

Relationship between implementation of systematic advance care planning and the quality of death among nursing home residents: a survey

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Abstract

Background: Advance care planning (ACP) is beneficial for the quality of death (QOD). However, the effects of ACP on the QOD may vary across cultures.

Objectives: This study aimed to explore the relationship between the 15-step ACP program and the QOD among Japanese nursing home residents.

Design: A cross-sectional survey.

Methods: A cross-sectional survey was conducted among the family members of 39 nursing home residents who died between April 2017 and March 2019 by distributing the survey questionnaire by post. The survey included questions about the QOD of residents, and responses were evaluated using the Good Death Inventory (GDI) scale.

Results: Responses were obtained from 30 of the 39 bereaved families (76.9%). Data were analyzed using hierarchical clustering to determine five groups and conduct multiple comparisons. The following three domains of interest were identified: 'Dying in a favorite place', 'Good relationship with the medical staff', and 'Independence'. GDI scores were significantly higher for residents with higher ACP completion rates than for those with lower rates ($p < 0.01$). Residents who had taken ACP interviews had significantly higher GDI scores ($p < 0.01$) than those who had not taken interviews.

Conclusion: Overall, these findings suggest that systematic ACP might be related to the QOD among Japanese nursing home residents in the above mentioned three domains. Limitations of the present study were small sample size, cross-sectional survey design as opposed to a cohort survey design, and multiple biases, including the emotional instability of bereaved family members, the length of stay of the residents, the degree of dementia of the residents, and their tendency to talk about the place of death and to develop good relationships with the medical staff.

Keywords: advance care planning, communication training, nursing home, quality of death

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Introduction

Advance care planning (ACP) has been reported to provide several benefits.^{1–5} For example, previous studies have reported that ACP enables the provision of a wider scope of advance directives,⁶

supports end-of-life care (EOLC) based on individual preferences,⁷ and improves patient-centered communication.⁸ However, there are several barriers to ACP implementation, including emotional reactions of the individual and family,

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limited number of healthcare professionals, lack of time, and poor communication skills of the practitioners.⁹

Nevertheless, a systematic review by Martin *et al.*¹⁰ and the *Guidelines for End-of-Life Care of Non-Cancer Diseases* by the Research Group to Develop Guidelines for End-of-life Care (EOLC) for Non-cancer Diseases¹¹ showed the effectiveness of ACP for nursing home residents. However, information on the best intervention approaches is still limited.

The outcomes of ACP have generally been identified on the basis of readmission rates,¹² place of death,¹³ and care consistent with residents' wishes¹⁴ according to the setting.

Studies using the quality of death (QOD) as an outcome are also limited.^{10,11,15}

A literature review on ACP programs in Japan concluded that ACP implementation is limited due to the lack of opportunities for individuals to express their preferences and values. Another challenge is limited knowledge among healthcare providers on how to improve their communication skills and facilitate QOD in various care settings.^{16–18}

The role of culture in ACP implementation cannot be overlooked. Although ACPs have been successfully developed in regions that value autonomy, mainly English-speaking countries,^{1,6,7} research conducted in a culture where individual autonomy is subordinate to family values and the authority of doctors, such as East Asian countries like Japan, has been limited.^{19,20} In Japan, individuals commonly refrain from clearly expressing their true intentions during consultations in clinical settings. To ensure effective care, healthcare providers are mandated to elicit information closer to an individual's 'true wishes' through further communication.²¹ The term 'individuals' here applies to nursing home residents, family members, and healthcare professionals. Regardless of the presence or absence of dementia, the elderly have difficulty implementing ACP.²² Furthermore, Japanese elderly people do not express their true intentions due to their cultural background. Therefore, in cooperation with family members and facility care teams, we implemented the 15-step ACP program as listed in Table 1.

The purpose of this study was to explore the relationship between the 15-step ACP program and QOD.

