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Original Article

## Clinical Factors Affecting the Remaining Activity of Daily Living in Severe Dementia

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### SUMMARY

**Background:** Maintenance of the remaining abilities of dementia patients is necessary to improve their quality of life and reduce the burden on caregivers. This study aimed to identify the clinical factors that affect patients with severe dementias' remaining abilities in activities of daily living (ADL).

**Methods:** The participants were 93 patients with severe dementia as assessed using the Clinical Dementia Rating. The variables (ADL, cognitive function, behavioral symptoms, nutritional state, pain, comorbidities, muscle condition) were measured using the Physical Self-Maintenance Scale (PSMS), Mini-Mental State Examination (MMSE), Cognitive Test in Severe Dementia (CTSD), Neuropsychiatric Inventory Nursing Home version (NPI-NH), Cornell Scale for Depression in Dementia (CSDD), Mini-Nutritional Assessment Short Form (MNA-SF), Pain Assessment in Advanced Dementia (PAIN-AD), Charlson Comorbidity Index (CCI), Cumulative Illness Rating Scale-Geriatrics (CIRS-G), and muscle tone assessment.

**Results:** The logistic regression analyses identified the association between each item in PSMS as a dependent variable and the other rating as an independent variables. Toileting correlated with CTSD, MMSE, MNA-SF, CSDD, and hypertonus of the knee. Feeding correlated with CTSD, MMSE, NPI-NH, and CSDD. Physical ambulation correlated with CTSD, MMSE, CSDD, CCI, hypertonus of the knee, and MNA-SF.

**Conclusion:** Many factors other than cognitive function affect each item of the ADL, such as agitation, comorbidities, hypertonus of the knee, and nutrition. We emphasize that intervention strategies need to be modified for the impairment of each ADL item to perform the remaining abilities for severe dementia.

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## 1. Introduction

It is well known that the activities of daily living (ADL) in individuals with dementia are significantly affected by cognitive dysfunction.<sup>1</sup> As dementia progresses, the clinical condition of the disease becomes more complex, and factors other than cognitive dysfunction also affect their ADL.<sup>2–4</sup> Dependence with ADL increases the caregiver burden<sup>5</sup> and the total need for assistance is one of the predictors of death.<sup>6</sup> Thus, it is important for individuals with dementia to retain their independence as long as possible even in severe stage. There is a case report of severe dementia improving ADL with daily treatment and rehabilitation.<sup>7</sup> However, this result was not based on an intended, strategic rehabilitation approach that would treat the factors contributing to each impairment of the ADL.

Therefore, we examine the factors that affect the ability to perform the remaining ADL in individuals with severe dementia, including various factors other than cognitive functioning.<sup>8</sup> Our results suggest that cognitive function is strongly associated with ADL, even in patients with severe dementia. In addition, we found that agitation assessed by CSDD, comorbidities, and nutritional status affected

ADL. Our previous study was based on the total ADL score using the PSMS as the dependent variable. However, each ADL item will require different abilities, and the associated factors are expected to be varied. Therefore, intervention strategies for care should be considered for each ADL item.

In this study, we focused on the remaining abilities of severe dementia and examined the factors that affect these abilities for each ADL item.

## 2. Methods

### 2.1. Study setting and participants

During the period April 2015 to March 2017, we conducted a single-center observational study at a 270-bed rural recuperation hospital in Hyogo Prefecture, Japan. Almost all patients in this hospital have dementia of varying types and severity and approximately half of the patients have severe or profound dementia. The patients assessed as grade 3 by the Clinical Dementia Rating (CDR)<sup>9</sup> were included.

This study provides further analysis of our previous study that reported on individuals with severe dementia. All participants underwent a standard clinical interview, physical and neurological ex-

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aminations, and a computed tomography scan. Major neurocognitive disorders were assessed using the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) and classified into the following subtypes: Alzheimer's disease (AD), vascular dementia (VaD), or Lewy body disease (LBD). In addition, a few other conditions were diagnosed, including normal pressure hydrocephalus (NPH) and chronic subdural hematoma (CSDH).

