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Classification tree model of the personal economic burden of dementia care by related factors of both people with dementia and caregivers

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6 1 Classification tree model of the personal economic burden of
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5 19 **Abstract**

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7 20 **Objective:**

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10 21 The purpose of this study was to clarify the micro-level determinants of the economic
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12 22 burden of dementia care at home in community settings by classifying them into
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15 23 subgroups of factors related to people with dementia and their caregivers.
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17

18 24 **Methods**

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20
21 25 A cross-sectional online survey was conducted from March 7 to March 14, 2016. For
22
23
24 26 the calculation of informal care costs, the average wage stratified by sex and age group
25
26
27 27 was used as the opportunity cost. We conducted a chi-square automatic interaction
28
29
30 28 detection analysis to identify the factors related to each cost divided into sub categories.
31

32 29 **Results**

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34
35 30 In the resultant classifications, informal care cost was mainly related to caregivers'
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38 31 employment status. When caregivers acquired family care leave, informal care costs
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41 32 were the highest. On the other hand, out-of-pocket payments for long-term care were
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43
44 33 related to care-need levels and family economic status. ADL and IADL functions such
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46
47 34 as bathing, toileting, and cleaning were related to all costs.
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49 35 **Conclusion**

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52 36 This study clarified the difference in dementia care costs between classified
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55 37 subgroups by considering the combination of the situations of both people with
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6 38 dementia and their caregivers. Informal care costs were related to caregivers'
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9 39 employment and cohabitation status rather to the situations of people with dementia. On
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11 40 the other hand, out-of-pocket payments for long-term care services were related to
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14 41 care-need levels and family economic status. These classifications will be useful in
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17 42 understanding which situation represents a greater economic burden, and helpful in
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20 43 improving the sustainability of the dementia care system in Japan.
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6 45 **Strengths and limitations of this study**
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8 ● This study clarified the difference in dementia care costs between classified
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12 47 subgroups by considering the combination of the situations of both people with
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15 48 dementia and their caregivers.

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17 ● The chi-square automatic interaction detection dendograms provide a visual
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19
20 50 depiction of criteria and predictor variable interactions that might not be detected in
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23 51 traditional analytic procedures.

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25 ● The sample may therefore not be representative of all caregivers because the
26
27
28 53 sample is limited to those who have access to the Internet and are registered with an
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31 54 Internet research company.

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34 ● We only assessed objective burden of dementia care such as informal care time or
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37 56 costs, then we didn't consider the subjective burden of care and depressive
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40 57 symptoms.

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59 **1. Introduction**

60 In the aging society of Japan, it is estimated that there are approximately 4.7 million
61 people living with dementia and that there will be approximately 7 million people with
62 dementia in 2025 [1]. Given that it is also estimated that the total number of people with
63 dementia throughout the world will double every 20 years [2], we need to reconsider
64 how to prepare for dementia care in the community.

65 Long-term care (LTC) services in Japan used by people with dementia in home care
66 can be classified into three main types: (1) LTC insurance services, (2) LTC services not
67 covered by insurance, and (3) informal care as mutual assistance by family members.

68 When a person with dementia uses the LTC insurance service, the user bears 10% or
69 20% of the service expenses as out-of-pocket payments depending on the person's
70 income (Article 49-2 of the Long-Term Care Insurance Act). Aside from such
71 copayments, when LTC services not covered by insurance or exceeding the LTC
72 insurance limit amount are used, people must pay the full amount. Furthermore, it has
73 been pointed out that informal care is an important component of home care, yet it
74 places a burden on caregivers [3,4]. Nevertheless, given the estimates of the societal
75 costs of dementia care throughout the world, the impact of informal care is essential
76 [5,6].

77 The Japanese government recommends policies to shift to patient-centered and

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6 78 home-centered care to reduce the fiscal burden of the insurance system on
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9 79 community-based integrated systems. While micro level of impact of dementia care has
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11 80 not been insufficiently understood[7], to construct a sustainable dementia care system,
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14 81 we clarified the personal economic burden of dementia care for different residence types
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17 82 and demonstrated that the cost at home in a community setting was equal to or higher
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20 83 than in various institutions[8]. Sustainable dementia care systems should be provided
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23 84 not only to benefit the government or insurance system but also to benefit people with
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26 85 dementia and their caregivers. Furthermore, although there are increasing dementia care
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29 86 costs related to the severity of dementia [9–12], it can be seen that the cost of dementia
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32 87 care increases through the interaction of characteristics or situations of people with
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35 88 dementia and their caregivers. Given this interaction, it is necessary to understand the
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38 89 actual conditions by classifying cases where the greatest economic burdens in dementia
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41 90 care are felt.

