Mental and Physical Self-Awareness of Alzheimer Patients: Decreased Awareness of Amnesia and Increased Fear of Falling Compared to Views of Families: The Tajiri and Wakuya Projects

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Keywords

Self-awareness · Anosognosia · Alzheimer disease ·
Everyday Memory Checklist · Fear of falling

Abstract

Introduction: The purpose of this study is to examine self-awareness of patients with Alzheimer disease (AD) regarding forgetfulness and physical status, with the goal of further psychological understanding of these patients. **Methods:** The 255 subjects included 33 healthy volunteers and 48 patients with mild cognitive impairment who were elderly community residents selected from the 2017 Wakuya Project and 174 consecutive outpatients with AD at the Tajiri Clinic. Test data were selected from a pooled database. Results from the Mini-Mental State Examination, Clinical Dementia Rating (CDR), Short Falls Efficacy Scale International (FES), and Everyday Memory Checklist (EMC) were used in the study. FES and EMC data were also obtained from family members for comparison. **Results:** EMC scores in the AD groups (mild to moderate and moderate to severe) were significantly higher (more complaining memory impairment) than those in the CDR 0 (healthy) group and significantly lower (less self-awareness for memory impairment) than the corresponding EMC scores of families of the subjects. In con-

trast, FES scores of the AD groups did not differ significantly from those of the CDR 0 group, and these scores were higher (more fear of falling) than those of family members. Additionally, family-FES scores of the AD groups were higher than those of the CDR 0 and 0.5 groups. **Conclusion:** The results showed an evidence of the heterogeneity of awareness, an emotional response (concern or fear, FES), and a cognitive appraisal of function (EMC). These may be explained whereby awareness of/fear of falling increases with AD due to a preserved emotional awareness, whereas awareness of cognitive impairment is impaired due to memory deficits.

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Introduction

In our memory clinic, which involves departments of neurology and psychiatry, confirmation of forgetfulness and psychological tests are performed daily. The Everyday Memory Checklist (EMC) is an evaluation scale for awareness of forgetfulness [1]. The EMC can be performed for patients, caregivers, and families of patients, and patients tend to evaluate their level of forgetfulness to be lower than that evaluated by caregivers [2–5]. This

may be due to anosognosia (lack of awareness). Patients do not complain of their physical status due to the presence of other diseases or a decrease of their declarative ability [6–8], but they were able to answer questions about pain and fear of falling despite lack of their memory impairment.

The Falls Efficacy Scale (FES) is used to evaluate fear of falling [9]. High FES scores are related to fear of falling [9, 10], experience of falling [11], fracture [2], anxiety and depression [9, 10], gait velocity [9, 10], and cognitive dysfunction and dementia [2] in elderly people. Another previous study [12] showed that FES scores in subjects with mild cognitive impairment (MCI) were significantly higher than those in healthy subjects, but that those in patients with Alzheimer disease (AD) were significantly lower. This was discussed probably due to anxiety of MCI participants compared with AD patients.

Physical status and forgetfulness have been evaluated separately using the FES and EMC in previous reports, but surprisingly, there are no comparative studies that have used both scales. The objective of this study was to examine self-awareness in elderly patients regarding forgetfulness and fear of falling, using subjective and objective scales for further psychological understanding of such patients. The working hypothesis of the study was that the level of self-awareness of patients with AD for forgetfulness and fear of falling would be lower than that observed by their families.

Methods

The Wakuya Project

The town of Wakuya is an agricultural area of Miyagi Prefecture, in northern Japan. The population is 16,485, with 2,907 older residents aged ≥ 75 years in 2018. Based on Clinical Dementia Rating (CDR) assessments (see below), the Wakuya Project aimed to investigate physical activity and associations between lifestyle-related diseases and cognitive function among older residents. Eighty-one subjects were identified in the 2017 Wakuya project pooled database (36 CDR 0 [healthy] group, 48 CDR 0.5 [MCI] group, and 16 CDR 1+ [dementia] group).

