

1 **Original**

2 Title: Development, Validity, and Reliability of a Japanese Version of End-of-Life in
3 Dementia Scales.

4

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33

34 **Abstract**

35 **Background & Aims:** In Japan, there are no reliable instruments to measure the quality of
36 care for a person with end-stage dementia. This study aimed to develop a Japanese version
37 of the End-of-Life in Dementia scales (EOLD-J) and evaluate its reliability and validity.

38 **Methods:** The EOLD-J was created by translating measurements of original scales:
39 Satisfaction with Care (SWC-EOLD-J), Symptom Management (SM-EOLD-J), and
40 Comfort Assessment in Dying with Dementia (CAD-EOLD-J). Participants comprised 113
41 family members of a deceased person with dementia and 113 nurses. The reliability and
42 construct validity of the EOLD-J were evaluated using the scores of the SWC-EOLD-J, the
43 Japanese Decision Regret Scale (DRS-J), the SM-EOLD-J, a short version of the Quality-
44 of-Life Questionnaire for Dementia (short QOL-D), and the CAD-EOLD-J.

45 **Results:** Responses from 83 family members and 62 nurses were analyzed. The Cronbach's
46 alphas of SWC-EOLD-J, SM-EOLD-J, and CAD-EOLD-J were 0.77, 0.60, and 0.88,
47 respectively. While the SWC-EOLD-J score was significantly correlated with DRS-J ($r =$
48 $0.504, p < 0.001$), SM-EOLD-J and CAD-EOLD-J scores were significantly correlated with
49 negative dimension scores: $r = 0.587, p < 0.001$ and $r = 0.509, p < 0.001$, respectively.

50 **Conclusions:** This study's results demonstrate the EOLD-J scale's internal consistency and
51 convergent validity.

52 **Key words:** Dementia, End-of-life care, Older adults, Palliative care, Nursing homes

53 **Background**

54 The number of persons with dementia worldwide is estimated to reach 82 million in 2030¹,
55 and has been increasing in Japan's super-aging society². A 2010 survey estimated that the
56 daily lives of 4.6 million older Japanese individuals were affected by dementia³. Dementia
57 is a progressive terminal disease, and as symptoms progress, older persons with dementia
58 often need suitable end-of-life care⁴. In Japan, approximately 36% of persons with dementia
59 reside in nursing homes³. Furthermore, according to the results of a previous study that
60 investigated the place of death of persons with dementia in Japan, 32% died in nursing
61 homes⁵. Therefore, there is a need to provide appropriate end-of-life care to residents, and
62 to improve the quality of such end-of-life care, it should be monitored and evaluated.
63 Consequently, appropriate end-of-life care for residents and care evaluation methods are
64 highly required.

65 End-of-life care quality should ideally be evaluated by persons with dementia
66 themselves. However, clinical symptoms and conspicuous cognitive and physical decline in
67 end-stage dementia makes it difficult for older persons with dementia to evaluate end-of-
68 life care by themselves and express their will and symptoms^{6,7}. Therefore, family members
69 are often good proxies for evaluating satisfaction with end-of-life care.

70 Nurses should be responsible for examining the conditions of persons with
71 dementia and providing end-of-life care to these patients in Japanese nursing homes^{8,9}.

72 Although there is a smaller number of nurses compared to care workers at Japanese nursing
73 homes¹⁰, nurses need to properly examine end-of-life care using scales evaluated for
74 reliability and validity. Thus, there is a need for an end-of-life care quality assessment scale
75 relevant to persons with end-stage dementia that can be conducted by nurses.

76 The scales available in Japan to evaluate end-of-life care include the Good Death
77 Inventory and the Japanese version of the Support Team Assessment Schedule (STAS-J).
78 The Good Death Inventory was developed to objectively assess the quality of end-of-life
79 care provided to cancer patients¹¹. Nurses in hospices and palliative care wards could use
80 the STAS-J¹² to evaluate the efficacy of care in hospices and palliative care wards.
81 However, it is difficult to find Japanese versions of the end-of-life care assessment scales,
82 that specifically measure the quality of care for older adults with dementia in nursing
83 homes.

