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**Practice and Perceived Importance of Advance Care
Planning and Difficulties in Providing Palliative Care in
Geriatric Health Service Facilities in Japan: A Nationwide
Survey**

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Abstract

Background: The provision of end-of-life (EOL) care by geriatric health service facilities (GHSFs) in Japan is increasing. Advance care planning (ACP) is one of the most important issue to provide quality EOL care. This study aimed to clarify the practice and perceived importance of ACP and the difficulties in providing palliative care in GHSFs.

Methods: A self-report questionnaire was mailed to head nurses at 3,437 GHSFs nationwide. We asked participants about their practices regarding ACP, their recognition of its importance, and their difficulties in providing palliative care. We also analyzed the relationship between these factors and EOL care education.

Results: Among 844 respondents (24.5% response rate), approximately 69 to 81% of head nurses confirmed that GHSF residents and their families understood disease conditions and goals of care. There was a large discrepancy between the actual practice of ACP components and the recognition of their importance (e.g., asking residents about existing advance directive (AD) (27.5% practiced it while 79.6% considered it important), recommending completion of an AD (18.1% vs. 68.4%), and asking for designation of a health care proxy (30.4% vs. 76.8%)). EOL care education was provided at 517 (61.3%) facilities. Head nurses working at EOL care education–providing GHSFs practiced ACP significantly more frequently and had significantly fewer difficulties in providing palliative care.

Conclusion: A large discrepancy was found between GHSF nurses' practice of ACP and their recognition of its importance. Providing EOL care education in GHSFs may increase ACP practices and enhance respect for resident's preferences concerning EOL care.

Keywords

elderly, end-of-life care, long-term care facilities, geriatric health service facilities, advance care planning, advance directives, palliative care, education

1. Introduction

People's need for care increases as they grow older because of cognitive impairment¹, frailty² and multi-morbidity.³ Family care givers contribute a great deal of time and money for day-to-day support and care of patients at home.⁴ While individuals who require care prefer to live at home for as long as possible⁵, they cannot always do so until death because of difficulties involving family-provided care. In such cases, many enter long-term care facilities such as nursing homes.

In Japan, elderly people are cared for in various locations depending on their health condition, social situation, and availability including home care, long-term care hospitals, and long-term care facilities. Most of the services are free access and 70 to 90% of medical and care costs are covered by public health insurance and long-term care insurance. Long-term care facilities for the elderly include "special nursing homes for the elderly," which are residences for elderly people in need of constant care; "geriatric health services facilities" (GHSFs); and "group homes for elderly with dementia." According to the statistics of the Japanese government in 2015, the number of GHSF beds was 339,142, compared with 1,673,669 hospital beds nationwide. In average, each GHSF facility had 87.9 beds and hired 52.4 employees, including 1.1 doctors, 9.9 nurses, 28.1 care workers, and 3.2 rehabilitation professionals. In most GHSFs, nurses are responsible for the health management of residents and the supervision of care.

Originally, the role of GHSFs was to provide nursing care and rehabilitation services to elderly individuals who did not require hospitalization so that they could return home.⁶ However, due to the rapidly growing elderly population in Japan and a lack of nursing homes, end-of-life (EOL) care was added by public insurance to the list of services provided by GHSFs in 2006. In 2015, 29,127 Japanese died in GHSFs (2.3% of the total), compared to 962,597 (74.6%) in hospitals.⁷ Although the number of deaths in GHSFs increased more than two-fold between 2009 (12,600; 1.1%) and 2015 (29,127; 2.3%), it remains a small proportion of the total number of deaths.

Despite hopes that residents could remain in Japanese nursing homes until death, it was found that they were often hospitalized toward the EOL and died in hospitals.⁸ It is possible that the same

phenomenon is occurring in GHSFs.

Management of EOL care is often achieved via advance care planning (ACP), a process whereby the patient, in consultation with health care providers, family members, and important others, makes decisions about his or her future health care.^{9,10} ACP improves satisfaction with EOL care among patients and their families,¹¹ and reduces stress, anxiety, and depression in surviving relatives.^{11,12} In nursing homes, ACP significantly reduces both rates of hospitalization and the use of health resources.¹³ Several studies have reported that between 61% and 91% of older individuals would like to discuss their EOL care with others.¹⁴

In GHSFs that are increasingly responsible for caring for residents at EOL, the practice of EOL care is important.⁹ Hirakawa et al. showed that palliative care was provided significantly less often at facilities with regressive policies toward EOL care.¹⁵ In order to improve EOL care at GHSFs, it is necessary to characterize the actual state of this care, including palliative care based on ACP, at these facilities. Very few studies have been conducted on ACP in GHSFs, as compared with many studies in palliative care units and nursing homes.