Methods

Definition

As described in the Japan Geriatrics Society statement, ACP is a process that supports people in making decisions and accords respect to each individual as a human being about their future medical needs and long-term care. This definition implies that older adults who have been admitted to a long-term care facility should initiate and consider ACP discussions even if they are suffering from physical and/or mental disabilities, which make it difficult for them to express their wishes and preferences.²¹

Research design and study site

This cross-sectional questionnaire survey was conducted in a Japanese nursing home practicing the 15-step ACP approach since April 2016. The facility chief nurse, social worker, registered dietitian, facility director, and physician developed and tested the feasibility of a 15-step ACP approach for an ACP, named ACPiece-15, based on Kolb's experiential learning theory.²³ Full implementation of all steps is required, but no one will be held responsible for failure to implement the program. ACPiece-15 is recognized as a good practice within the facility to protect residents' rights. A completed ACP interview is defined as completing the 15-step approach and ACP form, whereas systematic ACP implementation refers to completing the 15-step approach.

The 15-step ACP approach was implemented as a usual care and not a clinical study.

Attendance at ACP training was defined as participating in a 1-h group ACP training for residents and their families, held twice a year at the facility. During the ACP training, the advantages and disadvantages of life-prolonging treatments were shared between one facilitator and several participants in an interactive manner, using PowerPoint slides and videos. A question and answer session was held after the ACP training.

Participants

We mailed a questionnaire to the bereaved families of 39 residents who died in a Japanese nursing home between April 2017 and March 2019 on 1 February 2021 and asked them to return it within 1 month. Respondents were selected based on the following inclusion criteria: family members aged

Table 1. The 15-step approach for ACP implementation in nursing homes.

Step 1: When nursing home caregivers notice that a resident is in the process of natural weakening, they inform the recognition among conference members that ACP communication is necessary for residents and their family dyads in daily conversations and conferences.

Step 2: Conference members review ACP conversations with residents and their family dyads.

Step 3: Facility nurses trained in ACP introduce the ACP program to the dyads.

Step 4: Nurses suggest an ACP interview involving the dyads and multidisciplinary team members, such as chief nurse, social worker, registered dietitian, facility director, and physician.

Step 5: A 5-min conversation among the team members was allowed before the ACP interview.

Step 6: Team members initiate the ACP interview with the resident and family dyad. If the resident is unable to participate in the ACP interview due to impaired decision-making capacity or physical function, the team members conduct a family-centered ACP interview focusing on the resident. In parallel, the resident is informed and assents to the content of the ACP interview.

Step 7: The facility physician shares the process of the ACP interview with the dyads.

Step 8: The physician explains the illness and physical functioning status of the resident to the dyads.

Step 9: The chief nurse encourages the dyads to express their emotions. Team members use communication skills, such as repetition and silence, to support the dyad's feelings.

Step 10: When the dyads decide to spend their final period in the facility, the next step is taken. When the dyads request further treatment to improve the resident's condition, the facility physician makes a referral to a hospital. At that time, the physician will include the following points about the time-limited trial in the medical information form. If the resident's condition does not improve during the hospital's treatment, such as infusions, they may spend their final period in the facility.

Step 11: Participants in the ACP interview share that the dyad's decision may change.

Step 12: The facility staff, who are participants in the ACP interview, discuss the use of opioids as needed and the delay in confirming the resident's death due to the physician's part-time employment.

Step 13: The ACP form is completed by both the physician and dyad, and it includes not only Do-Not-Attempt-Resuscitation and Do-Not-Hospitalize orders but also information about the dyadic relationship and values.

Step 14: Participants conduct a life review and discuss the care that will keep the resident calm. This is the most important step of the ACP interview process.

Step 15: Participants share their best efforts, and the ACP interview is completed.

A dyad is a pair of people: a nursing home resident and his or her advocate.
ACP, advance care planning.

at least 20 years of age and those members with 2–4 years interval between the death of the resident and survey participation. We selected this specific time frame because we anticipated that the family members would have a clear recollection of the resident's death and have had time to cope with their loss. Bereaved family members who were still experiencing intense grief were excluded. One family member who was still grieving was excluded from the survey at the discretion of the facility's care team as they deemed the

person emotionally unstable and unable to complete the survey.

Participants were recruited for the survey using the consecutive sampling method.

