Social problems in daily life of patients with dementia

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Running Head: Social problems in dementia
Abstract

Aim: Most patients with dementia frequently encounter various problems in their daily lives. Those troubles embarrass both patients and their families and cause problems for society. However, there have been few scientific reports on the difficulties in daily life of patients with dementia. Therefore, we tried to clarify the frequency and characteristics of troubles experienced by patients with dementia.

Methods: Seven medical centers treating dementia in Okayama Prefecture, Japan, participated in this survey. A total of 737 patients were placed in one of the three groups: a dementia group (n = 478), a mild cognitive impairment (MCI) group (n = 199), and a control group (n = 60). The frequency of thirteen difficulties was scored for each patient.

Results: Among normal subjects, no person caused these problems once a year or more frequently. “Massive, recurrent buying” and “Acts that risk causing a fire” were reported once a year or more for more than 10% of MCI patients. “Troubles with wealth management” and “Troubles with money management” were the most frequent troubles of dementia patients.

Conclusions: Several problems were already sometimes encountered in patients with MCI. It would be useful to know which
social difficulties are often seen in dementia in order to protect the safety of the patients. It is always difficult to balance respecting the autonomy of dementia patients and ensuring their safely.

**Key words:** daily life, dementia, mild cognitive impairment, sex, trouble

**Number of Words:** 3,284 (text 3,063, abstract 221)
**Introduction**

The number of aged people is rising dramatically both as a real number and as a ratio to the total population in Japan. In accordance with the increase in older persons, the number of patients with dementia is also rapidly increasing.¹ Most patients with dementia frequently encounter various problems in their daily lives. Those difficulties embarrass both patients and their families intensely as well as causing social problems.² Lack of awareness of cognitive deficits and/or performance deficits might explain why subjects want to live just like they did before.³

A major therapeutic goal in caring for patients with dementia is to maintain their autonomy as long as possible.⁴ However, it is sometimes difficult to preserve individual autonomy in dementia patients who cause social problems, such as accidentally starting a fire or poor driving.

In the medical literature, patients with dementia are often evaluated in the view of cognitive function, activities of daily living (ADL), and behavioral and psychological symptoms of dementia (BPSD). Of course, cognition level, ADL level, and neuropsychiatric symptoms are very important. However, many family members suffer from various difficulties in daily life caused by dementia patients in addition to the ADL impairment and neuropsychiatric symptoms.²
Trouble in daily life is a concept closely related to cognitive dysfunction, BPSD, and ADL disturbances. However, BPSD and ADL are concepts focusing mainly on the patient as an individual, whereas social trouble is a concept focusing on interaction between patients and their surrounding circumstances, including other persons. Although problems in the daily life of dementia patients, such as going missing temporarily or acts that risk causing a fire, are very important, there have been few scientific reports on the troubles in daily life of patients with dementia. Therefore, we tried to clarify the frequency and characteristics of troubles experienced by patients with dementia.
Methods

Selection of survey items

In 2015, we conducted a preliminary survey targeting families caring for patients with dementia in Aichi Prefecture. The details of the survey were reported previously. In the questionnaire, we asked family members to report problems caused by dementia patients. One hundred ninety-six family members returned the survey. A total of 284 cases of trouble were reported in detail by family caregivers. Later, experts in dementia nursing and care, family caregivers for dementia patients, and experts in dementia medication discussed and finally classified the reported cases of trouble into 13 categories.

The thirteen categories are: 1. nearly going missing, 2. problems in driving a car, 3. shoplifting, 4. massive, recurrent buying, 5. nearly being cheated, 6. trouble with wealth management, 7. trouble with money management, 8. trouble with refuse disposal, 9. acts that risk causing a fire, 10. violence toward family members, 11. violence toward care staff or others, 12. domestic problems due to delusions, and 13. neighborhood problems due to delusions.

Ethics

This study adhered to the 1975 Helsinki Declaration of Human Rights.
The study protocol with a list of participating psychiatric hospitals was approved by the Internal Ethical Committee of Okayama University Graduate School of Medicine, Dentistry and Pharmaceutical Sciences (approval number: 1610-027).