Patients with the following conditions were excluded: 1) severely impaired consciousness (e.g., coma from head injury or kinetic mutism); 2) severe aphasia and motor function disabilities as a result of a stroke; 3) blindness and deafness; 4) having taken antipsychotic drugs in the week prior to the administration of the tests; and 5) attending doctor's assessment for participation would adversely affect the patient's condition.

## 2.2. Measures

### 2.2.1. ADL

The PSMS includes six items relating to the performance of physical activities and a lower total score indicating greater impairment in ADL.<sup>10</sup> ADLs in severe dementia often show a floor effect. Therefore, in this study, each item was scored on a 0–4 point scale, for a total score of 24 points.

### 2.2.2. Cognitive function

The Cognitive Test for Severe Dementia (CTSD)<sup>11</sup> has a total possible score of 30 and comprises 13 items spanning seven domains.

### 2.2.3. Behavioral psychological symptoms of dementia

The Neuropsychiatric Inventory, Nursing Home version (NPI-NH)<sup>12</sup> is used to assess 12 behavioral and psychological areas and it has each of the 12 items, with a total score ranging from 0 to 144.

The revised Japanese version of the CSDD was used to assess the factor of decreased motivation and the factor of psychomotor agitation. This version of the CSDD has two factors and seven items in total, with a score ranging from 0 to 14, whereas the original version has 19 items in total with a score ranging from 0 to 38.<sup>13,14</sup>

### 2.2.4. Nutritional state

The Mini-Nutritional Assessment Short Form (MNA-SF) was administered to assess the participants' nutritional status. The MNA long form consists of 18 items,<sup>15</sup> whereas the shortened version comprises six items taken from the long-form tool. This tool is simple, easy to use, and can be applied in many different parts of the world. The MNA is useful for assessing nutritional status even for severe dementia.<sup>16</sup>

### 2.2.5. Pain

Pain in older adults is often undertreated, even more so in older adults with severe dementia. The Pain Assessment in Advanced Dementia (PAIN-AD) is an observational scale commonly used for assessing pain in patients with severe dementia.<sup>17</sup> PAIN-AD is easy to use and measures five items.

### 2.2.6. Comorbidity

The severity of any comorbidities present was measured using the CCI.<sup>18</sup> CCI is a method of predicting mortality by classifying or weighting comorbid conditions and has been widely utilized by health professionals and researchers to measure the severity of disease. The CCI comprises 19 items and a higher score indicates more severe comorbidities.

The number of illness categories was based on the Cumulative

Illness Rating Scale – Geriatrics (CIRS-G).<sup>19</sup> CIRS-G rates 14 organ systems on a 5-point Likert scale where 0 indicates no problem and 4 indicates severe problems. We used the total number of endorsed categories.<sup>2</sup>

### 2.2.7. Physical and muscle conditions

Since ADLs are related to physical conditions, muscle tone at the knee and elbow were assessed using a 4-point Likert scale to measure physical status. The scale was defined as “no abnormal muscle tone”, “mild hypertonic”, “moderate hypertonic”, or “severe hypertonic”. The assessment was performed by the occupational therapists and physical therapists in charge at the hospital.

## 2.3. Procedures

The first evaluation (baseline assessment) was conducted in the first week after informed consent was obtained from the participants. All evaluations were performed by five occupational therapists familiar with the participants' abilities. Bathing and dressing were excluded from the analysis since almost all participants were bathed in a special bathtub that allowed them to bathe while lying down. Dressing was carried out after bathing, while the participant was lying on the bed.