Outcome measure

The primary outcome was QOD, which was assessed using the Good Death Inventory (GDI). The GDI consists of 18 domains: 10 core and 8

optional domains. Each domain contains three items. For this study, only the 10 core domains were used, resulting in 30 items.²⁴ The GDI manual can be used on a per-domain basis. The manual was initially developed as a questionnaire to assess QOD for patients with cancer but has been recently adapted for patients without cancer.^{25,26}

The GDI is a questionnaire on QOD that has been tested for reliability and validity not only in Japan²⁴ but also in East Asian countries, such as China²⁷ and Korea.²⁸

The 10 core domains (Q01–Q10) included physical and psychological comfort, dying in a favorite place, maintaining hope and pleasure, having a good relationship with medical staff, not being a burden to others, having a good relationship with family, independence, environmental comfort, being respected as an individual, and life completion.²⁴ We focused on the following four domains: dying in a favorite place, having a good relationship with medical staff, independence, and life completion (Q02, Q04, Q07, and Q10, respectively). These domains can also be adapted for dementia.

Data collection procedure

This study was approved by the Institutional Review Board of the National Center for Geriatrics and Gerontology (No. 1262) and conformed to the provisions of the Declaration of Helsinki (as revised in Brazil, 2013). All study participants provided written informed consent, and their anonymity was preserved.

Participants were contacted *via* mail and consented in writing by returning the consent form and questionnaire survey.

Statistical analysis

Data were analyzed using Microsoft® Excel® 2016 provided by Microsoft Corporation, USA, EZR version 1.55, and R version 4.0.3 software. Continuous variables were presented as mean and standard deviation, whereas categorical variables were presented as frequency and percentage. Missing data were supplemented using the mean scores of other items available for each domain. The missing data were correctly and statistically analyzed according to the GDI scoring manual by Miyashita *et al.*²⁴

Hierarchical cluster analysis was performed with the assistance of a statistical expert to explore the overall trends in GDI scores, including participants' demographic characteristics. Thereafter, multiple comparisons were performed using the Holm method to adjust *p* values for each relevant domain. Adjusted *p* values of <0.01 were considered statistically significant.

Analyses, including age, sex, whether the bereaved families attended ACP training (usually conducted twice a year), whether they completed the ACP interview, and the elapsed time between the date of death and questionnaire administration were performed for each GDI domain. *p* Values, 95% confidence intervals, and effect sizes for score differences were calculated; *p* values of <0.05 were considered statistically significant. Effect sizes were reported as Cohen's *d*,²⁹ with 0.2 as small, 0.5 as medium, and 0.8 as large.

Results

Participant characteristics

Of the 39 bereaved families, 30 responded to the questionnaire. No follow-up invitations were sent to the nine individuals who did not respond to the questionnaire to avoid causing any emotional burden. This resulted in a response rate of 76.9%, with an acceptable margin of error of 9% at the 95% confidence level. The sociodemographic characteristics of 30 residents who died in the nursing homes are listed in Table 2. Among them, 23 (76.7%) had dementia and 26 (86.7%) completed ACP interviews while still being cared for. We defined 'senility' as per the 'Manual for Completing Death Certificate' by the Ministry of Health, Labour and Welfare as the 'death of an elderly person with no other cause of death noted, commonly known as natural death'. ACP training attendance, ACP interview completion, and opioid use were confirmed by reviewing medical records.

Multiple comparisons of GDI domains across the five clusters

Multiple comparison analysis was performed for 10 domains among the 5 groups classified *via* hierarchical cluster analysis and characterized by different ACP completion rates (Figures 1 and 2). Of the 10 domains, 4 significantly

Table 2. Characteristics of residents who died in a nursing home.

Characteristics	Male	Female
	<i>n</i> = 7	<i>n</i> = 23
Age (SD)	85.6 (9.8)	91.2 (4.2)
Disease (%)		
Dementia	5 (71.4%)	18 (78.3%)
Parkinson's disease	0 (0%)	1 (4.3%)
Heart failure	0 (0%)	2 (8.7%)
Senility	1 (14.3%)	2 (8.7%)
Cancer	1 (14.3%)	0 (0%)
Relationship with bereaved family members (%)		
Wife	3 (42.9%)	0 (0%)
Eldest son and his wife	2 (28.6%)	12 (52.2%)
Eldest daughter and her husband	1 (14.3%)	7 (30.4%)
Other	1 (14.3%)	4 (17.4%)
ACP training attendance		
Not attended*	5 (71.4%)	18 (78.3%)
Attended [§]	2 (28.6%)	5 (21.7%)
ACP interview completion		
Not completed [‡]	1 (14.3%)	3 (13.0%)
Completed [§]	6 (85.7)	20 (87.0%)
Opioid use		
Not used	6 (85.7%)	18 (78.3%)
Used	1 (14.3%)	5 (21.7%)
Interval between the date of death and questionnaire survey		
Days (SD)	1188.8 (183.7)	1049.8 (253.9)