84 The End-of-Life in Dementia (EOLD) scales were written in English and specifically
85 designed to examine the quality of end-of-life care for persons with dementia¹³⁻¹⁵. The
86 EOLD scales allow family members and care providers, as proxies, to objectively evaluate
87 end-of-life care for persons with severe dementia, which is difficult to evaluate
88 subjectively. Furthermore, it could be suitable for measurements, not only in hospitals, but
89 also in elderly care facilities¹⁵. The scales consist of three parts that measure the following
90 outcomes: Satisfaction with Care at End-of-Life in Dementia (SWC-EOLD) evaluated by

91 bereaved family members of deceased residents and Symptom Management at End-of-Life
92 in Dementia (SM-EOLD) and Comfort Assessment in Dying with Dementia (CAD-EOLD)
93 evaluated by nurses. The reliability and validity of the SM-EOLD and CAD-EOLD among
94 nurses in nursing homes have been examined previously in a western ¹⁶; however, they have
95 not been examined in the Japanese context. Therefore, the development of the Japanese
96 version of EOLD (EOLD-J) scales could be beneficial to facilitate end-of-life care and
97 improve quality of care in nursing homes. Thus, the purpose of the current research was to
98 develop the EOLD-J scales by verifying their reliability and validity in Japanese nursing
99 homes.

100

101 **Methods**

102 Development of the EOLD-J Scales

103 Consent for the development of the EOLD-J scales was obtained from authors of the
104 original EOLD scales^{13,14}. We also obtained permission from Saito et al.¹⁷, who developed a
105 Japanese version of the scale in 2013 but did not validate it. To evaluate face validity, five
106 researchers specializing in care for older adults were consulted about whether the contents
107 of the scales could be useful in Japanese nursing homes. We modified the Saito et al.¹⁷
108 version by changing the word “patient” to “care recipient,” among other changes. Nurses in
109 Japanese nursing homes were asked to use the modified EOLD-J scales to confirm their

110 ease of completion and that the scales would be useful for nurses to measure the quality of
111 end-of-life care. The nurses confirmed that the scale was understandable to family
112 caregivers. Subsequently, two professional translators with no prior knowledge of the
113 current scale, performed back-translation of the EOLD-J scales. The authors of the original
114 EOLD scales evaluated the back-translation, and necessary modifications were made, based
115 on their comments. Following their approval, the EOLD-J scales were considered complete.

116 Configuration of EOLD-J Scales

117 The SWC-EOLD-J is used to assess satisfaction with care and involvement in the decision-
118 making process, based on family members' responses¹⁶. It consists of 10 items, measured
119 on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree), with
120 higher scores indicating greater satisfaction¹⁶.

121 The SM-EOLD-J, along with its physical and psychological symptom subscales,
122 quantify the frequency of nine symptoms and signs, such as "shortness of breath," "skin
123 breakdown," and "resistiveness to care"¹⁶, as assessed by the nurses who cared for
124 residents. The frequency was quantified on a 6-point Likert scale ranging from 0 (every
125 day) to 5 (never), with higher scores indicating better symptom control¹⁶.

126 Meanwhile, the CAD-EOLD-J comprised 14 symptoms, including pain and
127 difficulty in swallowing, and conditions such as "serenity (inner peace)" and "peace,"¹⁶ as
128 assessed by the nurses. These items were rated from 1 (a lot) to 3 (not at all), with higher

129 scores indicating better symptom control¹⁶. The CAD-EOLD-J consists of four subscales:
130 Physical Distress, Dying Symptoms, Emotional Distress, and Well-Being¹⁶.

131 Participating Facilities and Participants

132 Participating facilities were nursing homes in Japan that provided end-of-life care for older
133 residents with dementia during the past year. We sent letters to the directors of such
134 facilities in two prefectures. Thirty-three nursing homes agreed to participate in the study.

135 Participants were family members/guardians of the deceased persons with
136 dementia (residents), who were involved in decision-making on behalf of the persons with
137 dementia, along with one nurse for each patient, who provided end-of-life care. Inclusion
138 criteria of deceased residents comprised: those who received diagnoses of dementia, were
139 provided end-of-life care, and died at facilities. According to previous studies^{18,19}, most
140 nursing homes have less than 10 end-of-life care cases per year. To ensure an adequate
141 sample size, the study population was defined to include those more than three months but
142 less than two years from death.

