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Original Article

Effects on activities of daily living and instrumental activities of daily living independence in patients with Alzheimer's disease when the main nursing caregiver consciously provides only minimal nursing care

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Abstract. [Purpose] We investigated whether the activities of daily living and instrumental activities of daily living independence in patients with Alzheimer's disease are positively affected by the main nursing caregiver consciously aiming to provide only minimal nursing care. [Participants and Methods] The participants comprised 105 patients (men: 46, women: 59, mean age: 80.1 ± 6.7 years). We conducted interviews to establish whether the main nursing caregivers consciously aimed to provide only minimal nursing care (care consciousness), and participants were thus divided into two groups. Hyogo Activities of Daily Living Scale scores of the groups with and without care consciousness were compared by dementia severity. [Results] In patients with mild Alzheimer's disease, activities of daily living and instrumental activities of daily living independence in the group with care consciousness were significantly higher than in the group without care consciousness. In patients with moderate Alzheimer's disease, instrumental activities of daily living independence was significantly higher in the group with care consciousness than in the group without care consciousness. [Conclusion] Thus, positive effects on the activities of daily living and instrumental activities of daily living independence are observed when the main nursing caregivers consciously aim to provide only minimal nursing care to patients with Alzheimer's disease.

Key words: Alzheimer's disease, Care consciousness, Instrumental activities of daily living

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INTRODUCTION

Dementia refers not only to cognitive function impairment, but also to impaired activities of daily living (ADL) and to instrumental ADL (IADL)¹⁻³. Therefore, support by a nursing caregiver is essential in enabling each dementia patient to go about his or her daily life. In this process, nursing caregivers need to focus on the remaining abilities, even if the dementia patient has impaired ADL or IADL⁴), as not using these abilities will result in a secondary decrease in ADL⁵).

Excessive nursing care is often observed clinically when treating dementia patients. Factors causing excessive nursing care are thought to include nursing caregivers not correctly grasping the remaining abilities of the dementia patient, resulting in them mistakenly believing that they cannot perform certain tasks, not wanting to wait for the patient to perform tasks to

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avoid wasting time, or an emphasis on avoiding dangers such as collisions or falls.

Yomogita⁶⁾ previously reported that nursing caregivers keep the patient from performing activities to prevent confusing those around them, and indicated that nursing caregivers need to clearly assess what the dementia patient can and cannot do, and only provide support for what they cannot do. This suggests that the nursing caregiver should accurately grasp the remaining ability of the dementia patient and respect their autonomy, by allowing them to engage in those activities that they are able to perform.

We hypothesized that if excessive nursing care has a harmful effect on the maintenance of ADL/IADL abilities in dementia patients, having the nursing caregiver consciously provide only minimal nursing care might have a beneficial effect on ADL/IADL independence.

While some previous studies on nursing caregivers for dementia patients have investigated elements such as care burden^{7, 8)}, depression^{9, 10)} and sleep¹¹⁾, we were unable to locate any reports that had investigated whether the nursing caregiver consciously providing only minimal nursing care has a beneficial effect on the ADL/IADL independence of dementia patients.

Alzheimer's disease (AD) accounts for approximately 70% of dementia patients¹²). The purpose of this study was to investigate, by dementia severity, whether the ADL/IADL of patients with AD are beneficially affected by the main nursing caregiver consciously aiming to provide only minimal nursing care.

PARTICIPANTS AND METHODS

The participants were 105 patients with AD currently hospitalized in a dementia ward (men: 46, women: 59, mean age: 80.1 ± 6.7 years). The selection criteria were (1) having been diagnosed with AD by a physician based on ver. 10 of the International Statistical Classification of Diseases and Related health Problems and (2) being able to follow verbal directions. Exclusion criteria were clearly severe physical disease, unstable chronic disease, or severe visual impairment.

The evaluation parameters used the Japanese version of the Clinical Dementia Rating (CDR)¹³, the Mini Mental State Examination-Japanese (MMSE-J), and the Hyogo Activities of Daily Living Scale (HADLS)¹⁴). Each participant underwent evaluation with the CDR and MMSE-J within one week of hospital admission. For the HADLS, the main nursing caregivers were interviewed within one week of hospital admission in order to assess each participant's lifestyle status immediately prior to hospitalization.

For the CDR, participants were assessed based on information obtained via daily observation of their behavior soon after hospital admission and questioning of family members who lived with them regarding their lifestyle immediately prior to hospitalization. Judgments were made based on agreement with the responsible nurse.

HADLS is a general impairment scale for ADL/IADL in patients with AD. Assessment is performed based on interviews with nursing caregivers. Eighteen questions regarding daily lifestyle activities are rated 3 to 7 scores each. A lower score indicates higher ADL/IADL independence.

