

# Awareness of Instrumental Activities of Daily Living Disability: Pilot Study for Elderly Requiring Care and Caregivers

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## Keywords

Dementia care · Elderly · Awareness · Instrumental activities of daily living

## Abstract

**Aim:** We aimed to investigate differences in the awareness of instrumental activities of daily living (IADL) disability between elderly patients with and without dementia requiring care. **Methods:** We assessed 25 elderly individuals requiring care and their primary caregivers using the Lawton IADL scale, with score differences between the patients and their caregivers representing the level of impaired awareness of IADL disability. **Results:** Among the participants, 80% exhibited impaired awareness of IADL disability. In terms of total score on the Lawton scale, there was no between-group difference in the occurrence of impaired awareness of IADL disability ( $p = 0.274$ ,  $\phi = 0.31$ ). Contrastingly, regarding the sub-items of the Lawton scale, the dementia group had a significantly higher number of participants with impaired awareness of responsibility for their own medications than the nondementia group ( $p = 0.030$ ,  $\phi = 0.47$ ). Further, there were no significant between-group differences in the ability to use telephone, shopping, mode of transportation, or abil-

ity to handle finances. **Conclusions:** It is important for caregivers to notice the emergence of impaired awareness among the elderly as soon as possible to ensure early diagnosis and treatment. The results of this study suggest the need for caregivers to take care of the elderly patients with the perspective that they may develop impaired awareness of responsibility for their own medications.

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## Introduction

Awareness refers to the objective evaluation of the validity of one's disability perception, that is, one's self-awareness of the experience of subjective changes. Impaired insight refers to a divergence between one's own disability perception and a professional's perceptions [1]. Patients with dementia often exhibit impaired awareness involving underestimation of their memory loss or functional decline [2, 3]. Impaired awareness among patients with dementia causes unexpected accidents and refusal of treatment and care. To formulate strategies for interacting with patients who have impaired awareness, there is a need to elucidate impaired awareness among patients

with dementia in clinical settings. There is little significance in discussing the presence or absence of insight in the advanced dementia stages due to the severely impaired intellectual function [4]. Therefore, we focused on awareness in elderly persons with relatively well-preserved cognitive function.

Several studies have investigated awareness in patients with schizophrenia. Gilleen et al. [5] studied awareness among 31 patients with schizophrenia and found that awareness of cognitive impairment was better preserved than awareness of psychiatric symptoms. Moreover, they observed differences between the awareness of the illness itself and the awareness of impairments and symptoms [5]. Recently, there has been interest in the differences in the awareness of illness and awareness of functioning [5]. In patients with dementia, memory loss and impairment in instrumental activities of daily living (IADL) occur soon after onset [6]. Several studies have investigated impaired awareness among patients with dementia [7–10]; however, they only addressed awareness of memory loss. Discrepancies between the patient's self-awareness and their family's awareness in terms of IADL, that is, impaired awareness of IADL disability, may result in a diagnosis of dementia. However, there have been no studies on impaired awareness of IADL disability.

The Lawton Instrumental Activities of Daily Living Scale (Lawton Scale) is a widely used tool for assessing IADL performance worldwide [11]. The Lawton scale scores independence across eight IADL items (ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances). In the Lawton scale, three items (food preparation, housekeeping, doing the laundry) are excluded in males. As such, men are evaluated on a scale of 0–5, while women are evaluated on a scale of 0–8. Elderly men in Japan perform household chores less frequently than elderly women, suggesting that men often do not perform the said activities (food preparation, housekeeping, doing the laundry) even before they start requiring long-term care [12]. Therefore, in this study, we decided to use Lawton's IADL scale, which is widely used in the world. A discrepancy in awareness of IADL between a patient and their primary caregiver according to the Lawton total score or a subitem score may be associated with the presence or absence of a diagnosis of dementia.

This study aimed to evaluate impaired awareness using discrepancies in awareness between patients and their primary caregivers. Moreover, we aimed to clarify differences in the occurrence of impaired awareness of IADL

disability between two groups divided according to the presence or absence of a diagnosis of dementia in elderly requiring care.

## Materials and Methods

### *Operationally Defined Terms*

We defined “elderly requiring care” as individuals aged  $\geq 65$  years who were not fully independent in basic activities, required care, and were living in a care facility. Regarding impaired awareness of IADL disability, the elderly individual and their caregiver were asked to complete the Lawton scale in terms of the extent of disability for each item. The self-assessment by the elderly individual requiring care was regarded as the “elderly requiring care Lawton scale score,” while the assessment of the elderly individual by their primary caregiver was regarded as the “primary caregiver Lawton scale score.” Differences between these scores were used to represent impaired awareness of IADL disability.

