Development, Validity, and Reliability of a Japanese Version of End-of-Life in Dementia Scales

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Research Article

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Abstract

Background: End-of-life care quality should ideally be evaluated by patients themselves. However, patients suffer clinical symptoms and conspicuous cognitive and physical decline in end-stage dementia. Therefore, family members and nurses are often good proxies for evaluating patients' satisfaction with end-of-life care and symptoms in end-stage dementia. The End-of-Life in Dementia scales, originally written in English, were specifically designed to examine the quality of end-of-life care for persons with dementia. This study aimed to develop a Japanese version of the End-of-Life in Dementia scales and evaluate its validity and reliability in Japan.

Methods: The Japanese version of the End-of-Life in Dementia scales (EOLD-J) was created by translating the following original scale measurements: Satisfaction with Care (SWC-EOLD-J), Symptom Management (SM-EOLD-J), and Comfort Assessment in Dying with dementia (CAD-EOLD-J). Participants were 113 family members of deceased residents who received end-of-life care and died at 33 participating nursing homes, and 113 nurses who provided care to the residents. Participants were asked to recall residents' last months and select related items on an evaluation form. The reliability of the scales was evaluated using a Cronbach's alpha. The construct validity of the relationships between the SWC-EOLD-J scores and the Japanese Decision Regret Scale (DRS-J), the SM-EOLD-J and the short version of Quality of Life Questionnaire for Dementia (short QOL-D), and the CAD-EOLD-J and the short QOL-D were evaluated using Spearman's rank correlation coefficient.

Results: Responses from 83 deceased residents' family members, and 62 nurses were analyzed. The Cronbach's alphas of the SWC-EOLD-J was 0.77, the SM-EOLD-J was 0.60, and the CAD-EOLD-J was 0.88. The SWC-EOLD-J score was significantly correlated with DRS-J ($\gamma=0.504, p < 0.001$). The SM-EOLD-J score was significantly correlated with subscale of the short QOL-D: negative dimension ($\gamma=0.587, p < 0.001$), the CAD-EOLD-J score was significantly correlated with subscale of the short QOL-D: negative dimension ($\gamma=0.509, p < 0.001$).

Conclusions: This study developed the EOLD-J and confirmed the reliability and validity of this scale.

Background

The number of persons with dementia (PWD) worldwide is estimated to reach 82 million in 2030 [1], and has been increasing in Japan's super-aging society [2]. A 2010 survey estimated that the daily lives of 4.6 million older Japanese persons were affected by dementia [3]. Dementia is a progressive terminal disease, and as symptoms progress, older PWD often need suitable end-of-life care (EOLC) [4]. In Japan, approximately 36% of PWD reside in nursing homes [3], and 32% die within the facilities [5]. Consequently, appropriate EOLC for residents and care evaluation methods are highly required.

EOLC quality should ideally be evaluated by PWD themselves. However, clinical symptoms and conspicuous cognitive and physical decline in end-stage dementia, such as difficulties in verbalization [6],

make it difficult for older PWD to evaluate EOLC by themselves and express their will and symptoms [6, 7]. Family members are often good proxies for evaluating satisfaction with EOLC.

Nurses should be responsible for examining the conditions of PWD and providing EOLC to these patients in Japanese nursing homes [8, 9]. Although there is a small number of nurses compared to care workers at Japanese nursing homes [10], nurses need to properly examine EOLC using scales evaluated for reliability and validity [11]. Thus, there is a need for an EOLC quality assessment scale relevant to people with end-stage dementia that can be conducted by nurses. However, there is no scale to evaluate EOLC in Japan.

The End-of-Life in Dementia (EOLD) scales were written in English and specifically designed to examine the quality of EOLC for PWD [12, 13]. The scales consist of three parts that measure the following outcomes: (1) satisfaction with care at end-of-life in dementia (SWC-EOLD) evaluated by bereaved family members of deceased residents, (2) symptom management at end-of-life in dementia (SM-EOLD), and (3) Comfort Assessment in Dying with dementia (CAD-EOLD), evaluated by nurses. The reliability and validity of the SM-EOLD and CAD-EOLD among nurses in nursing homes have been examined in a previous study [11]; however, they have not been examined in the Japanese context. Therefore, the development of the Japanese version of EOLD (EOLD-J) scales could be beneficial to facilitate EOLC and improve quality of care in nursing homes. The purpose of the current research was therefore to develop the EOLD-J scales by verifying their reliability and validity in Japanese nursing homes.