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43 91 Therefore, the purpose of this study is to clarify the micro-level determinants of the
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46 92 economic burden of dementia care at home in community settings by classifying them
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49 93 into subgroups of factors related to people with dementia and their caregivers.

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52 53 95 **2. Methods**

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55 96 This study was a cross-sectional study, based on a self-rated, web-based questionnaire
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6 97 survey. The economic burden of dementia care in this study is roughly divided into
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9 98 informal care costs as opportunity costs and out-of-pocket payments that people actually
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11 99 made.

100 *2.1. Web-based survey for data collection on people with dementia and their caregivers*

101 In this cross-sectional study, we conducted a web-based questionnaire survey from
102 March 3 to March 14, 2016 in cooperation with a commercial research company
103 (Automatic Internet Research System, Macromill, Inc., Japan). Potential participants
104 fulfilled the following criteria: (1) aged 30 years or older, (2) non-professional caregiver
105 of someone with dementia, (3) caring for only one person with dementia, and (4) having
106 no conflicts of interest with advertising or marketing research entities. A total of 3,600
107 participants were recruited from the research company's registrants and divided into
108 different age groups (850 participants each in the groups aged in 30's, 40's, 50's, and
109 60's; 200 participants in the group aged ≥ 70 years). We excluded caregivers under 29
110 years of age because, in Japan, they are estimated to represent only 2% of all caregivers
111 [13].

112 *2.2. Questionnaire*

113 Resource Utilization in Dementia (RUD) [15, 16] is a widely used tool to collect data
114 about resource use in persons with dementia and their caregivers [15]. RUD is available

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6 115 in more than 60 languages and it is widely used throughout the world. In this study, we
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9 116 used RUD (Japanese version) items related to the characteristics of people with
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11 117 dementia and their caregivers, informal care time, employed situation of caregivers,
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14 118 residential types of people with dementia, and resource use of nursing care services. We
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17 119 added items related to LTC services and residential types. The questionnaire
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19
20 120 components were divided into four categories: (1) characteristics of people with
21
22 121 dementia, (2) caregivers' situations (e.g., employment and cohabitation status), (3)
23
24
25 122 informal care duration and (4) frequency of utilization of LTC services.

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27
28 123 In this project, we could not get information about severity of dementia data because
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30
31 124 it was regarded as too difficult for caregivers to estimate that. However, we asked for
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33
34 125 substantial information about care-needs levels. Care needs reflect function, which is a
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37 126 stronger explanatory factor for costs than cognition [14], Care-needs levels
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40 127 (Support-needs levels 1-2, Care-needs levels 1-5) are determined using an
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43 128 evidence-based computer algorithm combined with an expert panel to indicate the
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45
46 129 amount of care required by each person while taking into consideration their symptoms
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48
49 130 and functional capability. This algorithm was estimated from the data on how much
50
51
52 131 LTC services were required in 48 hours for more than 3,000 elderly people. High
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55 132 care-needs levels indicate increasing dependency and requirement for LTC services [15].
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6 133 Care-need levels also affect the base amount of the maximum payment for LTC services
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9 134 allowance categories covered by insurance.

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11 135 *2.3. Informal care time*

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14 136 In the questionnaire, informal care time was divided in three domains; support for
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17 137 Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and
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19
20 138 Supervision [16]. We asked for the mean caregiving time per day and mean caregiving
21
22
23 139 days per week in the past 30 days. We then multiplied the mean daily caregiving time
24
25
26 140 and caregiving days per week to calculate both weekly and monthly informal care time.
27
28
29 141 Supervision time was excluded in calculating informal care time and costs because
30
31
32 142 supervision could be done simultaneously when caregiving for ADL and IADL
33
34 143 functions, or in other housekeeping for people without dementia and other family
35
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37 144 members.