143 Data Collection Procedure

144 Self-report questionnaires were distributed to 113 family members of deceased residents
145 and 113 nurses, and these were returned by mail. This study's sample size was determined
146 with reference to previous studies¹³. This study was conducted from April 2017 to
147 December 2019.

148 Instruments

149 To collect background information on deceased residents, nurses from participating
150 facilities were asked to verify medical and care records and provide information about
151 residents' age at death and gender. They were also asked to complete the Functional
152 Assessment Staging of Alzheimer's Disease scale (FAST)²⁰ to identify the degree of
153 dementia and cause of death.

154 Family members of deceased residents were asked about their age, gender, and
155 relationship with residents, and then asked to complete the SWC-EOLD-J and Japanese
156 Decision Regret Scale (DRS-J)²¹ regarding the end-of-life care provided in the month prior
157 to death. The DRS-J is a self-administered assessment scale composed of five items with
158 Likert-type responses from 1 (strongly agree) to 5 (strongly disagree). Higher scores
159 indicate greater regret²¹. The SWC-EOLD-J includes several assessment items related to
160 support for decision-making, and its score was considered to be related to the DRS-J score.

161 Nurses were asked to complete the SM-EOLD-J, CAD-EOLD-J, and the Short
162 Version of the Quality-of-Life Questionnaire for Dementia (short QOL-D)²². The short
163 QOL-D is a valid objective measure of QOL for a person with dementia²². The short QOL-
164 D was used to review care records, from one month prior to the residents' death. There are
165 two dimensions in the short QOL-D (positive dimensions: 6 items, negative dimensions: 3
166 items) with responses rated on a four-point Likert-type scale ranging from 1 to 4.

167 Accordingly, the positive dimension is evaluated based on participants' well-being and is
168 determined by considering the behavior of the persons with dementia. It includes statements
169 such as "enjoys seeing other people's activities"²². In contrast, the negative dimension is
170 evaluated based on the psychological symptoms of persons with dementia, including items
171 involving being "quick-tempered," "hits or kicks things," and "shouts loudly"²². The nurses
172 were also asked about their age, gender, years of nursing experience, and years of
173 experience at the current facility.

174 Ethical Considerations

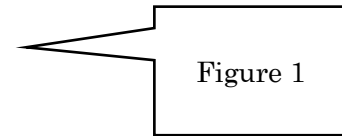
175 A written informed consent for participation in this study and for the use of the deceased
176 resident's data was obtained from the family members of deceased residents, as well as
177 participating nurses. Documents sent to the participants explained the purpose of the
178 research, informed them about the voluntary nature of participation, the fact that withdrawal
179 from the research would cause no disadvantage to them, and the research methods, and
180 reassured the promise of confidentiality and protection of personal information. Research
181 procedures were conducted with the approval of the School of Medicine Research Ethics
182 Committee (Examination number HS2018-199) governing Gunma University affiliates, and
183 that of the management of participating facilities. This study was conducted in accordance
184 with the principles of the Declaration of Helsinki.

185 Data Analysis

186 Samples without missing values were used in this study. Cronbach's alpha for each of the
187 scales (SWC-EOLD-J, SM-EOLD-J, and CAD-EOLD-J) was calculated to evaluate
188 reliability.

189 The Spearman's rank correlation coefficient was calculated for compared scores between
190 SWC-EOLD-J and DRS-J. As a hypothesis for these variables, we predicted that those with
191 less regret about their family members decisions regarding end-of-life care would be more
192 satisfied with the EOLC that their residents received; and the results show negative
193 correlation. The Spearman's rank correlation coefficient was calculated to compare the SM-
194 EOLD-J and short QOL-D scores and the CAD-EOLD-J and short QOL-D scores. As a
195 hypothesis for these variables, we predicted that deceased residents who had a high QOL
196 rating would have fewer distressing symptoms before death and would be rated as having
197 led a more comfortable life. These were conducted to evaluate convergent validity, which is
198 a verification of construct validity (Figure 1). The Spearman's rank correlation coefficient
199 for total scores between scales, was also calculated. An exploratory factor analysis was
200 conducted using the principal factor method, and varimax rotation to verify structural
201 validity. The number of factors was determined after checking the eigenvalues and scree
202 plots. We adopted the criterion that to be significant, the loadings must be greater than
203 0.4²³. All data were analyzed using IBM SPSS 24. Further, confirmatory factor analysis
204 was conducted to test the model fit of the subscales. The criteria for model fit are Goodness