Methods

Development of the EOLD-J Scales

Consent for the development of the EOLD-J scales was obtained from authors of the original EOLD scales [12, 13]. We also obtained permission from Saito et al. [14], who developed a Japanese version in 2013 but did not validate the scales. To evaluate face validity, five researchers in care for older adults were consulted about whether the contents of the scales could be useful in Japanese nursing homes. We modified the Saito et al. [14] version by changing the word “patient” to “care recipient,” among other changes. Nurses in Japanese nursing homes who were asked to use the modified EOLD-J scales to confirm their ease of completion and that the scales would be useful for nurses to measure EOLC quality. Subsequently, two professional translators with no prior knowledge of the current scale performed back-translation of the EOLD-J scales. The authors of the original EOLD scales evaluated the back-translation, and necessary modifications were made, based on their comments. Following their approval, the EOLD-J scales were considered complete.

Configuration of EOLD-J Scales

The SWC-EOLD-J is used to assess satisfaction with care and involvement in the decision-making process, based on family members’ responses [13]. It consists of 10 items, measured on a 4-point Likert

scale ranging from 1 (strongly disagree) to 4 (strongly agree), with higher scores indicating greater satisfaction [13].

The SM-EOLD-J with physical and psychological symptom subscales quantifies the frequency of nine symptoms and signs, such as “shortness of breath,” “skin breakdown,” and “resistiveness to care” [13], as assessed by the nurses who care for residents. The frequency was quantified on a 6-point Likert scale ranging from 0 (every day) to 5 (never), with higher scores indicating better symptom control [13].

Meanwhile, the CAD-EOLD-J comprised 14 symptoms, including pain and difficulty in swallowing, and conditions such as “serenity (inner peace)” and “peace” [13], as assessed by the nurses. These items were rated from 1 (a lot) to 3 (not at all) with higher scores indicating better symptom control [13]. The CAD-EOLD-J consists of four subscales: Physical Distress, Dying Symptoms, Emotional Distress, and Well-Being [13].

Participating Facilities and Participants

Participating facilities were nursing homes in Japan that provided EOLC for older residents with dementia during the past year. We sent letters to the directors of all facilities in two prefectures. Thirty-three nursing homes agreed to participate.

Participants were family members/guardians of the deceased PWD (residents), who were involved in decision-making on behalf of the PWD, along with one nurse each who provided EOLC. Inclusion criteria of deceased residents were those who received diagnoses of dementia, were provided EOLC, and died at the facilities (more than three months but less than two years prior to this study).

Data Collection Procedure

Self-report questionnaires were distributed to 113 family members of deceased residents and 113 nurses, and were returned by mail. This study was conducted from April 2017 to December 2019.

Instruments

To collect background information on deceased residents, nurses from participating facilities were asked to verify medical and care records and provide information about residents’ age at death and gender. They were also asked to complete the Functional Assessment Staging of Alzheimer’s Disease scale (FAST) [15] to identify the degree of dementia and cause of death.

Family members of deceased residents were asked their age, gender, and relationship with residents, and then asked to complete the SWC-EOLD-J and Japanese Decision Regret Scale (DRS-J) [16] regarding the EOLC provided in the month prior to death. The DRS-J is a self-administered assessment scale composed of five items with Likert-type responses from 1 (strongly agree) to 5 (strongly disagree). Higher scores indicate greater regret [16].

Nurses were asked to complete the SM-EOLD-J, CAD-EOLD-J, and Short Version of Quality of Life Questionnaire for Dementia (short QOL-D)[17]. The short QOL-D was used to review care records from one month prior to the resident’s death. It consists of positive and negative dimensions that respectively evaluate well-being and behavioral and psychological symptoms of dementia (BPSD) such as irritability and aggression. The presence of BPSD lowers the score of its negative dimension [17]. The nurses were also asked about their age, gender, years of nursing experience, and years of experience at the current facility.