Thus, the aims of this study were to clarify the following issues regarding GHSFs in Japan: the extent to which they practiced ACP and recognized its importance, and their difficulties in providing palliative care. We administered a questionnaire survey to the head nurses of GHSFs and analyzed the results to determine whether each institution provided EOL care education.

2. Methods

Participants

All 3,437 GHSFs that were members of the Japan Association of Geriatric Health Services Facilities in February 2012 were targeted. The questionnaire recipients were head nurses; they were considered the most appropriate subjects for our investigation of the practical implementation of ACP because they are responsible for nurses who provide day-to-day hands-on care. The total number of GHSFs in Japan in October 2011 was 3,533, and therefore this survey covered more

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5 than 90% of the facilities nationwide.
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8 9 **Design**

10 We conducted a nationwide cross-sectional survey by mailing a self-report questionnaire about
11 EOL care to the head nurse of each facility in May 2012. Each participant was sent a packet
12 containing a letter of invitation, the questionnaire, and a return envelope. Responses were
13 voluntary and anonymous. Informed consent for participation in the study was assumed upon
14 receipt of the completed questionnaire. A second request was sent 5 weeks after the initial survey.
15 The institutional review board of the Faculty of Medicine, University of Tsukuba, approved the
16 survey protocol (No. 635, approved on March 9, 2012).
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27 **Questionnaire**

28 The questionnaire examined each participating nurse's practices during residents' admissions to
29 the GHSF, their recognition of the importance of ACP, and their difficulties in providing palliative
30 care. The validity of the content of the questionnaire was verified by four experts in the fields of
31 geriatrics, palliative care, and gerontological nursing.
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37 Nurses' practices during residents' admissions and their perception of ACP were evaluated using
38 the questionnaire developed by Kizawa and Abe for the survey of palliative care physicians¹⁶. In
39 the original instrument, the Cronbach α coefficients for the parts of the questionnaire about
40 physicians' practice of ACP and their recognition of its importance were 0.884 and 0.881,
41 respectively. We required the participants to answer eight questions regarding their practices using
42 a 5-point Likert-type scale: "always," "often," "sometimes," "rarely," and "never." The 15
43 questions regarding their recognition of the importance of ACP were also scored on a 5-point
44 Likert-type scale: "very important," "important," "neither important nor unimportant," "not so
45 important," and "not important at all."
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56 Nurses' difficulties in providing palliative care were evaluated using the Palliative Care
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5 Difficulties Scale (PCDS), a 15-item, five-domain questionnaire. The five domains include
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7 “alleviation of symptoms,” “expert support,” “communication in multidisciplinary teams,”
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9 “communication with the resident and family,” and “community coordination.” Nurses evaluated
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11 how often they experienced difficulties in these areas using a 5-point Likert-type scale ranging
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13 from 1 to 5: 1 = never, 2 = occasionally, 3 = sometimes, 4 = often, and 5 = very frequently. The
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15 total score of the PCDS, obtained by adding the scores of the responses in each domain, ranges
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17 from 3 to 15. Higher scores indicate a higher level of difficulty providing palliative care. For the
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19 PCDS, the intraclass correlation for each domain ranged from 0.61 to 0.69.¹⁷ The validity and
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21 reliability of the scale has been established in Japanese hospital nurses.¹⁷
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24 In the text of all questions, instances of the word “patient” in the original were replaced with
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26 “resident.” The questionnaire also included items regarding each nurse’s demographic data,
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28 specifically age, sex, clinical experience, number of years of experience at a GHSF, the year that
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30 the GHSF at which they worked was established, the facility’s capacity, and provision of EOL care
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32 education to nurses at the same facility or elsewhere.
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34 35 36 **Statistical Analysis**