Regarding the evaluation criteria for impaired awareness, Starkstein et al. [13] used the patient-informant discrepancy method to evaluate awareness among patients with suspected Alzheimer's disease. This method evaluates awareness using a discrepancy score based on the difference between the disability as reported by the patient with dementia and that reported by an informant familiar with the patient's current condition. The patient-informant discrepancy score method is the most commonly used approach for evaluating impaired awareness in dementia [2]. This is because the discrepancy score can be easily obtained using a self- and informant-report questionnaire designed to fulfill the specific goals of the investigator [2]. Therefore, based on previous studies [13, 14], we used the patient-informant discrepancy score method to evaluate impaired awareness. Impaired awareness of IADL disability was considered as an impaired awareness level of  $\geq 1$  point on the Lawton scale.

### *Participants*

The study period was from February 1, 2020, to April 30, 2021, and the sample size was determined based on the number of elderly people who were newly admitted to Facility A during this period. We included 25 elderly individuals requiring care who were admitted to a long-term care health facility and their primary caregivers after they provided informed consent. The inclusion criteria for patients were age  $\geq 65$  years, requiring care and having a primary caregiver who could provide reliable patient information. We excluded the patients with conditions that can impair awareness, including comorbid depression, disorder of consciousness, aphasia, severe dementia, unstable health conditions, and any other reason for participant ineligibility according to the investigators. We did not consider the presence or absence of subjective or objective memory loss.

We collected data regarding participant characteristics (sex, age, years of education beyond elementary school, level of care required, the presence or absence of a diagnosis of dementia, current illnesses under treatment, number of oral medication types, and primary caregiver attributes [relationship to the elderly individual, profession, years of caregiving]) from medical records at the time of admission (Table 1). To diagnose dementia, we reviewed the

**Table 1.** Characteristics of the participants

	Total ( <i>n</i> = 25)	Dementia group ( <i>n</i> = 7)	Nondementia group ( <i>n</i> = 18)	<i>p</i> value
Male/female ratio	11/14	2/5	9/9	0.407
Age, years	86.2±6.1	83.3±6.1	87.3±5.9	0.139
Education, years	5 (0–10)	6 (3–7)	5 (0–10)	0.417
Comorbidities, <i>n</i>	2 (1–6)	2 (1–5)	2 (1–6)	0.379
Types of oral medicines, <i>n</i>	4 (1–15)	5 (1–15)	4 (1–11)	0.692
MMSE-J (points)	19.4±5.1	16.4±5.1	20.6±4.7	0.065
FIM (points)	80.0±27.9	78.7±36.9	80.6±24.8	0.886

Sex was compared using Fisher's exact test (number of persons). Age, MMSE-J scores, and FIM scores were compared using a two-sample *t* test (mean value ± standard deviation). Other items were compared using the Mann-Whitney's *U* test (median [range]). MMSE-J, Mini-Mental State Examination-Japanese; FIM, functional independence measure.

patients' medical records to check if they had been diagnosed by physicians at the hospitals where they had visited or been hospitalized before being admitted to the facility.

#### Evaluation

The eight items of the Lawton scale are rated using three to five levels, with a higher score indicating lower independence. Women respond to all eight items, while men only respond to five (ability to use telephone, shopping, mode of transportation, responsibility for own medications, ability to handle finances).

Additionally, we evaluated cognitive function (Mini-Mental State Examination-Japanese, MMSE-J) and activities of daily living (functional independence measure, FIM). All the participants were evaluated by an occupational therapist within 1 week of admission to the long-term care health facility. During the evaluation period, there were no changes to the participants' oral medications or condition.

#### Data Analysis

Participants were divided into those with and without a dementia diagnosis (dementia or nondementia groups), respectively. Attribute variables and Lawton scale scores were checked for normality using the Shapiro-Wilk test. Between-group comparisons of normally distributed variables (age, MMSE-J scores, and FIM scores) were performed using Welch's *t* test. Between-group comparisons of nonnormally distributed variables (years of education, number of illnesses currently being treated, and number of oral medication types) were performed using the Mann-Whitney *U* test. Between-group comparisons of the number of participants with impaired awareness according to the total or subitem scores were performed using the  $\chi^2$  test or Fisher's exact test. We excluded the three subitems of the Lawton scale that could only be evaluated on women (food preparation, housekeeping, laundry). Moreover, we calculated the effect size ( $\phi$ ) for between-group comparisons of the total and subitem scores. Based on Cohen's criteria [15], effect sizes of 0.1–0.29, 0.3–0.49, and >0.5 were interpreted as small, medium, and large effects, respectively. Statistical analyses were performed as SPSS (Ver.21.0, IBM Corporation, Armonk, NY, USA). Statistical significance was set as <5%.