Ethical Considerations

Written informed consent for participation in this study and for the use of the deceased resident's data was obtained from the family members of deceased residents, as well as participating nurses. Documents sent to the participants explained the purpose of the research, the voluntary nature of participation, that withdrawal from the research would incur no disadvantage, and the research methods, including the promise of confidentiality and protection of personal information. Research procedures were conducted with the approval of the School of Medicine Research Ethics Committee (Examination number HS2018-199) governing Gunma University affiliates, and that of the management of participating facilities. This study was conducted in accordance with the principles of the Declaration of Helsinki.

Data Analysis

Samples without missing values were used. Cronbach’s alpha for each of the scales (SWC-EOLD-J, SM-EOLD-J, and CAD-EOLD-J) was calculated to evaluate reliability.

The Spearman’s rank correlation coefficient was calculated for scores between SWC-EOLD-J and DRS-J, along with those between SM-EOLD-J and short QOL-J, or CAD-EOLD-J and short QOL-J. These were conducted to evaluate convergent validity, which is a verification of construct validity (Fig. 1). The Spearman’s rank correlation coefficient for total scores between scales was also calculated. An exploratory factor analysis was conducted using the principal factor method and varimax rotation to verify structural validity. The number of factors was determined after checking the eigenvalues and scree plots. All data were analyzed using IBM SPSS 24. Further confirmatory factor analysis was conducted to test the model fit of the subscales. The analysis was performed using IBM SPSS Amos Version 27.0.

Results

Characteristics of Research Participants

Questionnaires were sent to 113 family members and 113 nurses. Ninety-two family members (81.4%) and 90 nurses (79.7%) returned responses to researchers. The deceased residents with FAST stages ranging from one to three ($n = 3$) and those with incomplete questionnaires ($n = 20$) were excluded. Finally, we analyzed the responses with no missing values from 85 family members (75.2%) and 62 nurses (54.9%). The basic attributes of participants are shown in Table 1.

Table 1. Basic attributes of participants

Participant	Item		<i>n</i>	%	Mean	SD
Deceased Resident	Age at death		85		91.4	6.60
	Gender	Female	62	72.9		
		Male	23	27.1		
	FAST†	Stage 4	7	6.2		
		Stage 5	12	14.1		
		Stage 6	23	27.1		
		Stage 7	43	50.6		
	Cause of death	Senility	64	79.0		
		Others	21	21.0		
Family‡	Age		85		65.0	8.78
	Gender	Female	48	56.7		
		Male	37	43.5		
	Relationships with residents	Spouse	4	4.7		
		Sibling	1	1.2		
		Child	67	78.8		
		Child of spouse	8	9.4		
		Grandchild	1	1.2		
		Others	4	4.7		
	Years of nursing care		85		8.2	5.08
Nurse	Age		61		51.2	11.32
	Gender	Female	58	93.5		
		Male	4	6.5		
	Years of nursing experience		62		25.7	12.39
	Years of working at the facility		62		8.7	5.06
†FAST:Functional assessment staging of Alzheimer's disease						
‡Family:Family members of the deceased residents						

Scores for each part of the SWC-EOLD-J scales and DRS-J are shown in Table 2. The Cronbach’s alpha of the SWC-EOLD-J rated by family members of the deceased residents was 0.77 ($n = 83$).

Results of the convergent validity testing are presented in Table 3. The SWC-EOLD-J score was significantly moderately correlated with the DRS-J score ($\gamma = -0.504, p < 0.001$).