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38 Descriptive statistics were used to characterize sample demographics and other information.
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40 Respondents were divided into two groups depending on whether or not their facility provided
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42 EOL care education. Univariate analysis was used to compare the two groups in terms of the extent
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44 to which nurses practiced ACP, their recognition of the importance of ACP, and their difficulties
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46 in providing palliative care. The chi-square test was used for categorical variables and Student’s t-
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48 test was used for continuous variables. To adjust for differences in nurses’ and facilities’
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50 backgrounds, multivariate analyses were performed. Multivariate logistic regression was used for
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52 nurses who practiced ACP to calculate adjusted odds ratios (ORs) and 95% confidence intervals
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54 (95% CIs). Multiple linear regression was used for PCDS to calculate the standardized partial
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56 regression coefficient (β). The independent variables considered in these models were age, sex,
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5 clinical experience, experience at a GHSF, number of years since establishment, and number of
6 beds in the facility. The significance level was set at p values less than 0.05. All statistical analyses
7 were performed with IBM SPSS Statistics 24 for Windows (IBM Japan, Tokyo, Japan).
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10 11 12 13 **3. Results**

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15 A total of 844 head nurses participated in the survey, with a response rate of 24.5%. The
16 characteristics of the respondents are listed in Table 1. They were predominantly female, and their
17 median age was 53 years. The median durations of the nurses' clinical experience and experience
18 at a GHSF were 28 years and 7.5 years, respectively. Continuous education and training regarding
19 medical and nursing care were provided at 797 facilities (94.4%), and EOL care education was
20 provided at 517 (61.3%) facilities.
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30 **Nurses' Practices Regarding ACP in the GHSFs**

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32 Figure 1 shows nurses' practices regarding ACP in the GHSFs. A nurse was deemed to practice
33 regarding a certain aspect of ACP if he/she responded "always" or "often" in the survey. The
34 percentages of nurses who "always" or "often" confirmed the goals of treatment and care with the
35 resident's family, the goals of treatment and care with the resident, the resident's family's
36 understanding of the resident's illness(es), the preferred place of care desired by the resident, and
37 the resident's understanding of his/her illness(es), were 81.3%, 78.9%, 75.7%, 72.7%, and 68.5%,
38 respectively.
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46 The percentages of nurses who "always" or "often" asked the resident to designate a health care
47 proxy in case they were to lose their decision-making capacity, asked the resident about existing
48 advance directives (ADs), and recommended that the resident complete an AD in the event they
49 were to lose their decision-making capacity, were 30.4%, 27.5%, and 18.1%, respectively.
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Nurses' Recognition of the Importance of ACP

Figure 2 shows the results pertaining to nurses' recognition of the importance of ACP. A nurse was deemed to recognize the importance of a certain aspect of ACP if he or she responded "very important" or "important" in the survey. Items most commonly considered important were confirming the resident's family's understanding of the resident's illness(es) (96.8%), confirming the goals of treatment and care with the resident's family (95.8%), confirming the goals of treatment and care with the resident (95.0%), confirming the resident's understanding of his/her illness(es) (93.2%), confirming the preferred place of care desired by the resident (92.9%), and encouraging sharing of the goals of treatment and care between the patient and family (92.4%).

In contrast, items least frequently considered important were asking the patient whether they desired the use of antibiotics if they were to lose their decision-making capacity (54.6%), asking the patient whether they desired the use of fluid infusion if they were to lose their decision-making capacity (67.5%), and recommending that the resident complete an AD in case they were to lose their decision-making capacity (68.5%).

Discrepancies between Nurses' Practices of ACP and their Recognition of its Importance

For all items on the questionnaire, the percentages of nurses who "always" or "often" performed each ACP task were lower than those who considered the task to be "very important" or "important." These discrepancies were particularly large, at 52.1, 50.3, and 46.4 percentage points, respectively, with regard to asking the patient about existing ADs, recommending that the patient complete an AD in case they were to lose their decision-making capacity, and asking the patient to designate a health care proxy in case they were to lose their decision-making capacity.

Nurses' Difficulties in Providing Palliative Care

Table 2 shows the results pertaining to nurses' difficulties in providing palliative care. The mean value of the PCDS was 37.0. The scores of the five domains — "expert support," "alleviation of

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7 symptoms,” “communication in multidisciplinary teams,” “communication with the resident and
8 family,” and “community coordination” — were 9.3, 7.8, 7.0, 6.9, and 6.0, respectively.
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11 12 13 **Effect of EOL Care Education on Nurses’ Practice and Perception of ACP and Difficulties in** 14 **Providing Palliative Care** 15 16