## Results

### Characteristics of the Participants

In total, the study included 25 elderly people (participation rate: 25%) who consented to participate in the study after a total of 75 patients were excluded from the study: 1 patient with depression, 6 patients with disorders of consciousness, 4 patients with aphasia, 9 patients with severe dementia who could not answer the questionnaire, 12 patients with unstable health conditions who had difficulty participating, 18 patients without reliable informants, 25 patients who could not have family visits owing to preventative measures for COVID-19, and 1 patient who was discharged during the evaluation. Table 1 shows the distribution of the participants' characteristics. Among the 25 elderly individuals (11 men, 14 women; mean age 86.2 ± 6.1 years), 7 (28%) had been diagnosed with dementia (5 with Alzheimer's disease, 1 with Lewy body dementia, and 1 with an unknown type). Twenty participants were currently undergoing treatment for internal illnesses, including nine, two, and one for orthopedic illnesses, brain or nervous system illnesses, and other illness types (leg ulcers), respectively (participants were allowed to select multiple responses). Further, 8 and 17 participants were admitted to the facility from their homes and a hospital, respectively. The primary caregivers were 3 spouses (2 wives, 1 husband), 20 children (9 sons, 10 daughters, 1 spouse of a child), and 2 other relatives (1 nephew, 1 niece). There were no significant between-group differences in age, sex, years of education, number of illnesses currently being treated, number of oral medication types, MMSE-J score, and FIM score.

**Table 2.** Between-group comparison of the number of participants with impaired awareness

	Total (n = 25)	Dementia group (n = 7)	Nondementia group (n = 18)	p value	Effect size $\phi$
Impaired awareness according to the Lawton total score (present/absent)	20/5	7/0	13/5	0.274	0.31
Impaired awareness according to the Lawton subitem scores (present/absent)					
Ability to use telephone	7/18	1/6	6/12	0.626	0.19
Shopping	12/13	4/3	8/10	0.673	0.11
Mode of transportation	9/16	3/4	6/12	0.673	0.09
Responsibility for own medications	12/13	6/1	6/12	0.030*	0.47
Ability to handle finances	10/15	4/3	6/12	0.378	0.22

Fisher's exact test (number of persons). Impaired awareness of responsibility for own medications was significantly more common in the presence of a diagnosis group than in the absence of a diagnosis group ( $p = 0.030$ ,  $\phi = 0.47$ ). \*  $p < 0.05$ .

### *Between-Group Differences in the Number of Individuals with Impaired Awareness of IADL Disability*

Among the included participants, 20 (80%) had impaired awareness according to the Lawton scale total score, with no significant between-group difference ( $p = 0.274$ ,  $\phi = 0.31$ ). Regarding the subitems of the Lawton scale, the dementia group had significantly more participants with impaired awareness of responsibility for own medications than the nondementia group ( $p = 0.030$ ,  $\phi = 0.47$ ). However, there were no significant between-group differences in the ability to use telephone ( $p = 0.626$ ,  $\phi = 0.19$ ), shopping ( $p = 0.673$ ,  $\phi = 0.11$ ), mode of transportation ( $p = 0.673$ ,  $\phi = 0.09$ ), or ability to handle finances ( $p = 0.378$ ,  $\phi = 0.22$ ) (Table 2).

### **Discussion**

When a person suffers from a dementing disorder, he or she often has insufficient or lack of awareness of his or her declining ability [16]. Funaki and Tabuchi [17] pointed out that inadequate awareness of the ability of patients with dementia is not only in terms of awareness of memory impairment but also in terms of activities of daily living impairment, depression, anxiety, and executive function disorders. However, previous studies on awareness of patients with dementia and those with cognitive decline have mainly focused on memory impairment [3, 7–10], and little has been done to examine the awareness of disabilities other than memory impairment. This study investigated the awareness of IADL ability in the elderly, including patients with dementia. In our study, impaired awareness of IADL disability was observed in 80% of el-

derly individuals requiring care. Sevush et al. [8] examined the relationship between impaired awareness of cognitive disability and dementia severity in 128 patients with suspected Alzheimer's disease. They observed a correlation between impaired awareness and severity of cognitive dysfunction. Moreover, they found that approximately 80% of patients with Alzheimer's disease who had a mean MMSE score of about 18 points showed varying levels of impaired awareness. In our study, targets elderly individuals requiring care, with 80% showing impaired awareness of IADL disability. This suggests that most elderly individuals requiring care have impaired awareness of both cognitive and IADL disabilities.