Table 2
Score of SWC-EOLD-J scales and DRS-J

Scale	Respondent	Item	Range	Mean	SD	
The SWC-EOLD-J†	Family‡	I felt fully involved in all decision-making.	1–4	3.30	0.60	
		(n = 83)	I probably would have made different decisions if I had more information*.	1–4	3.24	0.60
		All measures were taken to keep my care recipient comfortable.	1–4	3.35	0.50	
		The healthcare team was sensitive to my needs and feelings.	1–4	3.41	0.61	
		I did not really understand my care recipient's condition*.	1–4	3.30	0.64	
		I always knew which doctor or nurse was in charge of my care recipient's care.	1–4	3.23	0.63	
		I feel that my care recipient got all necessary nursing assistance.	1–4	3.45	0.59	
		I felt that all medication issues were clearly explained to me.	1–4	3.11	0.52	
		My care recipient received all treatments or interventions that he or she could have benefited from.	1–4	3.28	0.57	
		I feel that my care recipient needed better medical care at the end of his or her life*.	1–4	2.88	0.97	
		Total	10–40	32.54	3.60	
The DRS-J	Family‡	Total	0–100	14.53	13.77	
(n = 83)						
‡Family: Family members of the deceased residents,						
†The SWC-EOLD-J: Japanese version of satisfaction with care at the end-of-life in dementia						
The DRS-J: Japanese decision regret scale						
*Reverse coded for calculation of the total score.						

Table 3
Correlation between the EOLD-J scales and the DRS-J/short QOL-D

	The SWC-EOLD-J†		The SM-EOLD-J‡		The CAD-EOLD-J§	
Respondent	Family¶		Nurse		Nurse	
<i>n</i>	83		55		55	
	<i>Y</i>	<i>p</i>	<i>Y</i>	<i>p</i>	<i>Y</i>	<i>p</i>
DRS-J	-0.504*	<0.001				
short QOL-D#			-0.238	0.080	-0.187	0.177
Positive dimension						
short QOL-D# Negative dimension			0.587*	<0.001	0.509*	<0.001
short QOL-D# Total			0.089	0.519	0.101	0.466
* $\leq$ 0.001. Spearman rank correlation coefficient.						
¶Family: Family members of the deceased residents						
†The SWC-EOLD-J: Japanese version of satisfaction with care at the end-of-life in dementia						
‡The SM-EOLD-J: Japanese version of symptom management at the end-of-life in dementia						
§The CAD-EOLD-J: Japanese version of comfort assessment in dying with dementia						
The DRS-J: Japanese decision regret scale						
#The short QOL-D: short version of the quality of life questionnaire for dementia						

SM-EOLD-J

Scores for each part of the SM-EOLD-J scales and short QOL-D are shown in Table 4. The Cronbach's alpha for the SM-EOLD-J among nurses was 0.80 ($n = 62$). The Cronbach's alpha for the SM-EOLD-J subscales of physical and psychological symptoms was 0.58 and 0.82, respectively.

Table 4
Score of SM-EOLD-J, CAD-EOLD-J scales and short QOL-D

Scale	Respondent	Item	Range	Mean	SD
The SM-EOLD-J§ (n = 62)	Nurse	Pain	0–5	3.39	2.00
		Shortness of breath	0–5	3.32	2.01
		Skin breakdown	0–5	3.81	1.85
		Calm*	0–5	4.05	1.69
		Depression	0–5	4.15	1.54
		Fear	0–5	4.47	1.28
		Anxiety	0–5	3.81	1.81
		Agitation	0–5	4.11	1.69
		Resistiveness to care	0–5	3.97	1.74
		Total	0–45	35.06	9.80
The CAD-EOLD-J¶ (n = 62)	Nurse	Discomfort	1–3	2.44	0.62
		Pain	1–3	2.44	0.64
		Restlessness	1–3	2.56	0.67
		Shortness of breath	1–3	2.39	0.69
		Choking	1–3	2.66	0.54
		Gurgling	1–3	2.31	0.69
		Difficulty swallowing	1–3	1.61	0.61
		Fear	1–3	2.69	0.56
		Anxiety	1–3	2.58	0.59
		Crying	1–3	2.74	0.54
		Moaning	1–3	2.68	0.57
		Serenity*	1–3	2.39	0.52
		Peace*	1–3	2.34	0.54
		Calm*	1–3	2.32	0.57
		Total	14–42	34.15	5.21
The short QOL-D#	Nurse	Total	4–24	22.38	4.18

Scale	Respondent	Item	Range	Mean	SD
(<i>n</i> = 55)		Negative dimension	3–12	10.72	2.01
		Positive dimension	7–36	11.68	4.02
§The SM-EOLD-J: Japanese version of symptom management at the end-of-life in dementia					
¶The CAD-EOLD-J: Japanese version of comfort assessment in dying with dementia					
#The short QOL-D: short version of the quality of life questionnaire for dementia					
*Reverse coded for calculation of the total score.					