All the hospitals agreed to take part in this study, and the Internal Ethical Committee of each hospital approved the study protocol. The representative of this project at each hospital displayed posters on the bulletin board in the outpatient department during the study period with an explanation of the project and informing patients and their families that they could decline to participate in this study. All the participants completing the questionnaire consented to be part of this study.

**Implementation of survey**

There were eight Medical Centers for Dementia in Okayama Prefecture as of January 2017, and seven of eight centers agreed to participate in this survey. The subjects were first-visit patients at each Medical Center for Dementia from January 2017 to June 2017. Subjects who had previously consulted other centers first during the survey period were excluded. Because of a labor shortage, the survey period at one center was shortened from January 2017 to April 2017.
The frequency of each problem was scored using a seven-grade evaluation: never, rarely, about once a year, once to several times in half a year, once to several times in a month, once to several times in a week, or almost every day. The frequency of each problem was evaluated by experts in clinical medicine for dementia or trained psychologists and was based on the information from family caregivers. The chief clinicians (experts in dementia medicine) diagnosed the patients and rated the dementia severity of the patient using the Clinical Dementia Rating (CDR).\(^6\) Demographic characteristics of patients and cognitive test scores, if implemented, were recorded.

Most patients took the Hasegawa Dementia Rating Scale-revised (HDS-R). HDS-R comprises a series of items to measure orientation, memory, attention/calculation, delayed recall, and verbal fluency. This is a brief and reliable measurement for the evaluation of global cognitive function. The maximum total possible score is 30 points.\(^7\)

**Diagnostic criteria**

Patients with severe mental disorders (n= 18) were not included in the analysis below. A total of 737 patients without severe mental disorders were placed in one of three groups: a dementia group (n= 478), an MCI group (n= 199), and a control group (n= 60). All
patients with dementia had a dementia severity of 0.5 (very mild, n=208), 1 (mild, n= 139), or 2 (moderate, n= 131) based on the CDR. Patients who had no evidence of organic dementing disorder or psychiatric diseases were used as a control group (n= 60).

All patients with Alzheimer’s disease dementia (ADD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), or vascular dementia (VaD) were diagnosed according to ADD criteria formulated by the National Institute on Aging-Alzheimer’s Association,\(^8\) the DLB diagnostic criteria formulated by McKeith et al.,\(^9\) the FTDC criteria for bvFTD,\(^10\) and the American Heart Association/American Stroke Association guidelines for VaD.\(^11\)

According to each set of criteria, patients in the dementia group were diagnosed with Alzheimer's disease dementia (probable ADD, n=276; possible ADD with ischemic change, n=80), dementia with Lewy bodies (probable DLB, n=41; possible DLB, n=17), behavioral variant frontotemporal dementia (probable bvFTD, n=1; possible bvFTD, n=3), vascular dementia (probable VaD, n= 9; possible VaD, n=13), and others (n=38). All patients with dementia were diagnosed according to the DSM-V criteria for major neurocognitive disorder.\(^12\)

Patients with MCI met the diagnostic criteria formulated by Petersen.\(^13\) According to the criteria, MCI patients were divided into
amnestic MCI single domain (n= 149), amnestic MCI multiple domain (n= 36), and non-amnestic MCI (n= 14).

**Statistical analysis**

Statistical analyses were performed using the IBM SPSS Statistics 23.0 software program. A value of p<0.05 was accepted as significant. Comparisons of the frequency of problems between three groups were performed using the Jonckheere-Terpstra trend test. Comparisons of the frequency of problems between two groups were performed using Mann-Whitney’s U test. Comparisons of age between three groups were done using one-way analysis of variance, followed by the Tukey HSD test. Comparisons of age between two groups were done using an independent t-test. χ² tests were employed for comparisons of categorical data (gender).
Results

Frequency of troubles in dementia, MCI, and control groups

The numbers and proportions of patients (dementia, MCI, controls) who caused troubles (once a year or more, once a month or more) are shown in Table 1. The numerical values for each dementia disease are not shown because the number of patients with DLB or VaD was very small.