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40 145 *2.4. Cost estimation*

41
42 146 In this study, we identified three costs as follows: informal care costs, out-of-pocket
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44
45 147 payments for LTC services covered by insurance (copayments), and out-of-pocket
46
47
48 148 payments for LTC services not covered by insurance. To calculate the informal care
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50
51 149 costs, there are two methods that are frequently used: the “opportunity cost” and
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53
54 150 “replacement cost” approaches [17–19]. With the opportunity cost approach it is

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6 151 assumed that there is an alternative use of caregiving time (such as paid work) and thus
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9 152 estimates the costs due to this lost opportunity, whereas the replacement cost approach
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11 153 assumes that informal care services can be valued similarly to home care services
12
13
14 154 provided by professional caregivers. Even though many previous studies on the
15
16
17 155 economic valuation of informal care have used the replacement cost approach [18], the
18
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20 156 ‘opportunity cost approach’ is recommended by the developers of RUD for estimating
21
22
23 157 informal care costs [2,5,20]. We used the opportunity cost approach to assess informal
24
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26 158 care time as forgone wages for caregivers [2,5,9]. We used caregivers’ monthly mean
27
28
29 159 wages stratified by sex and age to value informal care. We assessed informal care costs
30
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32 160 for caregivers who were not working or who were over 65 years of age at 35% of the
33
34
35 161 mean wage of employed caregivers [21–24]. A maximum daily informal care time of 16
36
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38 162 hours was assumed, in order to allow for other activities such as cooking for other
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41 163 family members and sleep [12,25,26]. Caregivers were asked to state their contribution
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44 164 to the total informal care in 5-point scale of 20%. In order to treat all caregivers as
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47 165 primary caregivers and estimate the costs associated with all informal care provided to a
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50 166 patient, we adjusted the informal care time by dividing its time by the median of these
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53 167 contribution levels, according to RUD instructions. This adjustment of informal care
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56 168 time was done only when calculating the informal care costs.
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6 169 Out-of-pocket payments for LTC services both covered and not covered by insurance
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9 170 were included in the questionnaire. We asked for these out-of-pocket payments through
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11 171 categories that were easy to answer (no payments, under JPY9,999, JPY10,000–24,999,
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14 172 JPY25,000–49,999, JPY50,000–74,999, JPY75,000–99,999, JPY100,000–124,999,
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17 173 JPY125,000–149,999, JPY150,000–299,999, JPY300,000–499,999, and over
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20 174 JPY500,000). We adjusted the answers by capping the upper limit of the limit amount
21
22
23 175 depending on each care-needs level if the answers were over it. These costs were
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26 176 substituted by a median of each category, and we calculated the weighted average as the
27
28 177 following formula: $\frac{\sum_{i=0}^k(\text{median of category}_i) * n_i}{\sum n}$
29
30

31 178 All costs were converted from Japanese yen to US dollars using the purchasing power
32
33
34 179 parity rate in 2016 (¥102 = \$1) provided by the Organization for Economic Cooperation
35
36
37 180 and Development.

38 39 40 181 *2.5. Inclusion and exclusion criteria*

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42 182 With respondents, we only focused on community settings for people with dementia
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44
45 183 who lived in their own home. We excluded respondents based on the following criteria:
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48 184 (1) people with dementia who were hospitalized or lived in nursing home, (2) lack of
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51 185 data about out-of-pocket payments for LTC services or care-needs levels, (3)
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54 186 contradictions in relationships between caregivers and people with dementia, and (4)
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6 187 contradictions in care time (over 24 hours). When the age difference was less than 15
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9 188 years and the person with dementia was a parent or child (not in-law), these cases were
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11 189 identified as contradictions.

14 190 *2.6. Statistical analysis*

17 191 We conducted descriptive analysis for characteristics of people with dementia and
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20 192 caregivers. We then stratified the informal care time and dementia care costs by the
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22
23 193 care-needs level and cohabitation to test our hypothesis that high care-needs level or
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25
26 194 people who lives with caregivers need more informal care time. In this description, we
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28 195 didn't adjusted informal care time by caregivers' contribution rate.

31 196 Also, we used chi-square automatic interaction detection (CHAID) analysis to
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34 197 identify the characteristics of people with dementia and caregivers who needed more
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37 198 care services. In CHAID analysis, the dependent variable would be divided into
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40 199 sub-groups by the most explanatory independent variables. These groups could be
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43 200 formed by any possible combination with all independent variables. Especially, we
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46 201 conducted an exhaustive CHAID analysis that repeats the trial until it finds the optimal
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48 202 combination of all independent variables. The CHAID dendograms provide a visual
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51 203 depiction of criteria and predictor variable interactions that might not be detected in
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54 204 traditional analytic procedures. We set informal care costs, out-of-pocket payments for