The results of convergent validity testing are presented in Table 3. The SM-EOLD-J score was significantly moderately correlated with the negative dimensions of the short QOL-D in nurses ($\gamma = 0.587$, $p < 0.001$). No correlation was found between the total scores of the SM-EOLD-J and the positive dimensions of the short QOL-D.

We conducted a confirmatory factor analysis to confirm the nine items of the SM-EOLD-J as similar to the two-factor structure of the original SM-EOLD. The results were goodness of fit index (GFI) = .833, adjusted GFI (AGFI) = 0.711, comparative fit index (CFI) = 0.856, root mean square error of approximation (RMSEA) = 0.130.

The results of the exploratory factor analysis are shown in Table 5. The SM-EOLD-J was found to have two-factor structures. Pain, shortness of breath, skin breakdown, and depression and anxiety were included in one factor, while fear, calm, agitation, and resistiveness to care were included in the other factor. A confirmatory factor analysis was conducted with the two-factor structure based on the results of the exploratory factor analysis conducted in this study (GFI = .854, AGFI = .756, CFI = .885, RMSEA = .114).

Table 5. Rotated factor structure of the SM-EOLD-J and the CAD-EOLD-J

			Factor loading			
	Subscales	Item	Factor 1	Factor 2	Factor 3	Factor 4
SSM-EOLD-J	Physical	Pain	0.04	0.69		
		Shortness of breath	0.05	0.50		
		Skin breakdown	0.22	0.41		
	Psychological	Depression	0.26	0.43		
		Anxiety	0.50	0.69		
		Fear	0.54	0.38		
		Calm	0.55	-0.07		
		Agitation	0.78	0.38		
		Resistiveness to care	0.74	0.33		
	Contribution ratio		2.11	1.94		
	Cumulative contribution ratio		23.49	45.06		
ICAD-EOLD-J	Physical distress	Discomfort	0.73	0.09	0.27	-0.27
		Pain	0.59	0.18	0.10	-0.11
		Restlessness	0.67	0.27	0.13	0.00
		Shortness of breath	0.47	0.14	0.45	0.10
	Dying symptoms	Choking	0.30	0.12	0.67	-0.21
		Gurgling	0.19	-0.13	0.73	0.43
		Difficulty swallowing	-0.05	-0.03	0.03	0.64
	Emotional distress	Fear	0.70	0.16	0.43	-0.15
		Anxiety	0.79	0.24	0.18	0.01
		Crying	0.77	0.22	0.09	0.03
		Moaning	0.69	0.18	0.24	0.18
	Well-being	Serenity	0.25	0.83	0.01	0.06

	Peace	0.22	0.91	-0.02	-0.06
	Calm	0.28	0.88	0.16	-0.12
	Contribution ratio	4.05	2.61	1.59	0.82
	Cumulative contribution ratio	28.96	47.56	58.91	64.73
§The SM-EOLD-J: Japanese version of symptom management at the end-of-life in dementia					
¶The CAD-EOLD-J: Japanese version of comfort assessment in dying with dementia Loadings used to identify factors are bold texted.					

CAD-EOLD-J

Scores for each part of the CAD-EOLD-J scales are shown in Table 4. The Cronbach's alpha of the CAD-EOLD-J rated by nurses was 0.88 ($n = 62$). The Cronbach's alpha for the CAD-EOLD-J subscales of physical distress, dying symptoms, emotional distress, and well-being were 0.76, 0.58, 0.87, and 0.93, respectively.

The results of convergent validity testing are presented in Table 3. The CAD-EOLD-J score was significantly moderately correlated with the negative dimensions of the short QOL-D score in nurses ($\gamma = 0.509$, $p < 0.001$). However, no correlation was indicated between the CAD-EOLD-J scores and the positive dimensions of the short QOL-D scores in nurses.

