influenced by multiple factors beyond VNA-led ACP, including disease trajectory, family caregiving capacity, symptom management, physician and care manager involvement, and community-level resources (26, 27). ACP implementations conducted in hospitals or other community settings may also have influenced end-of-life care. Therefore, the observed association should be understood at the agency-level rather than as evidence of a direct causal effect on individual patients' place of death.

Despite these complexities, the findings suggest that ACP practices by VNAs may be important in supporting home-based end-of-life care. Because ACP in home medical care requires collaboration among multiple professionals (16, 28, 29), future studies should examine how visiting nurses and multidisciplinary teams implement ACP despite barriers such as time constraints, heavy workloads, and competing responsibilities (15, 30).

# Limitations

This study has several limitations. First, because this was a cross-sectional study, causal relationships between ACP practices in VNAs and the predominance of home deaths could not be determined. Second, ACP implementation was assessed using nurse managers' self-reports at the agency level. Therefore, the results may have been affected by social desirability bias or overestimation of ACP practices, and this study could not determine whether individual patients received ACP. Third, not all characteristics of VNAs were considered. In Japan, VNAs vary in their specialties, such as end-of-life care and mental health, and agencies specializing in end-of-life care may be more likely to actively implement ACP. Fourth, some individuals may prefer end-of-life care in hospitals or other facilities, and as noted above, the place of death may also be influenced by various factors, such as patient, family, provider, and community situations.

## Conclusion

This study investigated the implementation of ACP as evaluated by VNA managers and found that differences in ACP implementation were evident between those with a higher number of home deaths and those with a higher number of hospital deaths. Higher self-assessed ACP practices by visiting nurses were associated with a greater number of home deaths. These findings suggest that ACP practices by visiting nurses may be important in supporting home-based end-of-life care within multidisciplinary home care teams.

## Declarations

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**Authors' contributions**

Y.F. designed the study, main conceptual ideas, and proof outline. Y.F., K.G., and K.K. interpreted the results and wrote the manuscript. K.K. and M.K. supervised the project and collected data. Y.F. wrote the manuscript with the support of T.W., K.G., Y.A. and K.K. All the authors discussed the results and commented on the manuscript.

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**Data availability**

The data that support the findings of this study are available from the corresponding author upon reasonable request. The results of this survey are available at https://www.jmar.co.jp/asset/pdf/job/public/llgr1_43_report.pdf .

**Declaration**

**Ethics approval and consent to participate**

This study was approved by the Ethics Committee of Osaka University Hospital

(Approval No. 19239). The study was conducted in accordance with the relevant

guidelines and regulations, including the Declaration of Helsinki.

Respondents provided consent to participate by checking a confirmation box in the questionnaire.

**Consent for publication**

Not applicable.

**Conflict of interests**

The authors declare that they have no conflict interests.

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## Figures

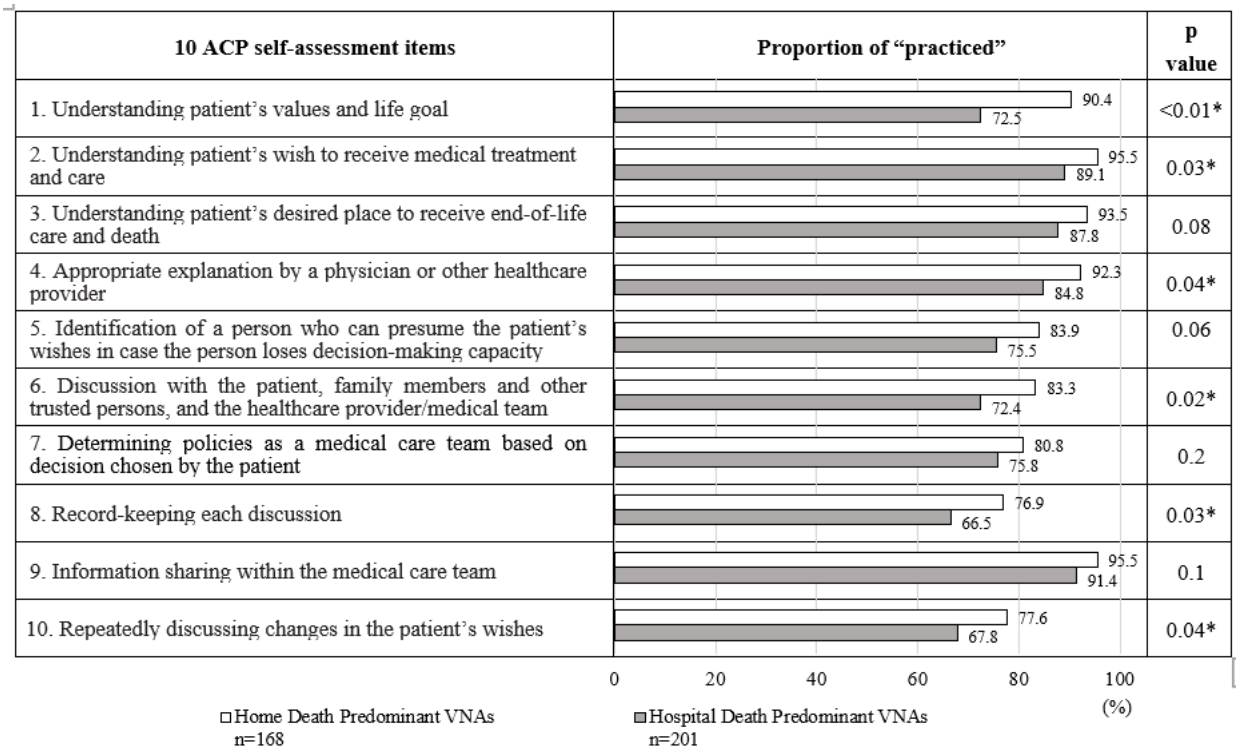



**Figure 1**

Proportion of "practiced" responses for each item in the 10 ACP self-assessment items: Comparison between Home Death Predominant VNAs and Hospital Death Predominant VNAs