Comparison between MCI and control groups showed that MCI patients caused trouble more frequently than control subjects in the fields of “trouble with money management” (p=0.005), “trouble with wealth management” (p=0.007), “massive, recurrent buying” (p=0.019), and “act that risk causing a fire” (p=0.022). Comparison between dementia and MCI groups showed that dementia patients caused difficulties more frequently than MCI patients in the categories of “troubles with money management” (p<0.001), “trouble with wealth management” (p<0.001), “domestic problems due to delusions” (p<0.001), “neighborhood problems due to delusions” (p<0.001), “nearly going missing” (p<0.001), “violence toward care staff or others” (p<0.001), “trouble with refuse disposal” (p=0.011), “nearly being cheated” (p=0.032), and “violence toward family members” (p=0.036).
Frequency of troubles in very mild, mild, and moderate dementia groups

The numbers and proportions of dementia patients (CDR 0.5, CDR 1, CDR 2) who caused the troubles (once a year or more, once a month or more) are shown in Table 2.

Comparison of very mild (CDR 0.5) and mild (CDR 1) dementia groups showed that mild dementia patients caused trouble more frequently than very mild dementia patients in the areas of “troubles with wealth management” (p<0.001), “troubles with money management” (p<0.001), “violence toward care staff or others” (p=0.004), “domestic problems due to delusions” (p=0.014), and “violence toward family members” (p=0.016). Comparison between mild (CDR 1) and moderate (CDR 2) dementia groups showed that moderate dementia patients caused problems more frequently than mild dementia patients in the area of “violence toward care staff or others” (p<0.001), and that mild dementia patients caused problems more frequently than moderate dementia patients in the fields of “problems in driving a car” (p=0.046), and “trouble with wealth management” (p=0.047).

Frequency of troubles in men and women with dementia
The numbers and proportions of men and women with dementia who caused the troubles (once a year or more, once a month or more) are shown in Table 3. Comparison between men and women groups showed that men caused trouble more frequently than women in the areas of “problems in driving a car” (p<0.001) and “violence toward family members” (p=0.015), and that women caused trouble more frequently than men in the area of “trouble with money management” (p<0.001), “trouble with wealth management” (p=0.001), “massive, recurrent buying” (p= 0.001), and “acts that risk causing a fire” (p=0.001).
Discussion

We selected thirteen survey items based on case reports from family caregivers for dementia patients. Surprisingly, in normal subjects, there was no person who caused these troubles once a year or more. Because the number of control subjects was small, the results are not decisive. However, we think that the social problems reported by family caregivers for dementia patients are very rare in aged people with normal cognition.

Meanwhile, “massive, recurrent buying” and “acts that risk causing a fire” were reported once a year or more in more than 10% of the MCI patients. The frequencies of both problems in MCI patients were not significantly different from those in dementia patients. Recurrent buying and acts that risk causing a fire are both closely related to severe memory disturbance. Therefore, it is no wonder that not a few MCI patients suffer from these two troubles.

Massive, recurrent buying was most frequent in mild dementia, and the frequency of the problem decreased in moderate dementia. We think that the decrease is because patients with moderate dementia gradually become unable to shop by themselves.

Acts that risk causing a fire are reported to be one of the most commonly reported risks in people with dementia in France. It was reported that one-fifth of people with dementia in the community
have at least one identifiable fire risk factor with serious morbidity.\textsuperscript{16} In this study, acts that risk causing a fire are reported once a month or more in more than 10\% of the dementia patients. The frequency of acts that risk causing a fire in patients with very mild dementia is not significantly different from that in patients with mild or moderate dementia. Our results are roughly in line with previous reports.\textsuperscript{15,16}

“Trouble with wealth management” and “trouble with money management” were both reported once a year or more in nearly 10\% of MCI patients. These two are the most frequent problems in dementia patients, and 25\% of dementia patients suffered from these two difficulties once a month or more. Money and property management are very important issues in modern society. Severe memory disturbance might cause difficulty with money and property management.\textsuperscript{2} In a study on the quality of life in dementia, it was reported that dementia patients thought their financial security essential for themselves, but that dementia caregivers paid relatively little attention to it.\textsuperscript{17} We should pay more attention to the financial situation of patients and to their difficulties in money and property management from the stage of MCI.