The inclusion criterion is CDR 0 and CDR 0.5 participants, and the exclusion criterion is those with missing data of EMC or FES scores. Three subjects from the CDR 0 group were excluded due to a missing EMC or FES score ($n = 33$). All 48 CDR 0.5 subjects were included in the analysis. The CDR 1+ group was not used due to the small number of subjects, and patients with AD were instead selected from the Tajiri Clinic Database (2014–2020) (see below).

Consecutive Outpatients at Tajiri Clinic

The Tajiri district in Osaki City is adjacent to Wakuya and is also an agricultural district. For outpatients who visited the clinic for the first time, psychological tests, such as MMSE, and question-

naires for FES and EMC were performed. From December 2014 to February 2020, 298 patients visited the outpatient department of dementia in the Tajiri Skip Center, and 221 were diagnosed with AD, including those with cerebrovascular disease, based on the diagnostic criteria below. However, since 47 patients had no EMC or FES scores, 174 patients were targeted. Finally, 154 patients were included in the study (see below).

Diagnosis of AD was made by neurology and dementia specialists using the criteria of the National Institute of Neurological and Communicative Disorders and Stroke and the AD and Related Disorders Association (NINCDS-ADRDA). Patients also underwent MRI for imaging diagnosis. A cerebrovascular lesion was confirmed based on a low-intensity region in a T1-weighted image, a high-intensity region in a T2-weighted image, and a low-intensity area in this region in a fluid-attenuated inversion recovery image. If a lesion was found in a key area, such as the thalamus and head of the caudate nucleus, the case was diagnosed as vascular dementia. Other cases were diagnosed as AD + CVD and were included in the AD group for analysis.

The inclusion criterion is participants diagnosed as AD or AD with CVD. The exclusion criteria are those with VaD and those with their MMSE scores < 9 , due to probable poor understanding of the instructions. This is a retrospective data analysis, and unfortunately the AD diagnosis is based on the NINCDS-ADRDA criteria and DSM-IV, and DSM5 has not been compared.

Procedures

The CDR was assessed for the population of the Wakuya Project, and all participants underwent neuropsychological tests such as the Mini-Mental State Examination (MMSE), as well as the FES and EMC (see below).

Instruments

CDR Assessment

A clinical team, comprising medical doctors and public health nurses, determined the CDR, blinded to the results of the MMSE, FES, and EMC, as follows: before being interviewed by the doctors, the public health nurses visited the participants' homes to evaluate their daily activities. Observations by the family with respect to the participants' lives were described in a semistructured questionnaire. The participants were interviewed by doctors to assess episodic memory, orientation, judgment, etc. Finally, with reference to the information provided by the family as well as the public health nurses, the participants' CDR stages were decided at a joint meeting. A reliable Japanese version of the CDR Work Sheet [13, 14] was established, and dementia was diagnosed based on the DSM-IV criteria. One of the authors (K.M.) was certified as a CDR rater at the Alzheimer's Disease Research Center Memory & Aging Project, Washington University School of Medicine.

Questionnaires

Everyday Memory Checklist (EMC): the Japanese version of the EMC was used in the study. The reliability and validity of this version have been shown by Kazui et al. [15]. The EMC includes 13 questions on events in daily life associated with memory disturbance, which are evaluated on a 4-point scale (0, not at all; 1, sometimes; 2, frequently; and 3, always). The total points are defined as the EMC score (0–39 points), and a higher score indicates a higher level of memory disturbance in daily life. The subtraction-EMC

Table 1. Demographics

	CDR 0 group (<i>n</i> = 33)	CDR 0.5 group (<i>n</i> = 48)	Mild-moderate AD group (<i>n</i> = 94)	Moderate-severe AD group (<i>n</i> = 60)	<i>F</i> value	<i>p</i> value
Gender (men/women)	10/23	20/28	30/64	24/36	2.2	0.526
Age, years	80.0 (4.2)	80.3 (4.1)	80.4 (6.9)	83.7 ^{a-c} (5.3)	5.4	0.001
Education, years	10.9 (1.9)	10.6 (2.5)	11.1 (8.6)	10.7 (8.2)	0.08	0.969
MMSE score	25.9 (2.5)	23.8 ^a (3.0)	19.0 ^{a, b} (2.9)	12.6 ^{a-c} (1.7)	252.8	0.000