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6 205 LTC services covered by insurance and out-of-pocket payments for LTC services not
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9 206 covered by insurance as dependent variables. Then, we used the characteristics of
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11 207 people with dementia (age, sex, care-need level, dementia types, ADL and IADL
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14 208 functions, and primary disease as the reason for care), the characteristics of caregivers
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16
17 209 (age, sex, marital status, children, cohabitation with people with dementia, visiting time,
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19
20 210 relationship to people with dementia, and occupation), and economic factors (the ratio
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22
23 211 of copayments for healthcare services and family income of caregivers). We treated the
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25
26 212 ratio of copayments for healthcare services as income proxy variable because this ratio
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28
29 213 was decided by income of people with dementia. We set the following criteria: tree
30
31 214 depth was limited to three levels, no group smaller than 100 was split, no group smaller
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33
34 215 than 30 was formed, and the p-value for all statistical tests was under 0.05.

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36
37 216 All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan
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39
40 217 Inc., Tokyo, Japan).

41 42 218 *2.6. Ethical considerations*

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45 219 This study was approved by the Ethics committee of Kyoto University Graduate School
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48 220 of Medicine (R0487).

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222 3. Results

223 3.1. Characteristics of people with dementia and their caregivers

224 A total of 3,916 caregivers answered the questionnaire. We focused only on people
225 with dementia who lived in their own home (n=2277). However, we excluded the data
226 according to the criteria and the final sample comprised 1,383 respondents (Figure 1).

227 Table 1 shows the characteristics of people with dementia and their caregivers. More
228 than half of the people with dementia were female (66.7%), and the mean age was 81.8
229 years. In contrast, more than half of the caregivers were male (61.7%), and the mean
230 age was 52.2 years. 1,233 people (89.2%) responded that ADL functions such as meals
231 and toilet use could be managed by themselves, while IADL functions such as cleaning
232 and shopping could be done by one person in the same way. There were only 788
233 people (57.0%) who did the latter by themselves.

234 3.2. Informal care time and costs of dementia care

235 The mean daily informal care time was 9.36 hours in total. The time for only ADL
236 was 4.97 hours and for only IADL was 4.39 hours. On the other hand, monthly informal
237 care time (ADL+IADL) was 166.32 hours. Table 2 shows the differences in daily
238 informal care time and personal cost of dementia care among the care-need levels. In
239 this table, we didn't adjust by contribution rate. Informal care times increased with

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6 240 care-needs levels, especially in ADL. Out-of-pocket payments for LTC services were
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9 241 less than informal care costs in all of the care-needs levels.

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13 243 *3.3. Classification with classification trees*

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15 244 Figure 2 shows the results of CHAID analysis for informal care costs. Informal care
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18 245 costs were related to caregivers' employment status, cohabitation, age, and care-needs
19
20
21 246 levels or ADL function of people with dementia. When the caregiver acquired family
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23
24 247 care leave, informal care cost was the highest (node 2). Even if the caregiver did not
25
26
27 248 work, informal care costs were higher with high care-needs levels (node 6-8). The costs
28
29
30 249 for cohabiting caregivers (node 5) were higher than for those not cohabiting (node 4).
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32
33 250 For those not cohabiting and the person with dementia could not walk without
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35
36 251 assistance (node 9), informal care costs were higher than for those that could walk (node
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38
39 252 10) .

40
41 253 Out-of-pocket payments for LTC services covered by insurance were related to
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43
44 254 care-need levels, ADL or IADL functions, sex (both the people with dementia and
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46
47 255 caregivers) and caregivers' household incomes (Figure 3). Especially, if the people with
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49
50 256 dementia could bathe or use the toilet by themselves, out-of-pocket payments would be
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53 257 about 65% lower (nodes 9-10, 15-18). On the other hand, if out-of-pocket payments
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56 258 were not covered by insurance, they were related to caregivers' household incomes,

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6 259 income proxy variable, ADL or IADL functions of people with dementia, and age of
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9 260 people with dementia (Figure 4).