*Bereaved family members who never attended ACP training with residents.
[§]Bereaved family members who attended ACP training with residents.
[‡]Bereaved family members who never completed an ACP interview with residents.
[§]Bereaved family members who completed an ACP interview with residents.
 ACP, advance care planning; SD, standard deviation.

differed between the 5 groups (adjusted $p < 0.01$). These four domains were Q02: Dying in a favorite place, Q04: Good relationship with medical staff, Q07: Independence, and Q10: Life completion. Figure 1 presents the multiple comparison analysis of four domains. Figure 2

illustrates the relationship between the ACP completion rate within each of the five groups and the four domains showing significant group differences. Groups with higher ACP completion rates tended to have higher GDI scores in several domains than those with lower rates.

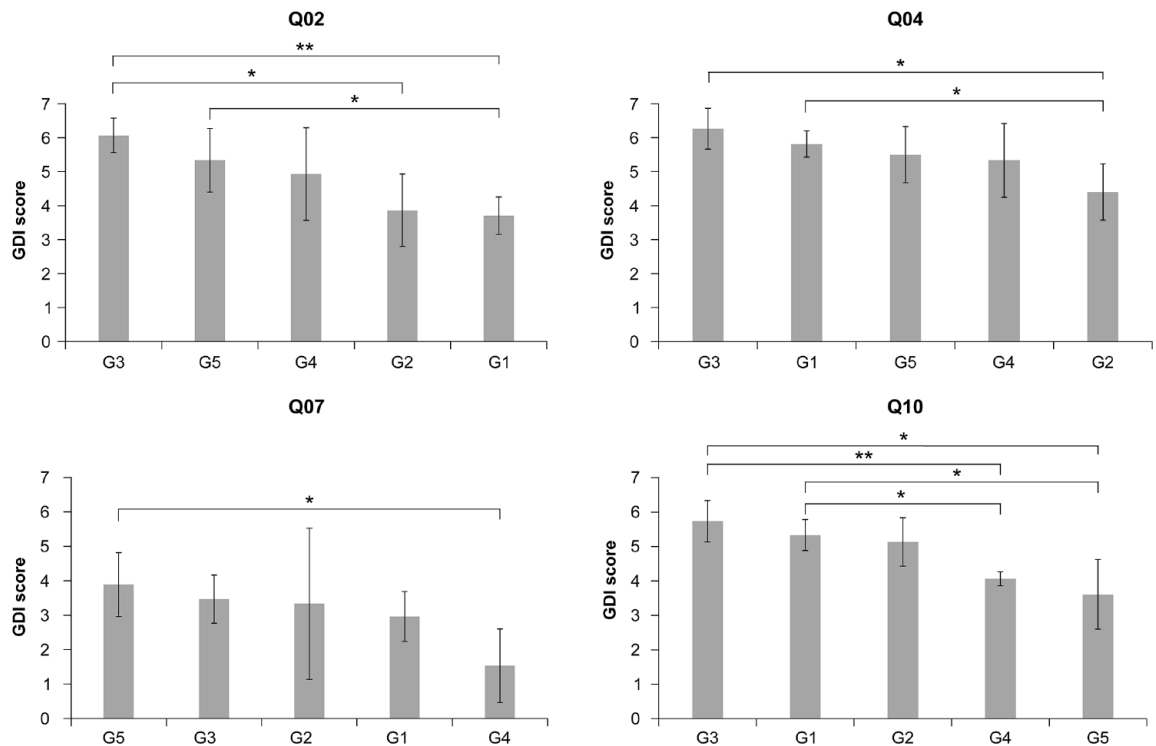


Figure 1. Multiple comparison analysis of the five groups classified *via* cluster analysis. Hierarchical cluster analysis was performed based on GDI scores and demographic characteristics of 30 participants. Five distinct groups were extracted: Groups 1–5. G1–G5 denote Groups 1 to 5. Multiple comparison analyses were performed using Holm method for each of the 10 GDI domains from Q01 to Q10 among G1–G5. Of the 10 domains, 4 showed significant differences between the five groups (adjusted $p < 0.01$ using the Holm method). These domains were Q02: Dying in a favorite place, Q04: Good relationship with medical staff, Q07: Independence, and Q10: Life completion. The bars denote the mean GDI score in each domain for the five groups and the error bars denote 95% confidence intervals.