ANOVA test for differences between diagnostic groups. Shown are the mean (SD). CDR, Clinical Dementia Rating; MMSE, Mini-Mental State Examination; AD, Alzheimer disease. ^aSignificantly different from the CDR 0 group. ^bSignificantly different from the CDR 0.5 group. ^cSignificantly different from the mild-moderate AD.

score is determined by subtracting the family-EMC score from the self-EMC score.

Falls Efficacy Scale (FES): the reliability and validity of the FES, FES-I, and Short FES-I were confirmed in a previous study [16], in which it was suggested that these 3 tests were related to fear of falling, regardless of the presence of cognitive dysfunction. Short FES-I provided the best evidence [16], and we used the Japanese version of Short FES-I, for which Kamide et al. [17] showed the reliability and validity. The Short FES-I (hereinafter referred to as the FES) includes 7 questions on daily life that are answered on a 4-point scale, based on which it is possible to understand the concern about the possibility of falling. The total score ranges from 7 to 28 points. The 7 scenes in daily life are 1, getting dressed or undressed; 2, taking a bath or shower; 3, getting in or out of a chair; 4, going up or downstairs; 5, reaching for something above your head or on the ground; 6, walking up or down a slope; and 7, going out to a social event. The answer options were 1, not at all concerned; 2, somewhat concerned; 3, fairly concerned; and 4, very concerned. The subtraction-FES score is the difference between the self-FES and family-FES scores.

Ethics

The study was explained at public halls. After written informed consent was obtained from individual subjects, health nurses visited the homes of the subjects on another day to obtain informed consent from their families. This study was approved by the Ethics Review Committee of Tohoku University (2014-1-565).

Statistical Analyses

The dependent variables were normally distributed by the Shapiro-Wilk test. Self-EMC scores were compared between the groups by one-way ANOVA for the demographics and analysis of covariance with the covariances of age and gender for the EMC and FES measures, followed by a Bonferroni test. Similar analyses were performed for family-EMC, subtraction-EMC, self-FES, family-FES, and subtraction-FES scores. Differences between patient and family EMC and FES scores in each group were analyzed by the *t* test. We set $\alpha = 0.05$, $\beta = 0.2$, and power = 0.8, showing the sample size as sufficient.

Results

Based on severity, the patients were divided into mild-moderate (*n* = 94, MMSE scores ≥ 16) and moderate-severe (60 subjects, $10 \leq$ MMSE scores ≤ 15) AD groups. The attributes of these groups and those of the CDR 0 and CDR 0.5 groups are shown in Table 1. A χ^2 test was conducted for gender, and ANOVA was performed for age, years of education, and MMSE score. There were no significant differences in sex and years of education among the groups, but the age of the moderate-severe AD group was significantly higher than those of the other groups. In addition, the MMSE scores decreased step by step as cognitive function decreased.

EMC scores are shown in Table 2. For self-EMC scores (1st line), the mean values showed CDR 0 = CDR 0.5 < mild-moderate AD = moderate-severe AD. For family-EMC (2nd line), they demonstrated CDR 0 = CDR 0.5 < mild-moderate AD < moderate-severe AD, together with the subtraction-EMC. Family-EMC scores were higher than self-EMC scores for mild-moderate AD and moderate-severe AD groups.

There were no significant differences between self- and family-EMC scores in the CDR 0 group (*t* test, *t* = 0.97, *p* = 0.34) and the CDR 0.5 group (*t* = 1.22, *p* = 0.22). There were no significant differences between self- and family-EMC scores in the CDR 0 group (*t* value = 0.97, *p* value = 0.34) and the CDR 0.5 group (*t* = 1.22, *p* = 0.22). However, in the AD groups (mild-moderate/moderate-severe), family-EMC scores were significantly higher than self-EMC scores (*p* < 0.0001).