17 Of the 844 participating GHSFs, EOL care education for nurses was provided at 517 facilities and
18 not provided at 322 facilities, with five facilities not responding. Characteristics of nurses and the
19 facilities at which they worked did not differ significantly based on whether the GHSF provided
20 EOL care education (Table 1).
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25 Figure 3 compares the extent to which nurses practiced ACP based on whether or not they
26 worked at GHSFs that provided EOL care education. Significantly more head nurses who worked
27 at GHSF providing EOL care education practiced all eight components of ACP investigated in this
28 study ($p < 0.001$).
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33 According to multivariate logistic regressions analysis, providing EOL care education was the
34 factor that most influenced the practice of all eight components of ACP, even after adjusting for
35 age, sex, experience at a GHSF, number of years since GHSF establishment, and number of beds
36 at the facility. Nurses’ clinical experience was correlated with age ($r = 0.673$, $p < 0.001$), and hence
37 clinical experience was not adopted as an independent variable in the multivariate models so as to
38 avoid the effects of multicollinearity. In terms of adjusted ORs, the largest was 2.60 (95% CI 1.72–
39 3.94, $p < 0.001$) for “recommending that the resident completes an AD in the event they lose their
40 decision-making capacity” and the smallest was 1.73 (95% CI 1.25–2.37, $p < 0.001$) for “asking
41 the resident to designate a health care proxy in case they lose their decision-making capacity.” Sex
42 (male = 1, female = 0) influenced the practice of “confirming the resident’s family’s understanding
43 of resident’s illness(es)” (adjusted OR 0.46, 95% CI 0.23–0.91, $p = 0.03$) while experience at a
44 GHSF influenced the practice of “confirming the preferred place of care desired by the resident”
45 (adjusted OR 0.70 every 10 years, 95% CI 0.52–0.95, $p = 0.02$). No other significant relationship
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5 was found between nurses' practices regarding ACP in the GHSFs and nurses' and facilities'
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9 In terms of recognizing the importance of ACP, significantly more head nurses at GHSFs that
10 provided EOL care education responded that it was important "to encourage sharing of the goals
11 of treatment and care between the resident and family" ($p = 0.044$), "to order DNR if determine
12 that the resident's family wishes for no CPR in the event of cardiopulmonary arrest" ($p = 0.008$),
13 and "to ask the resident whether they desire the use of tube feeding in the case of loss of their
14 decision-making capacity" ($p = 0.005$). The percentages of head nurses who answered "very
15 important" or "important" to the above three items at EOL care education–providing and non-
16 providing GHSFs were 94.5% vs. 88.8%, 92.1% vs. 84.4%, and 77.6% vs. 69.2%, respectively.
17 Although these differences were significant, the absolute differences were small.
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27 Table 2 compares nurses' difficulties in providing palliative care based on whether or not they
28 worked at a GHSF that provided EOL care education. Significantly fewer head nurses who worked
29 at a GHSF that provided EOL care education experienced difficulties in alleviation of symptoms
30 ($p < 0.001$), expert support ($p < 0.001$), communication in multidisciplinary teams ($p < 0.001$),
31 communication with the resident and family ($p = 0.006$), and community coordination ($p = 0.003$).
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38 According to multiple linear regression analysis, although age had an influence on the PCDS
39 score ($\beta = -0.103$, $p = 0.004$), providing EOL care education remained the most influential factor
40 ($\beta = -0.196$, $p < 0.001$) even after adjusting for age, sex, experience at a GHSF, number of years
41 since GHSF establishment and number of beds at the facility.
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48 **4. Discussion**