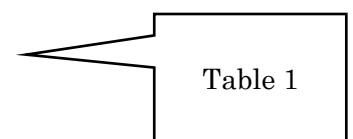
205 of Fit Index (GFI) and Comparative Fit Index (CFI) of 0.9 or higher, and Root Mean Square
206 Error of Approximation (RMSEA) of 0.08 or lower²⁴. The analyses were performed using
207 IBM SPSS Amos Version 27.0.



209 **Results**

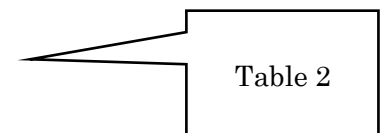
210 Characteristics of Research Participants

211 Questionnaires were sent to 113 family members and 113 nurses, out of which, 92 family
212 members (81.4%) and 90 nurses (79.7%) returned their responses to researchers. The
213 deceased residents with FAST stages ranging from 1 to 3 ($n = 3$), and those with incomplete
214 questionnaires (family members: $n=4$, nurses: $n=25$) were excluded. Finally, we analyzed
215 the responses with no missing values from 83 family members (74.3%) and 62 nurses
216 (54.9%), and the number of respondents for the short QOL-D was 55. The basic attributes
217 of participants are shown in Table 1.



218 SWC-EOLD-J

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



222 Results of the convergent validity testing are presented in Table 3. The SWC-
223 EOLD-J score was significantly moderately correlated with the DRS-J score ($r = -0.504, p$
224 < 0.001).

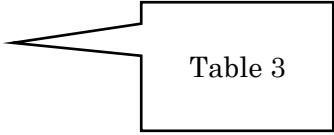


Table 3

225

226 SM-EOLD-J

227 Scores for each part of the SM-EOLD-J scales and short QOL-D are shown in Table 4. The
228 Cronbach's alpha for the SM-EOLD-J among nurses was 0.80 ($n = 62$). The Cronbach's
229 alpha for the SM-EOLD-J subscales of physical and psychological symptoms was 0.58 and
230 0.82, respectively.



Table 4

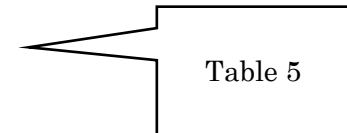
231 The results of convergent validity testing are presented in Table 3. The SM-
232 EOLD-J score was significantly moderately correlated with the negative dimensions of the
233 short QOL-D in nurses ($r = 0.587, p < 0.001$). No correlation was found between the total
234 scores of the SM-EOLD-J and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

235 We conducted a confirmatory factor analysis to confirm the nine items of the SM-
236 EOLD-J, as similar to the two-factor structure of the original SM-EOLD. The results were
237 $GFI = 0.833, CFI = 0.856, RMSEA = 0.130$.

238 The results of the exploratory factor analysis are shown in Table 5. The SM-
239 EOLD-J was found to have two-factor structures. Pain, shortness of breath, skin
240 breakdown, and depression and anxiety were included in one factor, while fear, calm,

241 agitation, and resistiveness to care were included in the other factor. A confirmatory factor
242 analysis was conducted with the two-factor structure based on the results of the exploratory
243 factor analysis conducted in this study (GFI = 0.854, CFI = 0.885, RMSEA = 0.114)

244



245 CAD-EOLD-J

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

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

254 We conducted a confirmatory factor analysis to confirm the 14 items of the CAD-
255 EOLD-J, as similar to the two-factor structure of the original CAD-EOLD. The results were
256 GFI = 0.812, CFI = 0.929, RMSEA = 0.088.