We conducted a confirmatory factor analysis to confirm the fourteen items of the CAD-EOLD-J as similar to the two-factor structure of the original CAD-EOLD. The results were GFI = .812, AGFI = 0.718, CFI = 0.929, RMSEA = 0.088.

The results of the exploratory factor analysis are shown in Table 5. The CAD-EOLD-J was found to have four-factor structures, different to the factors of the original scale. The subscales physical distress and emotional distress were included in one factor, and difficulty swallowing was an independent factor. Shortness of breath, choking, and gurgling were included in one factor, and the subscales for well-being consisted of the same items as the original EOLD scales. A confirmatory factor analysis was conducted with the four-factor structure based on the results of the exploratory factor analysis. The results were GFI = .839, AGFI = 0.748, CFI = 0.943, RMSEA = 0.086.

Discussion

SWC-EOLD-J

In this study, the reliability of the SWC-EOLD-J was confirmed by the Cronbach's alpha being above 0.7 [18]. Regarding the convergent validity of the EOLD-J scales, a moderate negative correlation was observed between the SWC-EOLD-J scores and the DRS-J scores. It can be said that when family members of deceased residents have some regret regarding their decision-making in the EOLC process, they gave higher scores in the SWC-EOLD-J, which means they were satisfied with the EOLC provided. Based on results from this study, the SWC-EOLD-J could measure the degree of satisfaction in the decision-making process among family members.

However, as participation in this study was limited, the generalizability of our results is limited. Furthermore, the data were collected retrospectively and the answers may have been influenced by selective recall. Therefore, further studies are required on whether the SWC-EOLD-J could be used for evaluation of current care and if the responses are biased by demographic characteristics of family members or availability of services [12].

SM-EOLD-J

The Cronbach's alpha for the psychological subscale and total score of the SM-EOLD-J, Cronbach's alpha was above 0.7 [18]. The Cronbach's alpha for the physical subscale was low (0.58), similar to that of previous studies [12]. Therefore, the reliability of the SM-EOLD-J could be confirmed.

The SM-EOLD-J scores were significantly moderately correlated with the negative dimensions of the short QOL-D. This means that nurses gave higher scores in the SM-EOLD when residents' symptoms were good; thus, residents' negative symptoms of dementia may be less evident. Further, the nurses gave lower scores for negative dimensions on the short QOL-D, which indicates the degree of negative symptoms associated with dementia through three items: "quick-tempered," "hits or kicks things," and "shouts loudly" [17]. It can be said that the convergent validity of the SM-EOLD-J was confirmed. However, there was no correlation between the total scores for positive dimensions of the short QOL-D, which are based on PWD behavior such as "enjoys seeing other people's activities" [17], and those of the SM-EOLD-J, which are based on PWD facial expressions and appearances. The validity of the SM-EOLD-J should be conducted using a scale that allows evaluation based on subjects' facial expressions and appearances. However, as there is no scale to examine subjects' facial expressions and appearances in Japan, further research is needed to evaluate the convergent validity of the SM-EOLD-J.

Scores of the SM-EOLD-J in this study were higher than in previous studies. This may indicate better symptom control in PWD in Japan [19]. In one study in New Zealand [19], the scores for pain, depression, and anxiety were lower than the scores in this study. This indicates better symptoms among PWD in this study than among the participants in the New Zealand study. In Japanese nursing homes, people with end-stage dementia are often hospitalized and die in the hospital [20, 21]. Thus, people with end-stage dementia with severe symptoms may not have died in Japanese nursing homes. Furthermore, the expression and perception of physical and psychological symptoms may have been influenced by the culture of the participants (e.g., stoic response to pain) [22]. These situations may have also affected the factor structure of the SM-EOLD-J.

The Cronbach's alpha of the CAD-EOLD-J was above 0.7. Therefore, the reliability of CAD-EOLD-J could be confirmed [18].

The CAD-EOLD-J scores were significantly moderately correlated with the negative dimensions of the short QOL-D. It could be said that when the residents showed fewer signs of discomfort, leading to nurses giving higher scores on the CAD-EOLD-J. Therefore, the convergent validity of the CAD-EOLD-J could be confirmed.