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12 13 262 **4. Discussion**

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15 263 In this study, we first demonstrated that informal care time for ADL or IADL
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18 264 functions increased with high care-needs levels as our hypothesis stipulated. Second, we
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21 265 found through classification tree analysis that a combination of characteristics of both
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23
24 266 people with dementia and their caregivers were related to dementia care costs.
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26
27 267 Caregivers' employment and cohabitation status were mainly related to informal care
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29
30 268 costs, and the costs were the highest when caregivers took nursing care leave, which
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33 269 caregivers leave work due to caregiving. Furthermore, when caregivers worked at an
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36 270 occupation and lived separately, or the people with dementia could not walk, the costs
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39 271 doubled. Out-of-pocket payments for LTC services covered by insurance were mainly
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42 272 related to care-need levels and ADL and IADL functions. In case where care was
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45 273 needed for toileting or bathing with low care-needs levels, high out-of-pocket payments
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47
48 274 were required for LTC services covered by insurance. On the other hand, out-of-pocket
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51 275 payments were related to caregivers' household income levels or income proxy variable.
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54 276 Caregivers with high annual incomes (more than \$117,648 US) made out-of-pocket
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56
57 277 payments for dementia care of full amounts that were two to five times more than

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6 278 others.

7
8 279 Informal care costs were mainly related to caregivers' characteristics such as
9
10 280 employment or cohabitation status in the classification tree, which illustrated related
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12 281 factors by order of precedence. In many previous studies, ADL functions or dementia
13
14 282 severity were explained as related factors in regression models [9–12]. Some studies
15
16 283 showed caregivers' characteristics such as employment status were related to informal
17
18 284 care costs [9,27,28], but few studies considered all of the caregivers' characteristics.
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20 285 Thus, caregiver factors may be as important as factors related to people with dementia
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22 286 are.
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31 287 Furthermore, we considered the combination of characteristics of both people with
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33 288 dementia and their caregivers. For example, informal care costs doubled when
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35 289 caregivers lived separately and people with dementia could not walk. Also, Figure 1
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37 290 shows the combination of caregivers without employment, care-need levels, and
38
39 291 caregivers' cohabitation. CHAID analysis provided the classification only for related
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41 292 characteristics in the outcome. Such combinations suggest that support should be
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43 293 provided to caregivers who cannot live with people with dementia or caregivers who are
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45 294 not employed.
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53 295 The association between out-of-pocket payments for LTC services covered by
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6 296 insurance and care-need levels is reasonable because the benefit limit standard amounts
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9 297 for formal care services at home are decided in relation to care-need levels. In addition,
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11 298 when people with dementia had a high care-needs level and their caregiver's household
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14 299 income was high, out-of-pocket payments were high. Because the determination of
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17 300 service usage within the limit amount is a free contract, people with dementia and their
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20 301 caregivers may decide how they use formal care services depending on how much they
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23 302 can pay for services. Even for low care-needs levels, the cost may be high when people
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26 303 with dementia need assistance with bathing or toileting. This was affected by LTC
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29 304 insurance services providing specific substitutions, such as bath assistance.

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31 305 Similarly, economic variables such as household income and income proxy variable
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34 306 were mainly related to out-of-pocket payments for LTC services not covered by
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37 307 insurance. This is because people must pay the full amount if they use LTC services
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40 308 without insurance. Furthermore, except when caregivers' income was high, the cost did
41
42
43 309 not change significantly due to differences in ADL and IADL functions as it did when
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46 310 covered by insurance. According to the questionnaire responses, people tended to pay
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49 311 for expendables such as diapers, employment of housekeepers, and home repair such as
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52 312 handrail installation as out-of-pocket payments not covered by LTC insurance. These
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55 313 application examples were not really affected by ADL or IADL functions.