In contrast, as noted in Table 3, self-FES scores (1st line), showed the following mean values: CDR 0 = CDR 0.5 = mild-moderate AD = moderate-severe AD. For family-FES (2nd line), they demonstrated CDR 0 = CDR

Table 2. EMC for the 4 groups

	CDR 0 group (<i>n</i> = 33)	CDR 0.5 group (<i>n</i> = 48)	Mild-moderate AD group (<i>n</i> = 94)	Moderate-severe AD group (<i>n</i> = 60)	<i>F</i> value	<i>p</i> value	Covariance	
							age	gender
Self-EMC	4.8 (3.2)	8.0 (4.1)	8.5 ^a (6.5)	10.4 ^a (6.1)	6.4	0.000*	0.43	0.85
Family-EMC	3.9 (3.6)	6.9 (4.9)	14.8 ^{a, b} (9.1)	20.8 ^{a- c} (8.3)	46.1	0.000*	0.59	0.37
Subtraction-EMC	0.8 (4.3)	1.1 (3.5)	-6.3 ^{a, b} (10.4)	-10.4 ^{a- c} (11.1)	19.4	0.000*	0.97	0.38

Multiple ANCOVA test for differences between diagnostic groups. Shown are the mean (SD). CDR, Clinical Dementia Rating; MMSE, Mini-Mental State Examination; EMC, Everyday Memory Checklist; subtraction-EMC, self-EMC minus family-EMC; AD, Alzheimer disease. ^a Significantly different from the CDR 0 group. ^b Significantly different from the CDR 0.5 group. ^c Significantly different from the mild-moderate AD. * Bonferroni correction, $p < 0.008$.

Table 3. FES for the 4 groups

	CDR 0 group (<i>n</i> = 33)	CDR 0.5 group (<i>n</i> = 48)	Mild-moderate AD group (<i>n</i> = 94)	Moderate-severe AD group (<i>n</i> = 60)	<i>F</i> value	<i>p</i> value	Covariance	
							age	age
Self-FES	12.8 (5.6)	13.8 (4.9)	13.9 (5.5)	15.3 (5.0)	0.8	0.517	0.000*	0.25
Family-FES	8.6 (2.9)	10.8 (4.1)	13.4 ^{a, b} (5.6)	14.5 ^{a, b} (6.4)	9.9	0.000*	0.000*	0.01
Subtraction-FES	4.2 (6.5)	3.0 (5.1)	0.6 ^a (5.6)	0.9 (7.9)	3.7	0.013	0.61	0.29

Multiple ANCOVA test for differences between diagnostic groups. Shown are the mean (SD). CDR, Clinical Dementia Rating; MMSE, Mini-Mental State Examination; FES, Short Falls Efficacy Scale International; subtraction-FES, self-FES minus family-FES; AD, Alzheimer disease. ^a Significantly different from the CDR 0 group. ^b Significantly different from the CDR 0.5 group. ^c Significantly different from the mild-moderate AD. * Bonferroni correction, $p < 0.008$.

0.5 < mild-moderate AD = moderate-severe AD. Interestingly, self-FES scores showed higher tendency than family-FES scores in all groups. Self-FES scores were significantly higher than family-FES scores in both CDR 0 and CDR 0.5 groups (CDR 0: $t = 3.86$, $p = 0.0002$; CDR 0.5: $t = 2.10$, $p = 0.04$). There was no significant difference between self- and family-FES scores in the AD groups (mild-moderate/moderate-severe) ($t = 1.04$, $p = 0.30$).

Discussion

Since all participants were living with their family at homes, the same number of family with that of participants for each group was interviewed. For the AD group, the family members were all daughters or daughters-in-law, and no cognitive impairments were observed by the clinic nurses and seeing the patients at the Tajiri Clinic. For the CDR 0 and 0.5 participants, the family was mostly the same as daughters or daughters-in-law, but several older spouses were included. However, they were interviewed (and thus checked) by the public health nurses of

the Wakuya town. Therefore, although the family members were not tested by cognitive tests such as MMSE, the information was thought to be reliable.