In the results of the exploratory factor analysis, the subscales of physical distress and emotional distress were included as one factor. This result suggests that nurses may be observing physical and psychological symptoms without distinguishing between them in Japanese nursing homes. Difficulty swallowing was analyzed as an independent factor. The scores of difficulty swallowing in this study were lower than those in previous studies [19]. In addition, the scores of difficulty swallowing tended to be lower than the scores for other items of the CAD-EOLD-J. These results may be affected by the factor structure of the CAD-EOLD-J. In the future, it is necessary to further examine whether this result is characteristic of Japan.

Research Limitations

First, as the participants were referred by the facility managers, the choice of participants may have been biased toward those who had a good relationship with the facility. Second, we did not ask the family members of deceased residents to complete the SM-EOLD-J and CAD-EOLD-J. The relationship between the assessment of symptoms by the deceased person's family and that of nurses is unknown. Third, PWD living in nursing homes in Japan differ from those in other countries in terms of the medical care they receive at the end of life. It may be necessary to verify whether the results of the EOLD-J scores revealed in this survey reflect trends specific to Japan.

Abbreviations

PWD
persons with dementia; EOLC:end-of-life care; EOLD:end-of-life in dementia; SWC-EOLD:satisfaction with care at end-of-life in dementia; SM-EOLD:symptom management at end-of-life in dementia; CAD-EOLD:Comfort Assessment in Dying with dementia; FAST:Functional Assessment Staging of Alzheimer's Disease scale; QOL-D:quality of life questionnaire for dementia; DRS-J:Japanese decision regret scale; BPSD:behavioral and psychological symptoms of dementia

Declarations

Ethics Approval and Consent to Participate

Written informed consent for participation in this study and for the use of the deceased resident's data was obtained from the family members of deceased residents, as well as participating nurses. Research procedures were conducted with the approval of the School of Medicine Research Ethics Committee (Examination number HS2018-199) governing Gunma University affiliates, and that of the management of participating facilities. This study was conducted in accordance with the principles of the Declaration of Helsinki.

Consent for Publication

Not applicable.

Availability of Data and Materials

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

Competing Interests

None of the authors had any financial or potential conflicts of interest to declare.

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Authors' Contributions

ST: conception and design of study, performance of statistical analysis, draft of manuscript reading and approval of final manuscript

YU: conception and design of study, performance of statistical analysis, supervision of study, reading and approval of final manuscript

TY: supervision of study, advice on statistical analysis, critical review of manuscript, reading and approval of final manuscript

TS: supervision of study, critical review of manuscript, reading and approval of final manuscript

YC: supervision of study, critical review of manuscript, reading and approval of final manuscript TK: supervision of study, critical review of manuscript, reading and approval of final manuscript.

YT: supervision of study, advice on statistical analysis, critical review of manuscript, reading and approval of final manuscript

HY: Consultation of study design, advice on statistical analysis, critical review of the manuscript, approval of the final version of the manuscript

References

1. Alzheimer's Disease International. World Alzheimer report. 2018. <https://www.alz.co.uk/research/World>. Accessed 20 July 2021.
2. The Cabinet Office, Government of Japan. Annual report on the aging society. 2017. https://www8.cao.go.jp/kourei/whitepaper/w-2017/html/gaiyou/s1_2_3.html. Accessed 20 July 2021.
3. Ministry of Health, Labour and Welfare. Toshibu ni okeru ninchishouyuubyouritu to ninntisyouno seikatukinousyogaihen taiou. 2013. http://www.tsukuba-psychiatry.com/wp-content/uploads/2013/06/H24Report_Part1.pdf (in Japanese). Accessed 28 July 2021.
4. Van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2014;28:197–209. doi:10.1177/0269216313493685.
5. Bessho Y, Deguchi Y, Yasui Y, Kusaka Y, Nagasawa S. Mortality, causes and places of death among the elderly with dementia in a community: results of a ten-year follow-up study. *Nihon Kosho Eisei Zasshi*. 2005; 52:865–73. (in Japanese)
6. Japanese Society of Neurology. *Ninchishou shikkan shinryo guidelines*. Tokyo: Igaku-Shoin; 2017. (in Japanese)
7. Kuebler KK, Berry PH, Heidrich DE, Beare PG. *End-of-life-care: clinical practice guidelines*. 1st Japanese ed. Tokyo: Igaku-Shoin Ltd; 2004.
8. Kurokawa Y, Yokojima K, Naganuma A, Matuura M. The actual status of end-of-life care given by nursing and care-giving staff members in nursing care homes. *Nursing Journal of Mukogawa Women's University*. 2016; 1:37–43.
9. Ono M, Hara S. Care provided by specialists during end-of-life care and actual conditions of multidisciplinary collaboration at geriatric health service facilities. *Bulletin of Shimane University Faculty of Medicine*. 2014; 37:9–25.
10. Japanese Nursing Association. *Tokubetuyougoroujinhome/Kaigoroujinhokensisetsu ni okeru kangoshokuin jittaichousa houkokusyo*. 2016.