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6 314 From the viewpoint of independent variables, if people with dementia lacked some
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8 315 ADL function, then costs might be higher but in the case of IADL functions this was
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11 316 reversed. There is a possibility that some services are used to support the independent
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14 317 lives of people with dementia. Some people with dementia who can do housework by
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17 318 themselves might move or walk around more, and therefore use more LTC services like
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20 319 commuting for care (day service) or commuting for rehabilitation. Also, care-need
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23 320 levels were not related to out-of-pocket payments not covered by insurance. The above
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26 321 application examples were also not related to care-needs levels. The relationship of
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29 322 cohabitation or employment status was the same as in previous studies [9,27,29].
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31 323 In creating policy for LTC services in an aging society, we must understand the actual
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34 324 conditions from not only a societal but also a personal perspective. This is true even if
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37 325 from a societal viewpoint, the societal cost of dementia care in the community has been
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40 326 established by other countries to be greater than that in institutional care [30].
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43 327 Furthermore, we need a wide range of perspectives of stakeholders to discuss the
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46 328 dementia care system, while almost all studies of economic burden of dementia stood
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49 329 on societal or payers' viewpoint[7,17–19]. Then, as a first step, we need to understand
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52 330 what people with dementia and their family caregivers are already spending too much
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55 331 money on. We need to recognize the complicated combination of characteristics
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6 332 associated with people with dementia and their caregivers. To this point, the results of
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8
9 333 this classification could be useful to understanding which situation requires more
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11 334 resources depending on cost types. Our results may suggest that a sustainable dementia
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14 335 care system in Japan should be reconstructed from a personal viewpoint.
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17 336 There are some limitations to this study. First, we conducted a web-based
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20 337 questionnaire survey with caregivers of people with dementia. Traditionally,
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23 338 respondents who use the Internet tend to be male and relatively young, reflecting the
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26 339 general characteristics of web-based research [31,32]. The sample may therefore not be
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29 340 representative of all caregivers because the sample is limited to those who have access
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32 341 to the Internet and are registered with an Internet research company [33]. Certainly, we
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35 342 cannot extrapolate our results to the population as a whole. However, public access to
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38 343 the Internet is common in developed countries these days [34]. Furthermore, this study
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41 344 focused on finding a combination of independent variables related to the dependent
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44 345 variables (informal care cost and financial burden), taking into account the interaction
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47 346 between multiple independent variables. Therefore, in this study, influence due to the
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50 347 difference in sample variable distribution is not considered to be a practical problem.
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53 348 Second, we didn't consider the subjective burden of care and depressive symptoms.
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56 349 These mental burdens are considered to be important factors in explaining the actual
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6 350 state of care costs, and many previous studies in Japan have covered subjective costs
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9 351 [35–37]. In the future, in addition to the burden of time and money, it would be
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11 352 preferable to measure subjective burdens.
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17 354 **Conclusions**

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20 355 This study clarified the difference in dementia care costs between classified
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23 356 subgroups by considering the combination of the situations of both people with
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25 357 dementia and their caregivers. Informal care costs were related to caregivers'
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28 358 employment and cohabitation status rather to the situation of people with dementia. On
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31 359 the other hand, out-of-pocket payments for long-term care services were related to
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34 360 care-needs levels and family economic status. These classifications will be useful in
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37 361 understanding which situation represents a greater economic burden, and helpful in
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40 362 improving the sustainability of the dementia care system in Japan.
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42 363

45 364 **Footnotes**

48 365 *Abbreviations*

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51 366 LTC: Long-Term Care

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54 367 RUD: Resource Utilization in Dementia
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6 368 ADL: Activities of Daily Life
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9 369 IADL: Instrumental Activities of Daily Life
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11 370 CHAID analysis: chi-square automatic interaction detection analysis
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14 371 *Authors' contribution*
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16
17 372 TN, SN and YI designed the study. All authors discussed for preparing the questionnaire.
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19
20 373 TN mainly analyzed all data, and HU, SK, AW and YI advised for analysis. TN
21

22 374 prepared the draft of the manuscript, then all authors contributed to rewrite it. All
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25 375 authors read and approved the final manuscript.
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30
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32

33
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36
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41

42 381 no role in the study design, data collection and analysis, decision to publish, or
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45 382 preparation of the manuscript.
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48 383 *Competing interest*
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51 384 None declared.
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6 385 *Consent for publication*

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9 386 Not applicable.

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11 387 *Ethics approval and consent to participate*

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14 388 This study was approved by the Ethics Committee of Kyoto University Graduate School
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17 389 of Medicine (R0487). All participants were volunteers and they finished to answer the
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20 390 questionnaire as substitution of informed consent.

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22 391 *Acknowledgements*

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25 392 None.

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28 393 *Conflicts of interest*

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31 394 None.

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33 395 *Data sharing statement*

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36 396 No additional data are available.