We observed no significant between-group difference in impaired awareness according to the Lawton total score. This indicates that based on the overall IADL performance, there was no difference between the patient's subjective awareness and their primary caregiver's objective evaluation. This may be because the patients are more aware of difficulties in some activities compared to others. Depending on the difficulties in activities, awareness may or may not have been present. For example, some participants were not aware of their inability to take their medications but were aware of their difficulties with shopping. Therefore, depending on the type of daily living disability, the difference between the dementia and the nondementia groups may not have been significant with respect to the presence or absence of impaired awareness in the total score of the Lawton scale.

Contrastingly, regarding the subitems of the Lawton scale, the dementia group had significantly more participants with impaired awareness of responsibility for own medications than the nondementia group, with a relatively high effect size ( $\phi$ ) at 0.47. This suggests an



association between low awareness concerning responsibility for medications and dementia diagnosis. Impaired awareness of responsibility for own medications could facilitate identification of early dementia symptoms.

Elderly persons with impaired awareness of responsibility for their own medications think that they are successfully managing their own medications; however, their primary caregivers perceive that they are not or that they require assistance. Elderly persons with impaired awareness have a higher likelihood of being diagnosed with dementia. For example, in case medication is required every morning, the patient may be unaware that they have not established taking medication at a certain time each day as a habit, and therefore, their timing is inconsistent, or even further, that taking medication is completely not a part of their morning routine. Similarly, in a scenario of taking medication with food, they may be unable to make the semantic association of “preparing medication” as a part of the series of actions performed when preparing a meal. Such individuals have a higher likelihood of being diagnosed with dementia. In contrast to familiar activities such as using the telephone or shopping, which the individuals have been performing for years, managing medications could be considered a relatively new activity. Osanai et al. [18] investigated the barriers to medication adherence among 709 adults taking oral medications [17]. Individuals with a short history of taking medication have low experience with medicines and therefore continuously become unable to take them due to the influence of pharmacological factors, including “the medication’s taste or smell” or “the medication’s shape.” Dementia-induced short-term memory loss impedes the creation of a habit of managing medications.

Only the awareness of responsibility for medications was impaired in the subitems. The reason is that responsibility for medications must be followed cautiously. Unlike other subitems, such as doing laundry and cooking, where quality is not as important, medications must be taken on time. Moreover, the correct dosage must be prepared, and care must be taken to avoid errors. The responsibility for taking medications is a task that requires more attention and involves more processes than those in other subitems, including preparation of water and cleaning up. Furthermore, if the dosage and time when a medication should be taken vary daily, the dosage to be prepared must be adjusted accordingly. Elderly people may be less likely to notice errors in any of these steps. Future longitudinal studies should explore the reasons underlying the association between responsibility for own medi-

cations and dementia diagnosis in elderly persons exhibiting impaired awareness of responsibility for own medications on the Lawton scale.

We observed no significant between-group differences in the subitem scores for ability to use telephone, shopping, mode of transportation, and ability to handle finances. This suggests that, unlike responsibility for own medications, impaired awareness of the other four subitems was not associated with a dementia diagnosis in elderly persons.

There are several limitations to this study. First, this study had a small sample size. Second, there is a possibility of selection bias since patients with severe dementia or those who could not complete the questionnaire were not included. Third, we could not determine the causal relationships since this was a cross-sectional study.

## Conclusions

In our study, the dementia group had significantly more participants with impaired awareness of responsibility for their own medications than the nondementia group. It was suggested that caregivers need to take care of their elderly patients with the perspective that the patients may develop impaired awareness of responsibility for their own medications. However, additional work that increased the number of participants is needed to confirm this.

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## Statement of Ethics

Consent for participation was obtained from the participants and the family members who they lived with prior to admission with after they received an oral and written explanation of the study purpose, voluntary study participation, and anonymity of the obtained data. This study was approved by the Institutional Review Board of the Faculty of Health Sciences, Kyorin University (Approval number: 2019-43).

## Conflict of Interest Statement

The authors have no conflicts of interest to declare.

## Funding Sources

The authors have no funding sources to declare.

## Author Contributions

Yukiko Suzuki designed this study, performed the statistical analysis, interpreted the results, and wrote the manuscript. Takayuki Sudo collected the data, searched the literature, and wrote the

manuscript. Hideki Mochizuki searched the literature, interpreted the results, and wrote the paper. Yukiko Suzuki, Takayuki Sudo, and Hideki Mochizuki approved this paper for submission.

## Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author.

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