257 The results of the exploratory factor analysis are shown in Table 6. The CAD-
258 EOLD-J was found to have four-factor structures, different from the factors of the original
259 scale. The subscales: physical distress and emotional distress constituted one factor. As for the

260 dying symptom subscale, shortness of breath, choking, and gurgling composed one factor,
261 whereas difficulty in swallowing composed the other. The subscales for well-being consisted of
262 the same items as the original EOLD scales. A confirmatory factor analysis was conducted with
263 the four-factor structure based on the results of the exploratory factor analysis. The results were
264 GFI = .839, CFI = 0.943, RMSEA = 0.086.

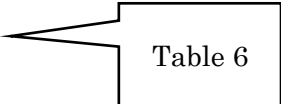


Table 6

265

266 Correlations among EOLD-J scales

267 The results of the correlation analysis of the EOLD-J scales are shown in Table 7. The total
268 scores of SM-EOLD-J and CAD-EOLD-J and most subscale scores were significantly
269 correlated with each other. The SWC-EOLD-J total scores were not correlated with SM-EOLD-
270 J and CAD-EOLD-J total scores and subscale scores.



Table 7

271

272 Discussion

273 SWC-EOLD-J

274 In this study, the reliability of the SWC-EOLD-J was confirmed by the Cronbach's alpha being
275 above 0.7²⁵. Regarding the convergent validity of the EOLD-J scales, a moderate negative
276 correlation was observed between the SWC-EOLD-J and DRS-J scores. It can be said that when
277 family members of deceased residents have no regret regarding their decision-making in the
278 end-of-life care process, they scored higher in the SWC-EOLD-J, which means they were

279 satisfied with the end-of-life care provided. Based on results from this study, the SWC-EOLD-J
280 could measure the degree of satisfaction in the decision-making process among family
281 members. This developed scale may also be used to identify modifiable factors that improve
282 family satisfaction with care for persons with dementia at the end of life²⁶.

283 The data were collected retrospectively, and thus, the answers may have been
284 influenced by selective recall. Therefore, further studies are required on whether the SWC-
285 EOLD-J could be used for evaluation of current care, and responses are biased by demographic
286 characteristics of family members or availability of services.

287 SM-EOLD-J

288 The Cronbach's alpha for the psychological subscale and total score of the SM-EOLD-J,
289 Cronbach's alpha was above 0.7²⁵. The Cronbach's alpha for the physical subscale was low
290 (0.58), similar to that of previous studies¹⁴. Therefore, the reliability of the SM-EOLD-J could
291 be confirmed from the results of this study.

292 The SM-EOLD-J scores were significantly moderately correlated with the negative
293 dimensions of the short QOL-D. This means that nurses gave higher scores in the SM-EOLD
294 when residents' symptoms were good; thus, residents' negative symptoms of dementia may be
295 less evident. It can be said that the convergent validity of the SM-EOLD-J was confirmed. The
296 SM-EOLD-J may be useful to assess the quality of end-of-life care for long-term care residents,
297 as in previous studies²⁷.

298 However, there was no correlation between the total scores for positive dimensions of
299 the short QOL-D, which are based on the behavior of persons with dementia, and scores of the
300 SM-EOLD-J, which are based on the facial expressions and appearances of persons with
301 dementia. The validity of the SM-EOLD-J should be tested using a scale that allows evaluation
302 based on the participants' facial expressions and appearances. As there is no scale to examine
303 the facial expressions and appearances of the persons with dementia in Japan, further research is
304 needed to evaluate the convergent validity of the SM-EOLD-J.

305 The factor structure of the original SM-EOLD scales in the previous study¹⁴ was
306 identified to comprise two subscales: physical (pain, shortness of breath, skin breakdown) and
307 psychological (calm, depression, fear, anxiety, agitation, resistiveness to care). In the
308 exploratory factor analysis results, pain, shortness of breath, skin breakdown, and depression
309 and anxiety composed one factor (Factor 1), whereas fear, calm, agitation, and resistiveness to
310 care composed the other factor (Factor 2). Persons with dementia find it difficult to adequately
311 express and communicate their physical or psychological distress to others because of cognitive
312 decline, and physical distress is also associated with psychological distress, such as
313 depression²⁸. This may have affected the structure of Factor 1. Moreover, for the evaluators,
314 fear, calm, agitation, and resistiveness to care, were symptoms that were easy to visually
315 observe. Persons with advanced dementia have greater difficulty communicating distressing

316 symptoms, making it difficult for care givers to assess the extent of their distress. These items
317 were easier to assess than the Factor 1 items and may have influenced the factor structure.