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6 **Figure 1: Selection process for the analysis**
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8 This diagram shows the flow of participants who we focused on.
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11 **Figure 2: Classification tree of chi-square automatic interaction detection for**
12 **informal care costs**
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15 The dendogram illustrates the combinations of independent variables to clarify who
16 need or provide more informal care.
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19 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
20 Living; SD, Standard deviation; LTC, Long-term care
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28 **Figure 3: Classification tree of chi-square automatic interaction detection for**
29 **out-of-pocket payments for LTC services covered by insurance**
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31

32 The dendogram illustrates the combinations of independent variables to clarify who
33 need more LTC insurance services.
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36 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
37 Living; SD, Standard deviation; LTC, Long-term care
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45 **Figure 4: Classification tree of chi-square automatic interaction detection for**
46 **out-of-pocket payments for LTC services not covered by insurance**
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49 The dendogram illustrates the combinations of independent variables to clarify who
50 need more LTC services without insurance.
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6 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
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8 Living; SD, Standard deviation; LTC, Long-term care
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For peer review only

Table 1 Characteristics of people with dementia and caregivers

People with Dementia		N=1383
Age, mean±SD, y		
Sex, n (%)		
	Female	922 (66.7)
	Male	461 (33.3)
Care-needs level, n (%)		
	Support-Needs Level 1-2	253 (18.3)
	Care-Needs Level 1	310 (22.4)
	Care-Needs Level 2	335 (24.2)
	Care-Needs Level 3	258 (18.7)
	Care-Needs Level 4	122 (8.8)
	Care-Needs Level 5	105 (7.6)
ADL/IADL functional capabilities		
	ADL score (0-6), mean	3.2 (2.0)
	IADL score (0-7), mean	1.3 (1.6)
Ratio of copayments for healthcare services, n(%)		
	10%	961 (69.5)
	20%	137 (9.9)
	30%	157 (11.4)
	Unknown	128 (9.3)
Caregivers		
Age, mean ± SD		
Sex, n (%)		
	Female	530 (38.3)
	Male	853 (61.7)
Relationship, n (%)		
	Mother	575 (41.6)
	Mother-in-law	169 (12.2)
	Father	288 (20.8)
	Father-in-law	90 (6.5)
	Spouse	99 (7.2)
	Sibling	11 (0.8)
	Child	10 (0.7)
	Friend	5 (0.4)
	Other (including grandparents)	136 (9.8)
Contribution level for caregiving, n (%)		
	1-20%	395 (28.6)
	21-40%	355 (25.7)
	41-60%	241 (17.4)
	61-80%	166 (12.0)
	81-100%	226 (16.3)
Currently employed, n (%)		

SD: Standard deviation, ADL: Activities of Daily Living, IADL: Instrumental Activities

of Daily Living

1 **Table 2 Daily informal care time and personal costs of dementia care sorted by care-needs levels**

			Support-required level	Care-need level 1	Care-need level 2	Care-need level 3	Care-need level 4	Care-need level 5
Informal care time (hours/day)	ADL	Mean [SD]	2.56 [3.23]	2.23 [2.54]	2.92 [2.90]	3.44 [2.90]	3.99 [2.40]	4.60 [3.85]
		Median [IQR]	1.67 [2.00]	1.50 [2.50]	2.00 [3.00]	3.00 [3.50]	4.00 [3.00]	3.33 [4.00]
	IADL	Mean [SD]	2.35 [2.62]	2.46 [3.05]	2.88 [3.26]	2.82 [2.92]	3.03 [2.59]	3.45 [3.77]
		Median [IQR]	2.00 [2.00]	1.50 [2.00]	2.00 [2.00]	2.00 [2.50]	2.00 [3.13]	2.00 [4.00]
Personal cost of dementia care (US\$)	Informal care cost	Mean [SD]	1518 [2017]	1271 [1526]	1754 [1982]	2181 [2220]	2112 [2104]	2672 [2314]
		Median [IQR]	747 [1646]	709 [1440]	1090 [1697]	1366 [2459]	1535 [1466]	1939 [2240]
	OPP for LTC services covered by insurance	Mean [SD]	148 [190]	158 [174]	244 [209]	313 [217]	301 [202]	318 [218]
		Median [IQR]	49 [172]	49 [123]	172 [319]	368 [441]	368 [196]	368 [441]
	OPP for care services not covered by insurance	Mean [SD]	158 [336]	95 [156]	278 [695]	303 [543]	241 [579]	352 [998]
		Median [IQR]	49 [172]	49 [172]	49 [368]	172 [319]	49 [368]	49 [368]

2 ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, SD: Standard deviation, IQR: Interquartile range