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50 This is the first nationwide survey of head nurses at GHSFs in Japan assessing practices regarding
51 ACP, recognition of the importance of ACP, and difficulties in providing palliative care.
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54 The most important finding of this study was that there were discrepancies between the actual
55 practice of ACP and the recognition of its importance. Large discrepancies were found in asking
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5 residents about existing ADs (27.5% practiced it while 79.6% recognized its importance),
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7 recommending completion of an AD (18.1% vs. 68.4%), and asking for designation of a health
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9 care proxy (30.4% vs. 76.8%). Of the various components of ACP, these three most directly
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11 involve determining and acting on the explicit wishes of the residents. Similar trends were seen in
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13 previous surveys of palliative care physicians.¹⁶ It has been pointed out that in Japan, patients are
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15 only minimally involved in EOL decision-making, whereas family involvement is strong.^{18,19} This
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17 is a common feature in other East Asian countries as well.^{20,21} Some people do not want to
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19 contemplate death when their own death is near.²² Given the traditional cultural background of the
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21 elderly in GHSFs, nurses may avoid talking with residents about issues related to death. On the
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23 other hand, it has been reported that many Japanese patients and families prefer collaborative
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25 decision-making and that a majority of patients have positive attitudes towards participation in
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27 medical decision-making if they are fully informed.²³ It is possible that educating GHSF nurses
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29 will enable them to provide appropriate EOL care, including encouraging residents to express their
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31 wishes.
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34 The second important finding was that in terms of administering palliative care, GHSF head
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36 nurses had particular difficulty in providing expert support. This contrasts with previous studies
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38 using the same questionnaire, which found that nurses at university hospitals, general hospitals,¹⁷
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40 and government designated cancer hospitals²⁴ had less difficulty in providing expert support than
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42 in fulfilling the other aspects of palliative care. Long-term care facility residents may receive
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44 inadequate EOL care,^{25,26} such as poor symptom control and transfer to an acute-care hospital to
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46 receive aggressive treatment when their death is inevitable and the estimated survival time is very
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48 short. It is possible that the quality of EOL care may be improved by consultation with experts
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50 such as palliative care physicians.²⁵
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53 The third important finding was that nurses who worked at GHSFs that provided EOL care
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55 education practiced ACP significantly more frequently, and their difficulty in providing palliative
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57 care was significantly lower. This result is supported by a survey of GHSF managing directors that
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5 we conducted at the same time as the present study.²⁷ According to the survey, many respondents
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7 whose facilities did not provide EOL care cited lack of EOL care education and 'fear of caring for
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9 dying residents as two of the major barriers to providing EOL care. In a qualitative study of nursing
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11 home, it was shown that poor staff education hindered ACP while continuous education
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13 encouraged it.²⁸ Previous studies suggested that education enhanced not only staff members'
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15 knowledge and attitudes, but also their practice and confidence regarding EOL care.^{29,30} Moreover,
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17 it was reported that education reduced physicians' difficulties in providing palliative care.³¹
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19 Hanson et al. showed that on-site education in nursing homes increased hospice palliative care
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21 consultation, pain management, and ACP discussion.³² EOL care education especially about ACP
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23 and palliative care is important to resolve the discrepancies between recognition of their
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25 importance and their actual implementation.
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28 In this study, it was found that providing EOL care education at GHSFs was significantly
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30 associated with a low level of nurses' difficulty in providing palliative care. However, while such
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32 education significantly improved communication with the resident and family as well as
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34 community coordination, the absolute difference was small. This may reflect insufficient
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36 educational content about communication and community coordination. Further qualitative
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38 research is required to clarify the contents of EOL care education provided at GHSFs.
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41 This study has some limitations. First, the response rate of 24.5% was low, and thus response
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43 bias cannot be excluded. Nurses interested in EOL care, palliative care, and ACP may have been
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45 more likely to respond. Historically, GHSFs sought to provide rehabilitation for medically stable
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47 elderly residents, and therefore some GHSFs still do not admit elderly individuals with terminal
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49 illnesses. Nurses who work at such facilities may not have responded to the questionnaire. Non-
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51 responders' practices regarding ACP, recognition of the importance of ACP, and difficulties in
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53 providing palliative care may differ from those identified in our results. Second, participants were
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55 restricted to head nurses, rather than all nurses at each facility. Head nurses have unique
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57 characteristics, including greater experience, and thus our results cannot be generalized to all
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5 nurses working at GHSFs. Third, the cross-sectional study design prevented us from determining
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7 causal associations between education on the one hand, and practices of ACP, recognition of the
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9 importance of ACP, and difficulties in providing palliative care on the other.
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11 In conclusion, large discrepancies were found between practicing ACP and recognizing its
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13 importance at GHSFs in Japan. Difficulties in providing palliative care were most pronounced in
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15 the area of expert support. Providing EOL care education including ACP in GHSFs may help
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17 minimize these discrepancies and achieve quality EOL care.
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37 Japan (2012).
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40 41 **Declaration of Conflicting Interests**

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43 The authors declare that there is no conflict of interest.
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Table 1. Characteristics of GHSF head nurses and facilities