*Adjusted p value < 0.01 . **Adjusted p value < 0.001 .

GDI, Good Death Inventory.

Group 5 was distinctive because Group 5 residents and bereaved families had higher ACP completion rates and positive significant differences in several GDI domains but negative significant differences only in the GDIQ10 domain.

Analyses of GDI scores for participants with and without ACP participation

Table 3 presents the analysis results based on the presence or absence of participation in ACP training and completion of ACP interviews. For Q02: Dying in a favorite place, GDI scores were significantly higher for those with ACP training experience than for those without ACP training experience ($p = 0.002$). For Q02: Dying in a favorite place, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience

($p = 0.042$). For Q04: Good relationship with the medical staff, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience ($p = 0.019$). For Q07: Independence, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience ($p = 0.004$). In contrast, for Q10: Life completion, GDI scores were not significantly different for those with ACP interview experience than for those without ACP interview experience ($p = 0.726$). In the analysis based on age, for Q10: Life completion, the GDI score for residents aged more than or equal to 90 years was significantly higher than that for those aged less than 90 years ($p = 0.032$; 95% confidence interval -1.690 to -0.087 ; effect size 0.901). The results for sex and elapsed days between the date of death and questionnaire administration showed no significant differences.

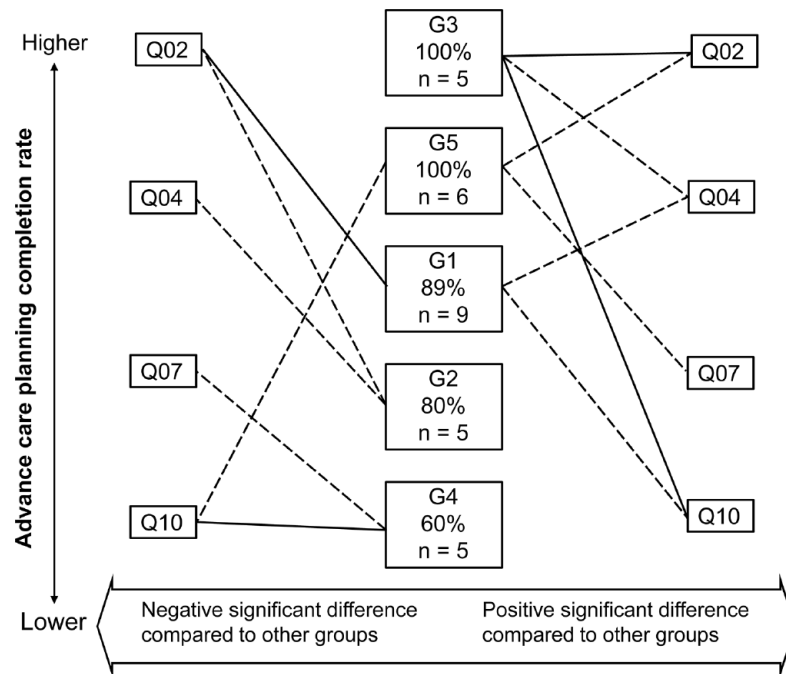


Figure 2. Relationship between ACP completion rates in each of the five groups and four GDI domains showing significant group differences. G1–G5 denote Groups 1 to 5 classified *via* cluster analysis. The GDI domains are as follows: Q02: Dying in a favorite place, Q04: Good relationship with medical staff, Q07: Independence, and Q10: Life completion. The ACP completion rates and the number of cases are indicated below the group names. Of the lines connecting G1–G5 and the four core GDI domains, the line on the left was negatively significant and the line on the right was positively significant. The dotted line indicates a significant difference compared with the other groups (adjusted $p < 0.01$), whereas the solid line indicates a large significant difference compared with the other groups (adjusted $p < 0.001$). The group located at the upper part of the figure has a higher ACP completion rate than the group located at the lower part. Similarly, the group located at the upper part of the figure has more positive significant differences in GDI score for each domain, whereas the group located at the lower part has more negative significant differences. In contrast, there is a negative significant difference in the GDI Q10 score in Group 5, despite the inclusion of other domains with positive significant differences.