“Nearly being cheated” and “trouble with refuse disposal” are both rare in MCI patients, but frequent in mild dementia patients. The frequencies of both problems in patients with very mild dementia
not significantly different from those in patients with mild or moderate dementia. It is reported that the ability to detect a threat is preserved well in the MCI stage but is somewhat lower in the dementia stage.\textsuperscript{18} The failure to detect danger might increase the risk of being deceived or nearly getting cheated. In other reports, patients with dementia, particularly those in early stages, are susceptible to predators.\textsuperscript{19}

In the MCI stage, most patients do not show the severe impairment in daily function, but in the dementia stage, patients gradually show an obvious decline in housekeeping. Therefore, it is natural that the frequency of “trouble with refuse disposal” increases only after the stage of dementia, and is not very frequently seen in the stage of MCI.

Going missing incidents are one of the most dangerous events with devastating results. Sometimes disappearance is erroneously described as wandering.\textsuperscript{20} However, it has been reported that there was only weak correlation between going missing and wandering.\textsuperscript{21,22} In Japan, about 10,000 people with dementia go missing every year, and about 3% to 4% of missing patients with dementia are found dead.\textsuperscript{23} We found that the frequency of “nearly going missing” gradually increases as the severity of dementia progresses from very mild to moderate. We think the increase is due
to declining visuospatial cognition in moderate dementia compared
to mild and very mild dementia.24

“Shoplifting” and “problems in driving a car” are relatively rare
troubles. Shoplifting by bvFTD patients is frequently reported.25 In
this study, bvFTD patients were extremely rare. The rareness of
bvFTD patients in this study may cause the scarcity of “shoplifting”.

In most previous studies, increased crash risk among drivers with
dementia was reported.3 For that reason, dementia patients are
prohibited from driving cars in Japan. Moreover, after March 2017,
aged persons ≥ 75 years old must pass a cognitive test when
renewing their driver’s license.26 Not a few elderly people voluntarily
relinquish their licenses because the hurdles for license renewal
have increased.26 The hurdles for license renewal may be reducing
the problems in driving cars.

Both violent accidents and troubles due to delusion are more
frequent in their home compared to outside. The prevalence of
psychosis in MCI is 3% to 14%.27 Psychosis may be observed in
patients with MCI, but it occurs much more frequently in dementia.28
In keeping with the cognitive decline from mild dementia to moderate
dementia, the frequency of delusion was reported to increase.29 In
this study, problems induced by delusions were relatively rare in the
stage of MCI but become more frequent as the stage of dementia
progresses from mild to moderate. The increase in problems due to delusions follows the increase of delusion in dementia.

Violence is also relatively rare in the MCI stage, but becomes more common as cognitive function deteriorates. Severe aggression by dementia care recipients toward caregivers is estimated at greater than 20% and is the strongest predictor of nursing home placement. Therefore, as the cognitive functions deteriorate, the frequency of violence might increase. Violence by dementia patients toward care providers, as well as abuse of people with dementia by caregivers, should receive more attention.

We think that the difference in the frequencies of several problems between men and women with dementia depends on the difference in opportunity to engage in the targeted actions.

Based on the relationship between the frequency of troubles and the severity of dementia, it is possible to divide troubles into several groups. As cognitive function deteriorates from MCI to moderate dementia, the frequencies of troubles increase in “nearly going missing”, “violence toward family members”, “violence toward care staff or others”, “domestic problems due to delusions”, and “neighborhood problems due to delusions”. As dementia grows worse, we should pay more attention to these troubles, especially delusions, violence, and going missing.
In the second group, the frequencies of troubles are continuously high from the MCI stage to the mid dementia stage, and decrease slightly in the moderate dementia stage. The second group includes “massive, recurrent buying” and “acts that risk causing a fire”. Probably, the category “problems in driving a car” also shows a similar pattern. Therefore, in the cases of unnecessary shopping, fire risk, and car trouble, it is necessary to pay sufficient attention from the very early stage of cognitive dysfunction.