Variable	All <i>n</i> = 844			End-of-life care education for nurses Providing <i>n</i> = 517			Not providing <i>n</i> = 322			<i>p</i> value
	Median	IQR	(Range)	Median	IQR	(Range)	Median	IQR	(Range)	
Sex, <i>n</i> (%) ^a										
Male	41	(4.9%)		24	(4.6%)		17	(5.3%)		0.74 ^b
Female	802	(95.0%)		492	(95.3%)		305	(94.7%)		
Age	53	10	(25–86)	53	11	(25–86)	54	10	(27–83)	0.48 ^c
Clinical experience, years	28	14	(0–52)	27	14	(0–52)	30	15	(1–49)	0.28 ^c
Experience at a GHSF, years	7.5	8	(0–24)	8	9	(0–24)	7	9	(0–24)	0.09 ^c
Number of years since GHSF establishment	9	4	(0–25)	9	8	(0–25)	9	8	(0–23)	0.93 ^c
Number of beds at the facility	100	20	(14–200)	100	20	(25–200)	100	23	(14–200)	0.09 ^c
Provision of education and training for nurses in or outside the facility, <i>n</i> (%)										
Continuous education about medical, nursing and hands-on care	797	(94.4%)		507	(98.0%)		288	(89.4%)		< 0.001 ^b
End-of life care education	517	(61.3%)		–			–			

IQR = interquartile range, GHSF = geriatric health services facility

^a Total percentages are not 100% due to one missing value.

^b *p* values were calculated from chi-square test, ^c *p* values were calculated from Mann–Whitney *U* test