318 Confirmatory factor analysis showed that the fit of the model was not good. In the
319 original EOLD, since confirmatory factor analysis was not conducted, the results cannot be
320 compared with the present results. On account of the small sample size, it is not possible to
321 conclude whether these results are unique to Japan or not. In this study, the structural validity
322 has not been sufficiently confirmed, it will continue to be examined in further studies.

323 CAD- EOLD-J

324 The Cronbach's alpha of the CAD-EOLD-J was above 0.7²⁵. Therefore, the reliability of CAD-
325 EOLD-J could be confirmed.

326 The CAD-EOLD-J scores were significantly moderately correlated with the
327 negative dimensions of the short QOL-D. It could be said that when the residents showed fewer
328 signs of discomfort, it led to nurses giving higher scores on the CAD-EOLD-J. Therefore, the
329 convergent validity of the CAD-EOLD-J could be confirmed. The CAD-EOLD-J may be used as
330 an outcome measure for intervention studies on EOL care for people with dementia in Japan²⁹,
331 as well as for prospective studies³⁰.

332 In the results of the exploratory factor analysis, the subscales of physical distress
333 and emotional distress constituted one factor. This result suggests that in Japanese nursing
334 homes, nurses may be observing physical and psychological symptoms without distinguishing

335 them. Difficulty in swallowing was analyzed as an independent factor. The scores for
336 difficulties in swallowing in this study were lower than those in previous studies²⁸. Moreover,
337 the scores of difficulties in swallowing tended to be lower than the scores for other items of the
338 CAD-EOLD-J. These results may have been affected by the factor structure of the CAD-EOLD-
339 J. The subscales for well-being were confirmed to comprise the same items as in the original
340 EOLD scales. In the future, it is necessary to further examine whether this result is characteristic
341 of Japan. Confirmatory factor analysis showed that the fit of the model was not good. The
342 CAD-EOLD-J showed a factor structure, in which the item for difficulty in swallowing was a
343 single factor, and the subscales of physical distress and emotional distress constituted one
344 factor. Since it is not possible to conclude whether these results are unique to Japan or not, we
345 shall continue to examine these results in future studies.

346 Correlations among EOLD-J scales

347 As in previous studies¹⁴, the SM-EOLD-J and CAD-EOLD-J total scores and most
348 subscale scores were significantly correlated with each other. However, the SWC-EOLD-J total
349 scores were not correlated with SM-EOLD-J and CAD-EOLD-J total scores and subscale
350 scores. In a previous study¹⁴, the original SWC-EOLD and SM-EOLD, CAD-EOLD was
351 evaluated by the family members of the deceased residents. In the current study, the SWC-
352 EOLD-J was evaluated by the family members of the deceased residents, whereas the SM-
353 EOLD-J and CAD-EOLD-J were evaluated by nurses. Therefore, the differences between these

354 categories of participants may have affected the EOLD-J scores. Prior studies have also found
355 differences in the original EOLD scale's scores between survivors and professionals^{31,32}. In the
356 future, we will also examine the rater's effect on the EOLD-J scores.

357

358 **Limitations**

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

367

368 **Conclusion**

369 Through this study, we developed the Japanese version of EOLD-J and confirmed it to be valid
370 and reliable when used in end-stage persons with dementia in Japan. The EOLD-J had a good
371 convergent validity and a good internal consistency. However, determination of the factor
372 structure of EOLD-J requires further study.