The operational definition for the main nursing caregiver consciously aiming to provide only minimal nursing care was based on interviews by occupational therapists of the main nursing caregivers as follows. A participant was included in the group with care consciousness if either case (1) or (2) described below applied. (1) The main nursing caregiver voluntarily stated words to the effect that they were consciously aiming to provide only minimal nursing care (e.g.: "I made sure to let them do things that they were able to perform themselves", "I didn't help them with things that they could do with just my verbal directions or guidance" and "Even if they could only do part of a task, I let them do that part"). (2) If a direct question by the occupational therapist to the main nursing caregiver resulted in the main nursing caregiver stating words to the effect that they were consciously aiming to provide only minimal nursing care (i.e. Answering "Yes" to question (1) "In everyday activities, did you consciously aim to provide only minimal nursing care so that the patient could perform the activities that they were capable of?" or answering "No" to question (2) "Did you also provide nursing care for tasks that the patient could easily perform themselves?"). If neither (1) nor (2) applied, the participant was assigned to the group without care consciousness.

For each dementia severity (CDR) class (CDR0.5/1: mild; CDR2: moderate; CDR3: severe), we compared the two groups in terms of number of patients, patient gender, age, and MMSE-J score. We used the χ^2 test to compare the number of patients and patient gender, and the Mann-Whitney U test to compare age and MMSE-J, between the two groups. We also used the Mann-Whitney U test to compare the HADLS-ADL and HADLS-IADL scores in the two groups for each dementia severity class. Statistical analyses were performed using SPSS Statistics, ver.21.0 (IBM Corporation, Armonk, USA). All p-values were two sided, and p-values of 0.05 or less were considered statistically significant.

This study was approved by the Ethics Committee of Juntendo Tokyo Koto Geriatric Medical Center (approval number 75-1) and the Health Department of Kyorin University (approval number 26-49). The participants and their live-in relatives were given an oral and written explanation of the objective and methods of the study, and they gave their written informed consent to participate in the study.

Table 1. Participants' characteristics and evaluation results

	Participants	p-value	Gender men/womer	p-value	Age (years) Median (range)	p-value	MMSE-J (scores) Median (range)	p-value
CDR0.5/1 (n=30)								
Group with care consciousness	16	0.715	2/14	0.144	79.0 (66–91)	0.251	22 (16-26)	0.600
Group without care consciousness	14		6/8		83.5 (73–91)		22 (13-26)	
CDR2 (n=50)								
Group with care consciousness	19	0.090	12/7	0.345	78.0 (65–93)	0.574	14 (4–21)	0.674
Group without care consciousness	31		14/17		80.0 (71–92)		13 (3–21)	

The χ^2 test was used to compare the number of participants and gender prevalence. Age and MMSE-J were compared using the Mann-Whitney U test.

CDR: Clinical Dementia Rating; MMSE-J: Mini-Mental State Examination-Japanese.

Table 2. Comparison of HADLS according to caregiver's care consciousness

Convenitor of Associatio	Group with care consciousness	Group without care consciousness	p-value
Severity of dementia	Median (range)	Median (range)	
CDR0.5/1 (n=30)			
HADLS-ADL	1.600 (0-12.4)	8.700 (0-31.3)	0.006**
HADLS-IADL	12.15 (4.7–28.8)	23.25 (6.8–37.3)	0.011*
CDR2 (n=50)			
HADLS-ADL	11.80 (3.1-41.9)	14.50 (4.1–43.3)	0.187
HADLS-IADL	26.20 (13.8–37.3)	33.70 (20.5–37.3)	0.015*

Mann-Whitney U test. **p<0.01; *p<0.05.

CDR: Clinical Dementia Rating; HADLS-ADL: Hyogo Activities of Daily Living Scale-ADL; HADLS-IADL: Hyogo Activities of Daily Living Scale-IADL. The lower the score, the higher the independence of ADL/IADL.

RESULTS

For the CDR0.5/1 (mild) patients with AD, no differences were noted between the group with care consciousness and the group without care consciousness in terms of the number of patients (p=0.715), gender (p=0.065), age (p=0.251), or MMSE-J (p=0.600). HADLYS-ADL (p=0.006) and HADLS-IADL (p=0.011) scores were significantly lower in the group with care consciousness (Tables 1 and 2).

For the CDR2 (moderate) patients with AD, no differences were noted between the group with care consciousness and the group without care consciousness in terms of the number of patients (p=0.090), gender (p=0.345), age (p=0.574), or MMSE-J (p=0.674). While no differences were observed for the HADLS-ADL (p=0.187) scores, the HADLS-IADL scores were significantly lower (p=0.015) in the group with care consciousness (Tables 1 and 2).