ACP, advance care planning; GDI, Good Death Inventory.

Implementation of the 15-step ACP program

Who conducted the 15 steps of ACP? Steps 1 and 2 were performed by nonphysician professionals such as caregivers, occupational therapists, dietitians, social workers, and nurses. Steps 3, 4, and 9 were performed primarily by nurses who had received the ACP training. Steps 5–8 and 10–13 were performed primarily by part-time physicians. Steps 14 and 15 were performed by dietitians, social workers, nurses, and part-time physicians.

Conversation content, and resident and family reactions. The conversations with family included the following examples:

All we want is for the pain and suffering to be taken away.

I want to pass away peacefully as I sleep.

She loved sweets, so I want her to have something sweet to eat even in her last moments.

He liked to drink alcohol, so I want him to be able to drink alcohol at the end of his life.

I want to spend my last days with my loved one at a facility (in the case of a young and strong family member).

I want to visit my loved one only during the daytime. I want the facility staff to watch over him at night (in the case of an older, frail family member).

Documentation of what was discussed. The following items were discussed and documented:

Table 3. Analyses of GDI scores between ACP implementation and non-ACP implementation in the four domains.

Variables	Sex	Attended ACP training	Completed ACP interview
Category	Male/female	No [§] /yes [‡]	No [§] /yes
<i>N</i>	7/23	23/7	4/26
Q01: Physical and psychological comfort			
Mean (SD)	6.0 (0.8)/5.4 (0.8)	5.4 (0.9)/6.0 (0.6)	5.5 (1.3)/5.5 (0.8)
<i>p</i> Value	0.116	0.0501	0.957
95% CI	-0.180 to 1.397	-1.218 to 0.002	-2.027 to 1.951
Cohen's <i>d</i>	0.735	0.811	0.036
Q02: Dying in a favorite place			
Mean (SD)	5.0 (1.4)/4.3 (1.2)	4.1 (1.2)/5.6 (0.8)	3.8 (0.5)/4.6 (1.3)
<i>p</i> Value	0.271	0.002**	0.042*
95% CI	-0.646 to 2.037	-2.271 to -0.611	-1.619 to -0.035
Cohen's <i>d</i>	0.526	1.406	0.822
Q03: Maintaining hope and pleasure			
Mean (SD)	4.9 (1.2)/4.5 (1.3)	4.6 (1.2)/4.7 (1.6)	4.0 (1.6)/4.7 (1.2)
<i>p</i> Value	0.543	0.826	0.467
95% CI	-0.846 to 1.516	-1.656 to 1.358	-3.182 to 1.797
Cohen's <i>d</i>	0.266	0.105	0.480
Q04: Having a good relationship with medical staff			
Mean (SD)	5.4 (0.8)/5.5 (0.9)	5.5 (0.9)/5.3 (0.8)	4.5 (0.6)/5.6 (0.8)
<i>p</i> Value	0.890	0.503	0.019*
95% CI	-0.821 to 0.722	-0.511 to 0.983	-1.961 to -0.270
Cohen's <i>d</i>	0.059	0.284	1.594
Q05: Not being a burden to others			
Mean (SD)	3.1 (0.7)/2.7 (1.4)	3.0 (1.3)/2.4 (1.1)	4.0 (1.4)/2.7 (1.2)
<i>p</i> Value	0.312	0.319	0.151
95% CI	-0.406 to 1.214	-0.584 to 1.640	-0.796 to -3.489
Cohen's <i>d</i>	0.368	0.434	1.039
Q06: Having a good relationship with family			
Mean (SD)	4.9 (0.9)/4.6 (1.0)	4.7 (1.0)/4.3 (1.0)	4.0 (0.8)/4.7 (1.0)
<i>p</i> Value	0.479	0.297	0.173
95% CI	-0.586 to 1.169	-0.463 to 1.370	-1.937 to 0.475
Cohen's <i>d</i>	0.308	0.474	0.819

(Continued)

Table 3. (Continued)