373

374 **Competing Interests**

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

376

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382

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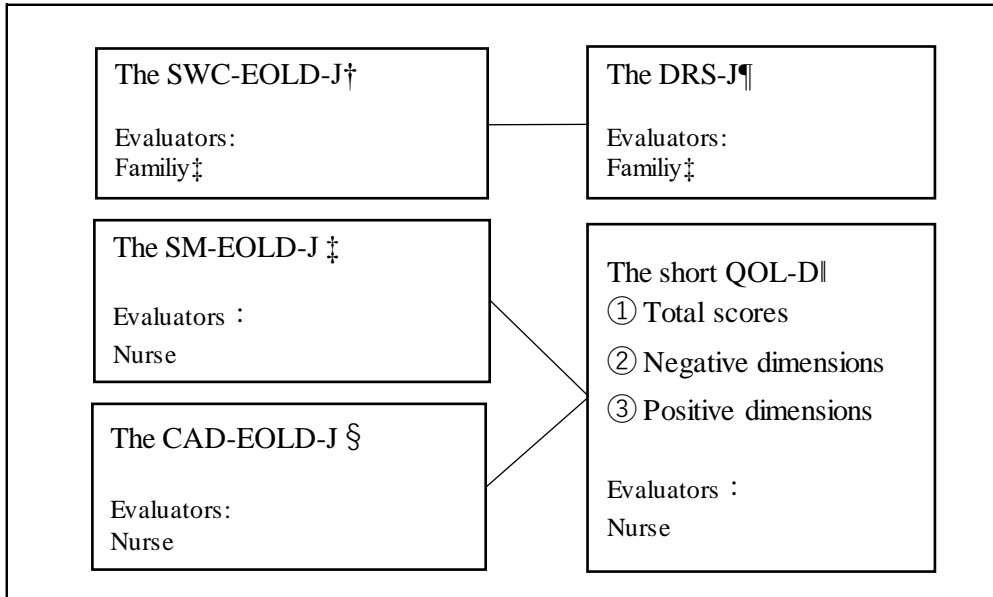


Figure 1: Convergence validation for End-Of-Life in Dementia scales

‡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

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Table 1. Basic attributes of participants

Participant	Item	n	%	Mean	SD	
Deceased resident	Age at death			91.2	6.52	
	Gender	Female	60	72.3		
		Male	23	27.7		
	FAST†	Stage 4	7	8.4		
		Stage 5	12	14.5		
		Stage 6	22	26.5		
		Stage 7	42	50.6		
	Cause of death	Senility	63	75.9		
Others		20	24.1			
Family‡	Age			64.8	8.83	
	Gender	Female	46	55.4		
		Male	37	44.6		
	Relationships with residents	Spouse	4	4.8		
		Sibling	1	1.2		
		Child	65	78.3		
		Child of spouse	8	9.7		
		Grandchild	1	1.2		
		Others	4	4.8		
	Years of nursing care			8.2	5.09	
Nurse	Age			51.2	11.32	
	Gender	Female	58	93.5		
		Male	4	6.5		
	Years of nursing experience			25.7	12.39	
Years of working at the facility			8.7	5.06		

†FAST: Functional assessment staging of Alzheimer's disease

‡Family: Family members of the deceased residents

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

Scale	Respondent	Item	Range	Mean	SD
The SWC-EOLD-J† (n = 83)	Family‡	I felt fully involved in all decision-making processes.	1–4	3.30	0.60
		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 (n = 83)	Family‡	Total	0–100	14.53	13.77

‡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

Respondents <i>n</i>	The SWC-EOLD-J†		The SM-EOLD-J‡		The CAD-EOLD-J§	
	Family¶		Nurses		Nurses	
	83		55		55	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
DRS-JI	-0.504*	<0.001				
Short QOL-D#						
Positive dimensions			-0.238	0.080	-0.187	0.177
Short QOL-D#						
Negative dimensions			0.587*	<0.001	0.509*	<0.001
Short QOL-D# Total			0.089	0.519	0.101	0.466

* $p < 0.001$: 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

IThe DRS-J: Japanese Decision Regret Scale

#The short QOL-D: short version of the Quality of Life questionnaire for Dementia