We did not use any specific instrument to assess anosognosia. Instead, we have used the differences between self- and family-assessed data. However, our findings may add a certain new finding in this field.

Patients with AD had lower self-EMC scores than the corresponding family-EMC scores, which can be explained by anosognosia, as found in a previous study. Thus, we can only discuss the overall data for FES scores.

In a previous study [12], a high level of anxiety in MCI subjects and anosognosia in AD patients was used to explain the lower FES scores in the patients with AD compared to those with MCI. In our study, self-FES scores for patients were higher than family-FES scores, and self-FES scores in patients with AD remained high. These results cannot be explained by anosognosia and behavioral symptoms.

We discuss this issue in combination with the EMC scores. It is notable that scores on the FES were relatively low, reflecting responses that would correspond to either

“not at all” or “somewhat concerned” on most items. Therefore, there is potentially an issue with the sensitivity of the FES to detect between-group differences (either family vs. self or AD vs. non-AD).

Family and AD patients judge the risk of falling similarly; this may be due to the fact that AD is not primarily a disease affecting mobility. Unlike the EMC that measures the major symptom of AD (amnesia), there is no clear or significant relationship between AD progression and falls. The difference between the EMC and FES results may therefore not be related to awareness, but to what is being measured.

Focusing on awareness, we can interpret that AD patients have preserved awareness of fear of falling but impaired awareness in the cognitive domain, namely, showing an evidence of the heterogeneity of awareness. This may be because the FES measures an emotional response (concern or fear) rather than a cognitive appraisal of function. There is some evidence that emotional responses may be more retained compared to explicit evaluation of performance [18]. There is an explanation whereby awareness of/fear of falling increases with AD due to a preserved awareness in this domain (falling) underpinned by preserved emotional/fear processing, whereas awareness of cognitive impairment is impaired due to more conventionally understood executive function/episodic memory deficits.

Finally, the result that AD patients have an increased fear of falling versus families might be due to confounders such as anxiety/depression that are not captured in the EMC assessments. An alternate explanation to be considered is that families may be more concerned about falls in cognitively impaired relatives than patients. A further investigation is needed, and some sociocultural issues should be discussed.

Many of our subjects lived together with their families in agricultural areas. Such families tend to be concerned about forgetfulness of elderly family members. This may affect forgetfulness, other behaviors, and sense of self in a manner that causes pessimism and loss of confidence in an elderly person, depending on the way such concerns are expressed. Emotional suggestions may include negative nonverbal communication, and a patient with AD may have a loss of their sense of worth. Anxiety that develops from such suggestions may be generalized as a decrease of cognitive function, including memory, and a decrease of self-efficacy and self-esteem; even worse, this may affect physical functions and daily life. Meguro [5] suggested that expression and attitude of a patient with AD differed during an examination depending on wheth-

er the family of the patient had suggested that he or she was forgetful. Kor et al. [19] found that an increase in the mindful attitude of caregivers was significantly correlated with a decrease of behavioral and psychological symptoms of dementia.

Conclusions

The results showed an evidence of the heterogeneity of awareness, an emotional response (concern or fear, FES), and a cognitive appraisal of function (EMC). These may be explained whereby awareness of/fear of falling increases with AD due to a preserved emotional awareness, whereas awareness of cognitive impairment is impaired due to memory deficits.

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Statement of Ethics

Written informed consent was obtained from each of the participants and their families. The study was approved by the Ethics Committees of the Wakuya government and Tohoku University Graduate School of Medicine (2014-1-565).

Conflict of Interest Statement

The authors have no conflicts of interest to disclose.

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Author Contributions

K.K.: data analysis and writing the manuscript. K.M.: design, direction, and writing the manuscript. N.K. and S.Y.: discussion. J.T. and K.N.: data collection.

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