## 2.4. Data analysis

Logistic regression analysis identified the association between each item in the PSMS, which was a dependent variable, and the MMSE or CTSD, PAIN-AD, CCI, MNA-SF, NPI-NH, and CSDD, which were independent variables. To investigate what factors affected the remaining ability in patients with severe dementia, we set the lowest score as a dummy variable (0) and all scores other than the lowest score as 1 for each item of the PSMS. This allowed us to determine the factors that affected the remaining abilities of patients with severe dementia. Before the logistic regression analysis, we assessed these variables to avoid multicollinearity. The correlation coefficient was used to evaluate the associations between each variable. The correlation coefficient among independent variables was < 0.70, indicating that they can be validly treated as independent variables.<sup>20</sup> When the correlation coefficient between variables was 0.7 or higher, one of the variables was removed to avoid multicollinearity. Next, a simple linear regression analysis was performed for each selected independent variable, and those with  $p < 0.2$  or less were inserted as independent variables in the logistic regression analysis. The backward elimination method was used for variable selection. There is a rule of thumb that logistic models should be used with a minimum of ten outcome events per independent variable. However, Vittinghoff et al. reported that between five and nine samples per independent variable were acceptable, although the rigor was slightly reduced. If only two to four samples are used, then the risk of error increases.<sup>20</sup> We adopted this criterion since we utilized a single-center study design.

Additionally, after examining the results of logistic analysis, we assessed the Variance Inflation Factor (VIF). If VIF of the variables exceeded 3, we excluded that variable.

We adjusted for age and sex as covariates. Statistical analyses were performed using SPSS version 28.  $p$  values ( $p < 0.05$ ) were considered statistically significant.

## 2.5. Ethical considerations

The participant's family members provided written informed

consent. This study was approved by the Ethics Committee of Osaka Prefecture University (2017-207).

### 3. Results

#### 3.1. Participants and score distribution at baseline assessment

Table 1 presents the participants' demographic characteristics (male, n = 22; female, n = 71; mean age = 87.4 years ± 6.3 years). The participants were classified into the following dementia classes: AD (n = 48), VaD (n = 28), LBD (n = 3), and others (front temporal dementia: 2; NPH: 7; and CSDH: 5) (n = 14).

#### 3.2. The factors that affect the remaining abilities in patients with severe dementia

The unadjusted associated factors are set out in Table 2, and the adjusted associated factors, as a result of the multivariable regression model, are presented in Table 3. The items that showed no significant difference between the groups with and without remaining abilities were PAIN-AD and CIRS (number of categories) (p = 0.199–0.913; Mann Whitney-U test). The highest percentage of participants with remaining abilities were for feeding (78/93; 83.9%), physical ambulation (43/93; 46.2%), and toileting (18/93; 19.4%).

Table 3 shows the results of the logistic regression analysis for each item in the PSMS. In all models, the X<sup>2</sup> values for the models described above were significant (p < 0.05). The Hosmer-Lemeshow test also showed a goodness of fit (p > 0.05 (0.758–0.930)), and the results of the analysis were not considered to be a poor fit. No variable with a VIF greater than 3 was observed in any model.

First, for the remaining ability of the toileting, CTSD (OR = 1.130, 95% CI = 1.005–1.272, p = 0.04), CSDD (OR = 1.542, 95% CI = 0.924–2.573, p = 0.097), and hypertonus of the knee (OR = 0.188, 95% CI = 0.065–0.543, p = 0.002) were included in this model. The CTSD and

hypertonus of the knee were significant. The lowest odds ratio for the item of toileting was obtained for the hypertonus of the knee. Second, for the remaining ability of feeding, CTSD (OR = 1.119, 95% CI = 1.019–1.230, p = 0.0019), CSDD (OR = 1.579, 95% CI = 0.883–2.824, p = 0.124), CCI (OR = 0.603, 95% CI = 0.355–1.023, p = 0.061) were included in this model. Only the CTSD was significant. Finally, for the remaining ability of physical ambulation, CSDD (OR = 2.069, 95% CI = 1.343–3.188, p = 0.001), CCI (OR = 0.489, 95% CI = 0.295–0.810, p = 0.005), hypertonus of the knee (OR = 0.396, 95% CI = 0.224–0.698, p = 0.001), MNA-SF (OR = 2.121, 95% CI = 1.301–3.458, p = 0.003) were included in this model. The CCI, CSDD, hypertonus of