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

Scale	Respondent	Subscales	Item	Range	Mean	SD
The SM-EOLD-J§ (n = 62)	Nurse	Physical	Pain	0-5	3.39	2.00
			Shortness of breath	0-5	3.32	2.01
			Skin breakdown	0-5	3.81	1.85
		Psychological	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	
		Subscale Physical Symptoms	0-15	10.52	4.31	
		Subscale Psychological Symptoms	0-30	24.55	7.07	
		The CAD-EOLD-J¶ (n = 62)	Nurse	Physical distress	Discomfort	1-3
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
Dying symptoms	Gurgling			1-3	2.31	0.69
	Difficulty swallowing			1-3	1.61	0.61
	Emotional distress			Fear	1-3	2.69
Anxiety				1-3	2.58	0.59
Crying				1-3	2.74	0.54
Moaning				1-3	2.68	0.57
well-being	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	
Subscale Physical distress	4-12			9.82	2.00	
Subscale Dying symptoms	4-12			8.97	1.69	
Subscale Emotional distress	4-12	10.69	10.69			
Subscale Well-being	3-9	7.05	1.53			
The short QOL-D# (n = 55)	Nurse	Total	7-36	22.38	4.18	
		Negative dimension	3-12	10.72	2.01	
		Positive dimension	4-24	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

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Table 5. Roated factor structure of the SM-EOLD-J

n = 62

Subscales		Factor loading		
		Factor1	Factor2	
§SM-EOLD-J	Physical	Pain	0.69	0.04
		Shortness of breath	0.50	0.05
		Skin breakdown	0.41	0.22
	Psychological	Depression	0.43	0.26
		Anxiety	0.69	0.50
		Fear	0.38	0.54
		Calm	-0.07	0.55
		Agitation	0.38	0.78
		Resistiveness to care	0.33	0.74
		Contribution ratio	1.94	2.11
Cumulative contribution ratio	45.06	23.49		

§The SM-EOLD-J: Japanese version of symptom management at the end of life in dementia

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Table 6. Roated factor structure of the CAD-EOLD-J

n = 62

Subscales		Factor loading				
		Factor1	Factor2	Factor3	Factor4	
¶CAD-EOLD-J	Physical distress	Discomfort	0.73	0.27	-0.27	0.09
		Pain	0.59	0.10	-0.11	0.18
		Restlessness	0.67	0.13	0.00	0.27
	Dying symptoms	Shortness of breath	0.47	0.45	0.10	0.14
		Choking	0.30	0.67	-0.21	0.12
		Gurgling	0.19	0.73	0.43	-0.13
		Difficulty swallowing	-0.05	0.03	0.64	-0.03
	Emotional distress	Fear	0.70	0.43	-0.15	0.16
		Anxiety	0.79	0.18	0.01	0.24
		Crying	0.77	0.09	0.03	0.22
Moaning		0.69	0.24	0.18	0.18	
well-being	Serenity	0.25	0.01	0.06	0.83	
	Peace	0.22	-0.02	-0.06	0.91	
	Calm	0.28	0.16	-0.12	0.88	
Contribution ratio		4.05	1.59	0.82	2.61	
Cumulative contribution ratio		28.96	58.91	64.73	47.56	

¶The CAD-EOLD-J: Japanese version of comfort assessment in dying with dementia

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Table 7. Correlations of the EOLD-J scales

#	Scale	Subscale	Correlations							
			1	2	3	4	5	6	7	8
1	SWC-EOLD-J†	Total	-	-	-	-	-	-	-	-
2	SM-EOLD-J‡	Total	0.027	-	-	-	-	-	-	-
3		Physical	0.075	.474**	-	-	-	-	-	-
4		Psychological	0.035	.825**	.863**	-	-	-	-	-
5	CAD-EOLD-J§	Physical distress	0.025	.641**	.609**	.708**	-	-	-	-
6		Dying symptoms	0.010	.371**	0.138	.321*	.490**	-	-	-
7		Emotional distress	-0.054	.491**	.649**	.671**	.750**	.426**	-	-
8		Well-being	0.043	0.161	.527**	.404**	.407**	0.098	.382**	-
9		Total	-0.057	.545**	.638**	.690**	.857**	.582**	.794**	.685**

**p<0.001, *p<0.005 Spearman rank correlation coefficient.

†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