<https://www.nurse.or.jp/home/publication/pdf/report/2016/kaigojittai.pdf> (in Japanese). Accessed 20 July 2021.

11. Kiely DK, Volicer L, Teno J, Jones RN, Prigerson HG, Mitchell SL. The validity and reliability of scales for the evaluation of end-of-life care in advanced dementia. *Alzheimer Dis Assoc Disord*. 2006; 20:176–81.
12. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. *Alzheimer Dis Assoc Disord*. 2001; 15:194–200. doi:10.1097/00002093-200110000-00005.
13. Volicer L, Hurley AC. *Assessment scales for advanced dementia*. Baltimore, MD: Health Professions Press; 2015.
14. Saito T, Chiba Y, Katsuse O, Akihide T, Yamamoto K, Togo T, et al. Retrospective study of the level of satisfaction of family members regarding care for patients with end-stage dementia. *Psychiatria et Neurologia Japonica*. 2013: S-560.
15. Sclan SG, Reisberg B. Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. *Int Psychogeriatr*. 1992, 4(Suppl 1):55–69. doi:10.1017/s1041610292001157.
16. Tanno K, Bito S, Isobe Y, Takagi Y. Validation of a Japanese Version of the Decision Regret Scale. *J Nurs Meas*. 2016;24:E44–54. doi:10.1891/1061-3749.24.1.E44.
17. Terada S, Oshima E, Ikeda C, Hayashi S, Yokota O, Uchitomi Y. Development and evaluation of a short version of the quality of life questionnaire for dementia. *Int Psychogeriatr*. 2015;27:103–10. doi:10.1017/S1041610214001811.
18. Streiner DL, Norman GR, Cairney J. *Health measurement scales: a practical guide to their development and use*. 5th ed. Tokyo: Medical Sciences International Ltd; 2016.
19. Boyd M, Frey R, Balmer D, Robinson J, McLeod H, Foster S, et al. End of life care for long-term care residents with dementia, chronic illness and cancer: prospective staff survey. *BMC Geriatr*. 2019;19:137. doi:10.1186/s12877-019-1159-2.
20. Koyama T, Sasaki M, Hagiya H, Zamami Y, Funahashi T, Ohshima A, et al. Place of death trends among patients with dementia in Japan: a population-based observational study. *Sci Rep*. 2019; 9:20235. doi:10.1038/s41598-019-56388-w.
21. Reyniers T, Deliens L, Pasman HR, Morin L, Addington-Hall J, Frova L, et al. International variation in place of death of older people who died from dementia in 14 European and non-European countries. *J Am Med Dir Assoc*. 2015; 16:165–71. doi:10.1016/j.jamda.2014.11.003.
22. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: "You got to go where he lives." *JAMA* 2001;286:2993–3001. doi:10.1001/jama.286.23.2993.

Figures

Figure 1

Convergence validation for End-of-Life in Dementia scales ‡Family:Family members of the deceased residents †The SWC-EOLD-J: Japanese version of Satisfaction with care at the end-of-life in dementia ‡The SM-EOLD-J: Japanese version of symptom management at the end-of-life in dementia §The CAD-EOLD-J: Japanese version of comfort assessment in dying with dementia ¶The DRS-J: Japanese decision regret scale ||The short QOL-D: short version of the quality of life questionnaire for dementia