**Table 1**  
Demographic characteristics of the subjects.

	Severe dementia subjects (n = 93)
Gender, male:female	22:71
Subtype, AD:VaD:LBD:other	48:28:3:14
Mean age ± SD, years	87.4 ± 6.3
CTSD	13.2 ± 9.1
MMSE	3.9 ± 4.0
PSMS	11.1 ± 2.7
PAIN-AD	1.8 ± 1.9
CIRS (the number of category)	3.6 ± 1.4
CCI	2.4 ± 1.3
MNA-SF	5.9 ± 1.8
BMI	16.0 ± 2.6
NPI-NH	13.4 ± 14.7
CSDD	1.5 ± 1.6
Hypertonus of knee	2.8 ± 1.2
Hypertonus of elbow	2.2 ± 1.0

AD = Alzheimer's disease; BMI = body mass Index; CCI = Charlson comorbidity index; CSDD = Cornell Scale for depression in dementia; CTSD = Cognitive Test for severe dementia; LBD = Lewy body dementia; MMSE = Mini-Mental State Examination; MNA-SF = Mini Nutritional Assessment-Short Form; NPI-NH = Neuropsychiatric Inventory-Nursing Home version; PAIN-AD = Pain Assessment in Advanced Dementia Scale; PSMS = Physical Self-Maintenance Scale; VaD = vascular dementia.

**Table 2**  
Characteristics in group with or without remaining ability.

	Toilet			Feeding			Physical ambulation		
	Group without remaining ability (n = 75)	Group with remaining ability (n = 18)	p value	Group without remaining ability (n = 15)	Group with remaining ability (n = 78)	p value	Group without remaining ability (n = 50)	Group with remaining ability (n = 43)	p value
Gender male:female	18:57	2:16		4:11	16:62		12:38	7:36	
Subtype AD:VaD:LBD:other	37:27:3:8	16:1:1:0		10:4:0:1	43:24:4:7		30:15:2:3	23:13:2:5	
Mean age ± SD, years	88.1 ± 6.5	85.0 ± 6.8	0.007**	88.3 ± 7.2	85.0 ± 6.6	0.724	88.4 ± 0.9	86.7 ± 6.2	0.215
CTSD	13.1 ± 8.8	20.5 ± 5.4	< 0.001***	8.4 ± 8.3	20.4 ± 8.5	0.027*	12.7 ± 9.2	16.2 ± 7.8	0.059
MMSE	3.6 ± 3.8	6.6 ± 2.8	0.002**	2.0 ± 3.7	6.6 ± 3.8	0.006**	3.3 ± 3.8	5.1 ± 3.8	0.025*
PSMS	10.7 ± 2.0	16.1 ± 1.7	< 0.001***	8.5 ± 1.3	16.2 ± 2.6	< 0.001***	10.0 ± 1.7	13.5 ± 2.7	< 0.001***
PAIN-AD	1.8 ± 2.0	1.2 ± 1.5	0.242	1.7 ± 1.7	1.2 ± 1.9	0.913	1.6 ± 1.8	1.8 ± 2.0	0.680
CIRS (the number of category)	3.6 ± 1.3	3.8 ± 1.7	0.685	3.5 ± 1.3	3.8 ± 1.4	0.660	3.8 ± 1.3	3.4 ± 1.3	0.199
CCI	2.6 ± 1.4	2.0 ± 1.4	0.188	3.0 ± 1.4	2.0 ± 1.4	0.207	2.8 ± 1.4	2.1 ± 1.2	0.014**
MNA-SF	5.8 ± 1.9	6.9 ± 2.0	0.086	5.2 ± 1.3	6.9 ± 1.9	0.215	5.4 ± 1.9	6.8 ± 1.7	< 0.001***
NPI-NH	14.1 ± 16.5	25.9 ± 20.1	0.054	7.2 ± 1.3	25.9 ± 18.0	0.016*	10.4 ± 11.7	23.1 ± 20.1	< 0.001***
CSDD	1.4 ± 1.6	2.5 ± 1.6	0.022*	0.7 ± 1.3	2.5 ± 1.6	0.088	0.98 ± 1.5	2.3 ± 1.5	< 0.001***
Hypertonus of knee	3.1 ± 1.1	1.5 ± 0.5	< 0.001***	3.2 ± 1.0	1.5 ± 1.2	0.087	3.3 ± 1.0	2.1 ± 1.1	< 0.001***
Hypertonus of elbow	2.4 ± 1.0	1.3 ± 0.5	< 0.001***	3.0 ± 0.9	1.3 ± 1.0	0.027*	2.7 ± 1.0	1.6 ± 0.8	< 0.001***

\*\*\* p < 0.001, \*\* p < 0.01, \* p < 0.05 (Mann whiteny-U test).