In the third group including “nearly being cheated” and “trouble with refuse disposal”, the frequencies of these troubles are most frequent in the stage of mild dementia and relatively rare in other stages.

In the fourth group, troubles concerning money or wealth management are most frequent in patients with dementia from very mild to moderate stages. Patients and their families had better discuss the handling of money or wealth management from the very mild stage of cognitive dysfunction.

Trying to avoid the problems thoroughly will hinder the autonomy of dementia patients, but if caregivers do not manage them at all, social problems will occur frequently. It is always difficult to balance respecting the autonomy of dementia patients and ensuring their safely.
This study has several limitations. First, it is retrospective. Therefore, memory bias might affect the recollection of problems. Great troubles remain in the memory and are overvalued; small troubles will be forgotten. Second, the number of control subjects was relatively small. Moreover, the number of patients with DLB or VaD was also very small. Thus, we could not compare the differences of frequency between different dementia groups. Third, the relationship of these problems to more detailed profiles of cognitive function is not considered. In the future, we will try to examine the relationship in more detail. Fourth, caregiver distress was not scored, and the specific coping skills of caregivers in these problems were not investigated.

Acknowledgements

We sincerely thank Ms. Yifei Tang and Ms. Sachiko Nagayama for their skillful assistance. This work was supported by grants from the National Center for Geriatrics and Gerontology (NCGG, Grant Number 28-10) and the Zikei Institute of Psychiatry.

Disclosure statement
The authors declare no conflict of interest.
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Table 1  Age, sex, and frequency of troubles in patients

<table>
<thead>
<tr>
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<th>Control</th>
<th>MCI</th>
<th>Dementia</th>
<th>Comparison</th>
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<tr>
<td></td>
<td>n = 60</td>
<td>n = 199</td>
<td>n = 478</td>
<td>C vs M</td>
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<td>75/126</td>
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<td>Age, mean ± standard deviation</td>
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<td>HDS-R, mean ± standard deviation</td>
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<td>23.2 ± 4.0</td>
<td>15.6 ± 6.9</td>
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<td>Troubles</td>
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<td>25 (12.6%)</td>
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<td>0 (0%)</td>
<td>2 (1.0%)</td>
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<td>35 (7.3%)</td>
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<td>Act that risk causing a fire</td>
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<td>0 (0%)</td>
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<td>Domestic problems due to delusions</td>
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<td>93 (19.5%)</td>
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<td>Neighborhood problems due to delusions</td>
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<td>0 (0%)</td>
<td>2 (1.0%)</td>
<td>35 (7.3%)</td>
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</table>

MCI, mild cognitive impairment; Comparison, comparison between groups

C, control; M, mild cognitive impairment; D, dementia; 1/Y, once a year or more; 1/M, once a month or more

Trend test, Jonckheere-Terpstra trend test; n.s., not significant; *, p<0.05; **, p<0.01; ***, p<0.001

Comparison of mean age was performed using Tukey post-hoc analysis; Comparison of sex was performed using X² test

HDS-R, Hasegawa Dementia Rating Scale-revised

HDS-R scores of 60 controls, 195 patients with MCI, and 438 patients with dementia

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Table 2  Age, sex, and frequency of troubles in patients with dementia

<table>
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<tr>
<th>Troubles</th>
<th>Very mild (n=208)</th>
<th>Mild (n=139)</th>
<th>Moderate (n=131)</th>
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<td>≥ 1/Y</td>
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<td>Age, mean ± standard deviation</td>
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<td>HDS-R, mean ± standard deviation</td>
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<td>15.6 ± 4.6</td>
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<td>Nearly going missing</td>
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<td>20 (15.3%)</td>
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<td>0 (0%)</td>
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<td>Nearly being cheated</td>
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</tr>
<tr>
<td>Violence toward care staff or others</td>
<td>1 (0.5%)</td>
<td>1 (0.5%)</td>
<td>4 (2.9%)</td>
<td>4 (2.9%)</td>
</tr>
<tr>
<td>Domestic problems due to delusions</td>
<td>25 (12.0%)</td>
<td>17 (8.2%)</td>
<td>32 (23.0%)</td>
<td>29 (20.9%)</td>
</tr>
<tr>
<td>Neighborhood problems due to delusions</td>
<td>9 (4.3%)</td>
<td>7 (3.4%)</td>
<td>10 (7.2%)</td>
<td>7 (5.0%)</td>
</tr>
</tbody>
</table>