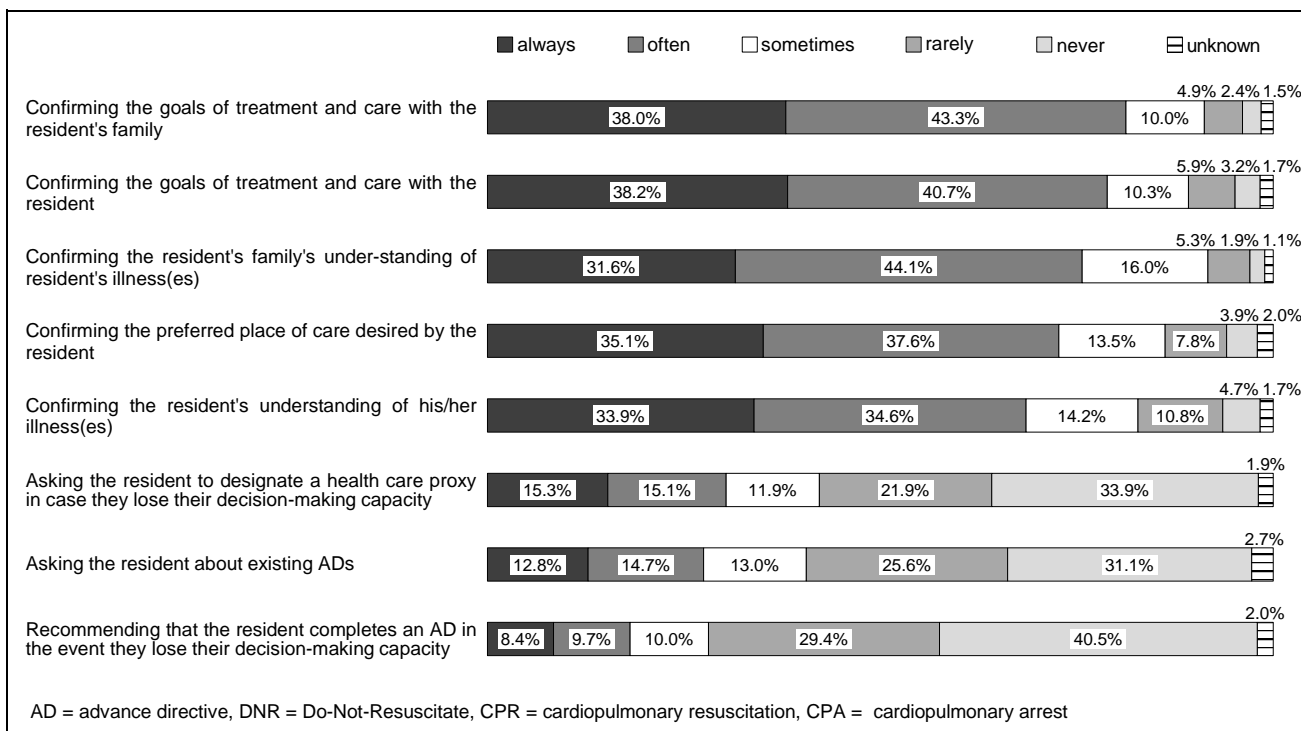


Figure 1. Nurse's practice regarding ACP

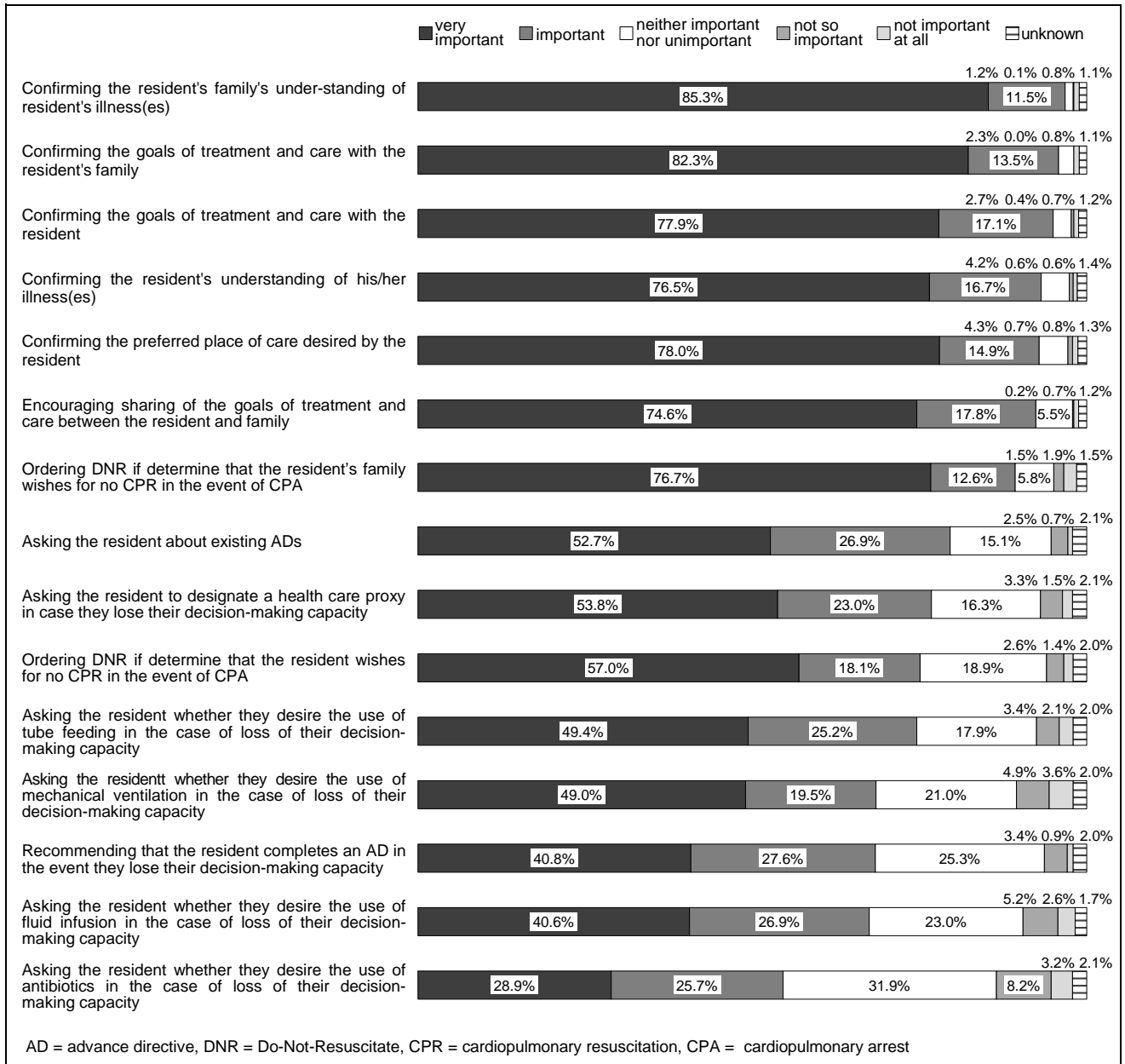


Figure 2. Nurse's recognition of importance of ACP

Table 2. Comparison of nurses' difficulties in providing palliative care based on whether or not a working GHSF provided end-of-life care education for nurses

	Total			End-of-life care education				
	Mean	SD	(Range)	Mean	SD	Mean	SD	<i>p</i> value ^a
Palliative Care Difficulties Scale (PCDS)	37.0	± 10.9	(15-75)	35.3	± 10.2	39.7	± 11.3	< 0.001
Expert support	9.3	± 3.8	(3-15)	8.8	± 3.8	10.1	± 3.7	< 0.001
Alleviation of symptoms	7.8	± 2.6	(3-15)	7.6	± 2.5	8.2	± 2.6	< 0.001
Communication in multidisciplinary teams	7.0	± 3.0	(3-15)	6.5	± 2.7	7.7	± 3.2	< 0.001
Communication with the resident and family	6.9	± 2.4	(3-15)	6.7	± 2.3	7.1	± 2.6	0.006
Community coordination	6.0	± 3.1	(3-15)	5.7	± 2.9	6.4	± 3.2	0.003