AD = Alzheimer's disease; BMI = body mass Index; CCI = Charlson comorbidity index; CSDD = Cornell Scale for depression in Dementia; CTSD = Cognitive Test for Severe Dementia; LBD = Lewy body dementia; MMSE = Mini-Mental State Examination; MNA-SF = Mini Nutritional Assessment-Short Form; NPI-NH = Neuropsychiatric Inventory-Nursing Home version; PAIN-AD = Pain Assessment in Advanced Dementia Scale; PSMS = Physical Self-Maintenance Scale; VaD = vascular dementia.

**Table 3**

The results of the logistic regression analysis with backward elimination method in severe dementia.

	B	SE	Wald	p	Exp (B)	95% CI		VIF
						Lower	Upper	
<b>Toilet</b>								
CTSD	0.122	0.060	4.155	0.042*	1.130	1.005	1.272	1.11
CSDD	0.433	0.261	2.753	0.097	1.542	0.924	2.573	1.08
Hypertonus of knee	-1.670	0.541	9.544	0.002**	0.188	0.065	0.543	1.17
Model $\chi^2$ test $p < 0.001$								
Hosmer-Lemeshow test $p = 0.930$								
<b>Feeding</b>								
CTSD	0.113	0.048	5.507	0.019*	1.119	1.019	1.230	1.03
CSDD	0.457	0.297	2.368	0.124	1.579	0.883	2.824	1.02
CCI	-0.506	0.270	3.515	0.061	0.603	0.355	1.023	1.01
Model $\chi^2$ test $p < 0.01$								
Hosmer-Lemeshow test $p = 0.875$								
<b>Physical ambulation</b>								
CCI	-0.716	0.258	7.721	0.005**	0.489	0.295	0.810	1.12
CSDD	0.727	0.221	10.863	0.001***	2.069	1.343	3.188	1.00
Hypertonus of knee	-0.927	0.290	10.246	0.001***	0.396	0.224	0.698	1.16
MNA-SF	0.752	0.249	9.093	0.003**	2.121	1.301	3.458	1.24
Model $\chi^2$ test $p < 0.001$								
Hosmer-Lemeshow test $p = 0.758$								

\*\*\*  $p < 0.001$ , \*\*  $p < 0.01$ , \*  $p < 0.05$ .

CCI = Charlson Comorbidity Index; CSDD = Cornell Scale for depression in dementia; CTSD = Cognitive Test for Severe Dementia; MNA-SF = Mini Nutritional Assessment-Short Form.

the knee, and MNA-SF scores were significant. The highest odds ratio for the item of physical ambulation was obtained for MNA-SF.

The logistic regression analysis could not be performed for grooming because the number of participants who showed the lowest score was extremely small ( $n = 8$ ).

#### 4. Discussion

Chiu et al. reported that the items related to ADL vary for each subtests of the MMSE.<sup>1</sup> We examined the relationship among various factors including cognitive function and sub-items of ADL. The strength of this study is that it focused on the remaining abilities in patients with severe dementia and attempted to clarify the clinical factors that affect these abilities. Notably, the factors affecting the remaining abilities were different. Gender differences did not appear to have a significant effect in this study; while there seemed to be a significant difference for Instrumental ADL, no such effect was observed for basic ADL such as toileting, eating, and physical ambulation.