Very mild, dementia patients with CDR score of 0.5; Mild, dementia patients with CDR score of 1; Moderate, dementia patients with CDR score of 2

Comparison, comparison between groups; Vm, Very mild; Mi, Mild; Mo, Moderate; 1/Y, once a year or more; 1/M, once a month or more

Trend test, Jonckheere-Terpstra trend test; n.s., not significant; *, p<0.05; **, p<0.01; ***, p<0.001

Comparison of mean age was performed using Tukey post-hoc analysis; Comparison of sex was performed using X2 test

HDS-R, Hasegawa Dementia Rating Scale-revised

HDS-R scores of 204 patients with a CDR score of 0.5, 129 with a CDR score of 1, and 105 with a CDR score of 2

GGI Editorial office (Email: ggi@blackwellpublishingasia.com)
<table>
<thead>
<tr>
<th>Troubles</th>
<th>Men</th>
<th>Women</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 186</td>
<td>n = 292</td>
<td>M vs W</td>
</tr>
<tr>
<td>Age, mean ± standard deviation</td>
<td>80.8 ± 7.3</td>
<td>82.5 ± 6.6</td>
<td>**</td>
</tr>
<tr>
<td>HDS-R, mean ± standard deviation</td>
<td>14.9 ± 6.0</td>
<td>16.1 ± 6.0</td>
<td>*</td>
</tr>
<tr>
<td>Nearly going missing</td>
<td>14 (7.5%)</td>
<td>6 (3.2%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Problems in driving a car</td>
<td>17 (9.1%)</td>
<td>4 (2.2%)</td>
<td>***</td>
</tr>
<tr>
<td>Shoplifting</td>
<td>3 (1.6%)</td>
<td>0</td>
<td>n.s.</td>
</tr>
<tr>
<td>Massive, recurrent buying</td>
<td>27 (14.5%)</td>
<td>24 (12.9%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Nearly being cheated</td>
<td>6 (3.2%)</td>
<td>1 (0.5%)</td>
<td>**</td>
</tr>
<tr>
<td>Trouble with wealth management</td>
<td>43 (23.1%)</td>
<td>38 (20.4%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Trouble with money management</td>
<td>47 (25.3%)</td>
<td>42 (22.6%)</td>
<td>***</td>
</tr>
<tr>
<td>Trouble with refuse disposal</td>
<td>9 (4.8%)</td>
<td>7 (3.8%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Act that risk causing a fire</td>
<td>19 (10.2%)</td>
<td>10 (5.4%)</td>
<td>***</td>
</tr>
<tr>
<td>Violence toward family members</td>
<td>20 (10.8%)</td>
<td>13 (7.0%)</td>
<td>*</td>
</tr>
<tr>
<td>Violence toward care staff or others</td>
<td>10 (5.4%)</td>
<td>9 (4.8%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Domestic problems due to delusions</td>
<td>29 (15.6%)</td>
<td>24 (12.9%)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Neighborhood problems due to delusions</td>
<td>11 (5.9%)</td>
<td>9 (4.8%)</td>
<td>n.s.</td>
</tr>
</tbody>
</table>

Comparison, comparison between groups; M, men; W, women
Comparison of mean age was performed using independent t-test
1/Y, once a year or more; 1/M, once a month or more
Comparison of the frequency of troubles between groups were performed using Mann-Whitney's U test
n.s., not significant; *, p<0.05; **, p<0.01; ***, p<0.001
HDS-R, Hasegawa Dementia Rating Scale-revised; HDS-R scores of 171 men and 267 women