For the CDR3 (severe) patients with AD, a difference was noted in the number of patients in the group with care consciousness (n=4) and the group without care consciousness (n=21, p=0.001). As the small sample size of the group with care consciousness reduced statistical power¹⁵), no other tests were conducted.

DISCUSSION

We used interviews to determine whether the main nursing caregivers of 105 patients with AD hospitalized in a dementia ward had consciously aimed to provide only minimal nursing care when the patient was at home, an attitude that we defined "care consciousness". We then investigated differences in ADL/IADL independence of patients with AD between the group with care consciousness and the group without care consciousness. Results indicated that for the patients with mild (CDR0.5/1) AD, both ADL/IADL independence were higher in the group with care consciousness. For patients with moderate (CDR2) AD, only IADL independence was higher in the group with care consciousness.

In the patients with mild (CDR0.5/1) AD, ADL/IADL independence were higher in the group with care consciousness than in the group without care consciousness. According to the CDR definition¹³⁾, the ADL of CDR0.5 patients show complete independence, while CDR1 patients sometimes require encouragement. If the nursing caregiver performs such tasks for the patient rather than giving them encouragement, for reasons such as not having enough time, the HADLS-ADL score increases (i.e. the independence level decreases). It appears that the main nursing caregivers in the group with care conscious-

ness were attempting to perform as few as possible ADL tasks for those patients who simply required encouragement. Rather, they appeared to be skillfully encouraging or guiding them. This might be one reason for the higher ADL independence noted in the group with care consciousness compared to the group without care consciousness. IADL ability starts to decrease from the early stages of AD^{16, 17}). For example, CDR0.5 and CDR1 patients often exhibit hesitancy when starting a task or confusion when faced with tasks involving many processes and when this happens, they are often able to complete the task if given appropriate verbal encouragement or guidance. It appears that main nursing caregivers in the group with care consciousness at least partially allocated IADL roles to the patient at home and, rather than quickly performing the tasks for the patient, offered verbal encouragement and guidance, also paying attention to the available equipment and the patient's environment. Thus, IADL independence was found to be higher in the group with care consciousness than in the group without care consciousness.

In the patients with moderate (CDR2) AD no differences were noted in ADL independence depending on the care consciousness of the main nursing caregiver. The ADL of patients with moderate AD is lower than that of patients with mild AD, and great individual variation is noted. Such significant individual variation might make it difficult to detect differences in independence resulting from whether the caregiver attempted to provide only minimal care. Meanwhile, IADL independence was found to be higher in the group with than in the group without care consciousness. While the IADL independence of patients with moderate AD was lower than that of patients with mild AD, little individual variation was noted. Clinically, even some patients with moderate AD could wipe the dining table or fold tea towels while seated. Accordingly, even for patients with decreased IADL independence, the nursing caregivers in the group with care consciousness appeared to be searching for IADL that the patient could perform and offering them support. Hence, IADL independence was found to be higher in the group with care consciousness. However, we can only conjecture as to what led to the results in this study for patients with mild (CDR0.5/1) and moderate (CDR2) AD. Going forward, various methods need to be used to determine the factors that led to these results. Such methods might include behavior observation at home for patients and caregivers in both care consciousness groups, as well as detailed interview analysis.

In the patients with severe (CDR3) AD, only 4 (16%) out of 25 main nursing caregivers were assigned to the group with care consciousness, which was significantly smaller than the group without care consciousness. This result suggests that it might be very difficult to aim to provide only minimal nursing care to patients with severe AD and that a heavy caregiving burden is necessarily associated with such patients.

There are three limits of this study. At first, the participants of this study were only inpatients of the university hospital, making it difficult to generalize the results for all the patients with general hospital hospitalization, institution entrance, and AD living an at-home life. The second, this study was a cross-sectional study examined based on the results of evaluation only at the time point immediately after hospitalization. We need to investigate by a longitudinal study in order to know whether conscious care of the main nursing caregiver has positive effects on ADL/IADL independence of patients with AD. The third, the result "positive effects on the ADL/IADL independence are observed when the main nursing caregivers consciously aim to provide only minimal nursing care" may be interpreted as "in cases where the main nursing caregiver is consciously care, there is a tendency for ADL/IADL to be hospitalized at a higher stage of independence". However, in cases where the main nursing caregiver consciously care, the main nursing caregiver is aware of the change in BPSD of patients with AD sensitively, leading to an early medical examination besides regular examination, ADL/IADL hospitalization at a high degree of independence there's a possibility that. It will be necessary in future to take a tendency toward the hospitalization at a high degree when we examine the effect that the main nursing caregivers consciously aim to provide only minimal nursing care.

Conflicts of interest

None.

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