In the analysis of each sub-item in this study, toileting ability was associated with high cognitive function, worse depression and agitation assessed by CSDD, and less severe hypertonus of the knees. The CSDD is usually an assessment of depression; the Japanese version of the CSDD consists of two factors: the factor of decreased motivation and psychomotor agitation. Assessment of depression in severe dementia is difficult to evaluate in detail because language ability is also impaired. In this study, only agitation was graded in almost all subjects in CSDD. In other words, CSDD was graded as agitation.

It is understandable that high cognitive functioning is related to toileting, as a certain level of muscle tone in the knee is required for transferring oneself to the toilet and for maintaining balance in the sitting position. Interestingly, in this model, the worse the participant's agitation as assessed by CSDD, the better their ability to use the toilet. Usually, worse agitation is associated with lower ability.<sup>22</sup> We note that this might be due to the reversal phenomenon since the analysis was specific to severe dementia. In daily clinical practice, patients with severe dementia often demand to use the toilets

verbally agitation has been said to occur in relation to personal caregiving, especially for toileting in daily living.<sup>23</sup> In such cases, caregivers may reluctantly take patients to the toilet. However, if the patient does not complain about going to the toilet, the caregiver may force the patient to wear a diaper. Therefore, it is possible that the patient's strong desire to urinate and defecate may have been assessed as agitation by the caregiver. The lowest PSMS score was graded as having no complaints of urination or defecation.

Feeding ability was associated with high cognitive function, severe agitation, and milder comorbidities. In the feeding model, this result may be caused by the same reason as the toileting findings. Most patients with severe dementia have impaired satiety centers. The patient's frequent feelings and demands of hunger have been perceived as agitation by caregivers. However, these demands might show their ability to eat independently. In contrast, it can be inferred that older persons with severe comorbidities may have decreased appetite and may not be able to feed on their own.<sup>24</sup>

Physical ambulation was significantly associated with milder comorbidities, worse agitation, less severe hypertonus of the knee, and good nutritional status in the model. However, physical ambulation was not associated with cognitive function. Some patients with severe dementia were able to move around the hospital because of stereotypical behavior. It does not appear that physical ambulation requires cognitive functioning. Nutritional status is known to be related to physical functioning.<sup>25</sup> Therefore, it is understandable that good nutritional status and muscle tone in the knee affect physical ambulation. Furthermore, the results showed that worsened agitation assessed by CSDD maintained the ability to perform physical ambulation. Agitation is also called "challenge behavior" and is said to be behavior with its own purpose.<sup>26</sup> Patients who exhibit agitation may still have the ability to move and a caregiver may mistake this movement as aimless, which may then be assessed as physical agitation. When dementia progresses to the profound stage, agitation disappears, and spontaneity is extremely reduced. The patient no longer moves on his or her own initiative, and full assistance is required for mobility. As in the case of feeding and toileting, patients who can express their own intentions may have the ability to move

for their purposes.

#### 4.1. Limitations

This study had some limitations. In terms of both clinical and statistical aspects, from clinical aspect: 1) the date on which and period since the participants had been diagnosed with dementia was not known or assessed since most of the participants were transferred from other hospitals; 2) we could not analyze the grooming, bathing, and dressing abilities of patients. From statistical aspect: 1) the sample size was small and the sample was taken from a single center; 2) there was also a risk of yielding false positives due to conducting three different analyses were using the same data set; 3) in the logistic regression analysis, we analyzed fewer than 10 individuals per variable, as suggested by previous studies.<sup>20</sup> However, these results may indicate an increase in bias and variability, unreliable confidence interval coverage, and problems with model convergence as events per variable decreased below 10. In order to generalize based on our results, it will be necessary to conduct cross-validation for internal validation by expanding the sample size and to validate the results at other facilities for external validity.

#### 5. Conclusion

We analyzed the factors associated with each PSMS item in patients with severe dementia. Our results suggest that intervention strategies need to be modified for the degree of impairment of each ADL item in order to assist the patient to perform the remaining abilities. It is noteworthy that the factors affecting the abilities that the patients were still able to perform were different for each item. Worse agitation was associated with a lower ability for toileting, feeding, and physical ambulation.

#### Conflict of interest

The authors declare no conflicts of interest.

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