Variables	Sex	Attended ACP training	Completed ACP interview
Q07: Independence			
Mean (SD)	2.3 (1.5)/2.4 (1.3)	2.3 (1.2)/2.7 (1.8)	1.3 (0.5)/2.5 (1.4)
<i>p</i> Value	0.871	0.550	0.004**
95% CI	-1.529 to 1.318	-2.137 to 1.230	-2.087 to -0.490
Cohen's <i>d</i>	0.074	0.295	1.255
Q08: Environmental comfort			
Mean (SD)	6.0 (0.6)/5.5 (0.7)	5.5 (0.8)/5.9 (0.4)	5.5 (0.6)/5.6 (0.8)
<i>p</i> Value	0.073	0.138	0.737
95% CI	-0.056 to 1.099	-0.788 to 0.117	-0.963 to 0.732
Cohen's <i>d</i>	0.792	0.541	0.172
Q09: Being respected as an individual			
Mean (SD)	5.9 (0.9)/5.8 (0.9)	5.7 (0.9)/6.1 (0.7)	5.9 (0.2)/5.7 (0.9)
<i>p</i> Value	0.852	0.191	0.321
95% CI	-0.792 to 0.941	-1.147 to 0.252	-1.362 to 0.749
Cohen's <i>d</i>	0.454	0.548	0.230
Q10: Life completion			
Mean (SD)	4.9 (0.9)/5.3 (1.1)	5.2 (1.1)/5.3 (0.8)	5.0 (1.2)/5.2 (1.0)
<i>p</i> Value	0.293	0.766	0.726
95% CI	-1.335 to 0.441	-0.898 to 0.674	-1.970 to 1.508
Cohen's <i>d</i>	0.454	0.117	0.211

For Q02: Dying in a favorite place, GDI scores were significantly higher for those with ACP training experience than for those without ACP training experience ($p=0.002$). For Q02: Dying in a favorite place, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience ($p=0.042$). For Q04: Good relationship with the medical staff, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience ($p=0.019$). For Q07: Independence, GDI scores were significantly higher for those with ACP interview experience than for those without ACP interview experience ($p=0.004$). In contrast, for Q10: Life completion, GDI scores were not significantly different for those with ACP interview experience than for those without ACP interview experience ($p=0.726$).

§Bereaved family members who never attended ACP training with residents.

‡Bereaved family members who attended ACP training with residents.

§Bereaved family members who never completed an ACP interview with residents.

||Bereaved family members who completed an ACP interview with residents.

* $p < 0.05$, ** $p < 0.01$.

ACP, advance care planning; CI, confidence interval; GDI, Good Death Inventory; SD, standard deviation.

Do not hospitalize.

With or without intravenous infusion.

Do not attempt resuscitation.

With or without nasogastric tube.

With or without opioid use.

With or without percutaneous endoscopic gastrostomy.

Timing of death confirmation

The timing of death was confirmed and documented in all cases. In Japan, approximately 80% of patients die in a hospital, and many of those who die are documented with a real-time death confirmation provided by their physicians. On the other hand, more than 90% of physicians in Japanese nursing home work part-time and cannot immediately confirm death. Additionally, the Japanese Medical Practitioners Law prohibits physicians from issuing a death certificate without directly examining the patient. Therefore, talking about the 'timing of death confirmation' was set as default.

Discussion

To the best of our knowledge, this is the first study to report that systematic ACP implementation in nursing homes might have some relationship with QOD for nursing home residents, depending on the QOD domain, in a Japanese context.

Several international studies have evaluated nursing home residents and examined intervention methods with their respective outcomes.^{10,30} However, these studies did not clearly define the intervention methods to show QOD improvement as an outcome.³¹ Moreover, due to cultural differences, intervention methods may not be similarly effective across all countries.³² Although some studies related to ACP have been conducted in Japan, none have clearly defined ACP implementation or used QOD as an outcome.³³ The results of this study will be more beneficial for patients in countries where people tend not to speak their true intentions and need to repeat ACP conversations more than written ACPs. In recent years, it has been pointed out that in English-speaking countries, ACP may be facilitated by a combination of a website and easy-to-read advance directives, with minimal intervention by healthcare professionals.³⁴ However, in Japanese culture, careful and repeated conversations are still necessary. This is because Japanese people live in a culture where they do not express their true intentions in words.