SD = standard deviation

^a *p* values were calculated from Student's *t*-test

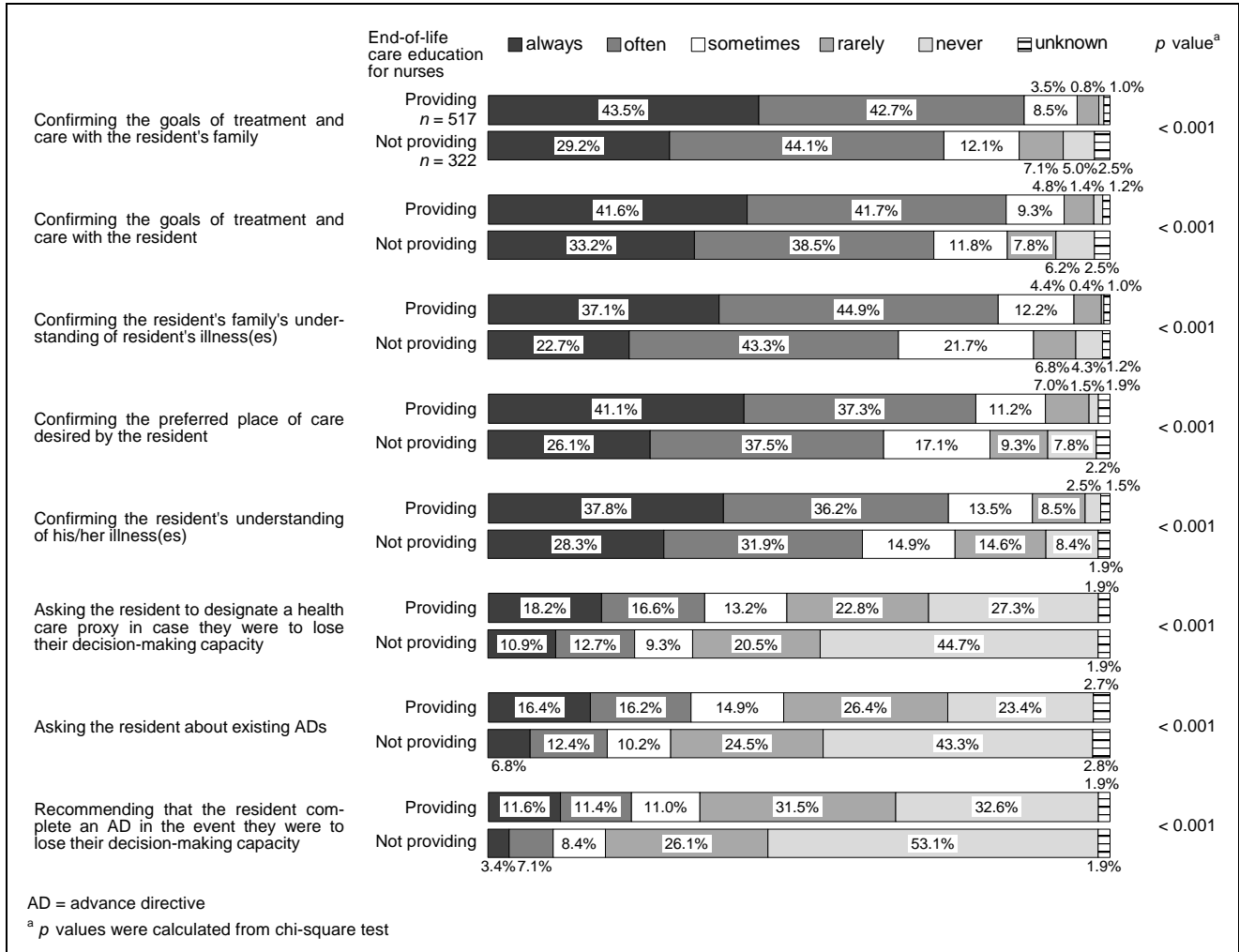


Figure 3. Comparison of nurses' practices regarding ACP based on whether or not a working GHSF provided end-of-life care education for nurses