Regarding the choice of the ACP program, the six-step Palliative Care for Older People (PACE) program falls short of improving comfort during the last week of life.³⁵ Both the 6-step PACE program and the 15-step ACP program implemented in this study comprise steps involving residents

and family members. Although the 15-step program included steps for care during the last days of life, as found in the 6-step program, it excluded care after death. Notably, the 14th step of the 15-step program involved a life review and discussion on the care that will keep residents calm. Given the cultural differences and different QOD metrics, generalizing these findings may be difficult. Nevertheless, the 15-step program described in this study may be suitable for the Japanese population and may be related with the QOD of Japanese nursing home residents.

The most important finding of this study is the use of QOD as an outcome measure to evaluate ACP implementation. Remarkably, the 15-step approach for ACP implementation, which was systematically practiced, might be related to QOD. The use of GDI allows the evaluation of not only high or low QOD scores but also the relationship between the 15-step program and various GDI domains.

An interesting finding of the present study was the description of the person in charge for the implementation of each step of the ACP program, the conversation topics that took place, and the specific content that was documented. This is the first study including new qualitative findings related to the discussion of the relationship between systematic ACP implementation and QOD in nursing homes.

The limitations of this study include the small sample size, cross-sectional survey design as opposed to a cohort survey design, impact of one bereaved family member excluded from the survey due to emotional instability, and impact of length of stay and degree of dementia on the domain 'Good relationship with the medical staff'.

Several other important study limitations should also be acknowledged. The dyads who implemented ACP may have been more likely to discuss their favorite place to die and to have a good relationship with medical staff even before the ACP implementation, compared to those who did not implement ACP. Additionally, only 7 of the 30 participants attended ACP training, although 26 out of the 30 participants participated in the ACP interview. Several factors might account for this discrepancy. The ACP training was conducted at a time when the residents were in good general condition and anyone could participate in the group session, whereas the ACP

interview, which was part of a 15-step process, was conducted at a time when the residents were in poor general condition and only the residents and the residents' family members invited by the facility could participate in individual interviews. In other words, it might be easier to implement ACP at a time when the general condition of the patient has deteriorated and when the dyad feels that it is a personal matter rather than an item of interest for someone else.

The following four reasons could be inferred for the failure to complete the ACP interview by 4 of the 30 participants: (i) the family was busy; (ii) the family had decided that if the resident's condition worsened, he/she would have to go to the hospital; (iii) the deterioration of the resident's condition was too rapid for the interview to be held; and (iv) the relationship between the family and the facility staff was poor.

These biases are more important study limitations, which can be attributed to the study design.

Moreover, the findings of this study are applicable to only East Asian countries due to cultural differences.

Conclusion

In conclusion, the findings of this study suggest that systematic ACP implementation in nursing homes in Japan has some relationship with QOD in three domains for nursing home residents, namely, 'Dying in a favorite place', 'Good relationship with medical staff', and 'Independence'. Thus, these findings indicate that QOD discussion should not be based solely on high or low ratings but on an understanding of all associated intricacies due to its diverse perspectives. Additional prospective studies such as cohort studies and randomized controlled trials are needed to evaluate ACP interventions using QOD as an outcome in nursing homes with careful consideration of the Japanese culture. This research should be conducted using mixed research methods, combining quantitative and qualitative research.

Declarations

Ethics approval and consent to participate

The study was approved by the Institutional Review Board of the National Center for Geriatrics

and Gerontology (No. 1262) and conforms to the provisions of the Declaration of Helsinki (as revised in Brazil, 2013). All study participants provided written informed consent.

Consent for publication

All study participants agree to the publication.

Author contributions

Yoshie Toyoda: Conceptualization; Data curation; Investigation; Methodology; Writing – original draft; Writing – review & editing.

Aya Tokumasu: Conceptualization; Investigation; Methodology; Supervision.

Yuki Minato: Conceptualization; Investigation; Methodology; Supervision.

Takayasu Sone: Project administration; Supervision.

Kyoko Oshiro: Project administration; Resources; Supervision.

Hideki Kojima: Funding acquisition; Project administration; Supervision.

Mitsunori Nishikawa: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Resources; Software; Supervision; Visualization; Writing – original draft; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

The datasets generated and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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