3 OPP: Out-of-pocket payments LTC: Long-term care

Figure 1

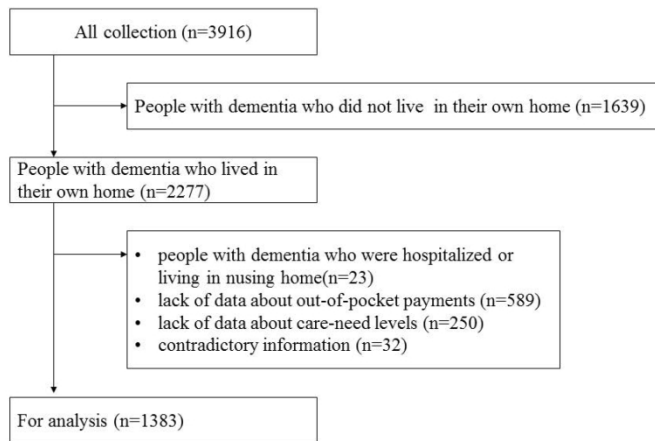


Figure 1: Selection process for the analysis
This diagram shows the flow of participants who we focused on.

338x190mm (300 x 300 DPI)

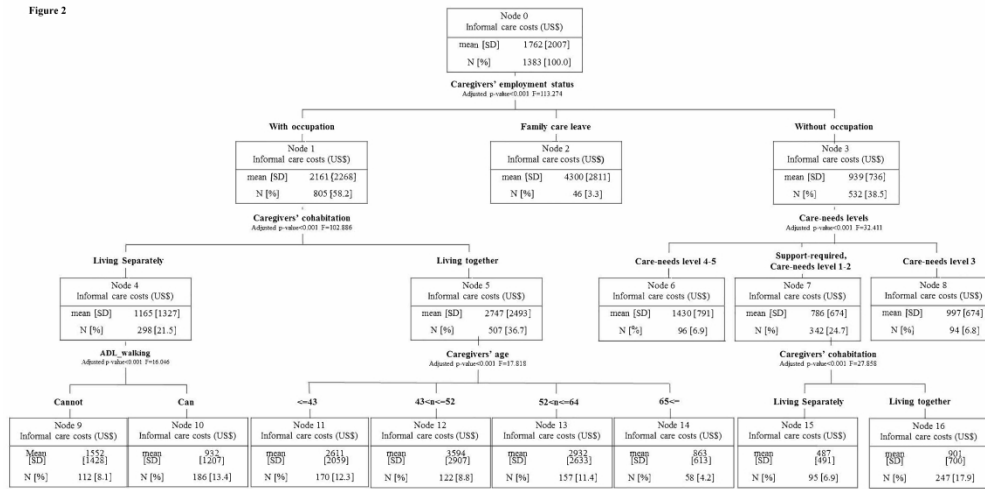


Figure 2: Classification tree of chi-square automatic interaction detection for informal care costs
 The dendrogram illustrates the combinations of independent variables to clarify who need or provide more informal care.

Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

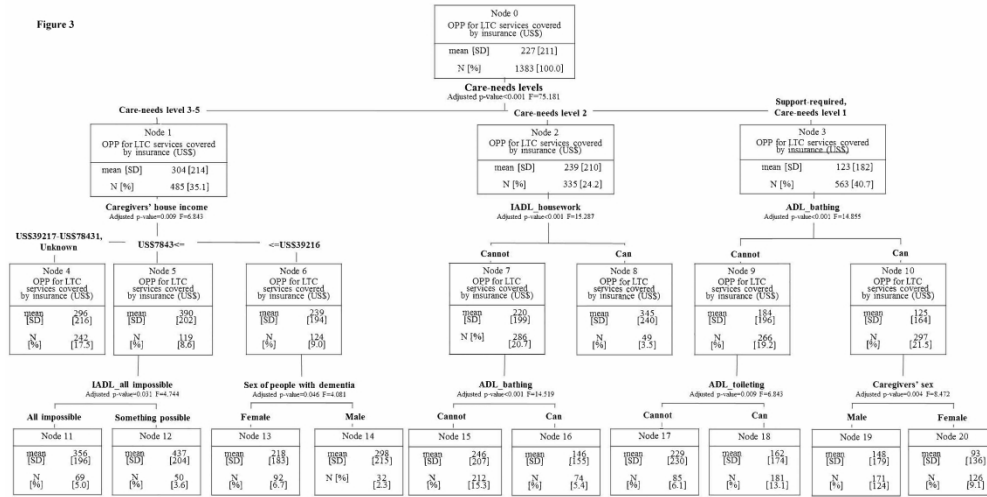


Figure 3: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services covered by insurance
 The dendrogram illustrates the combinations of independent variables to clarify who need more LTC insurance services.
 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

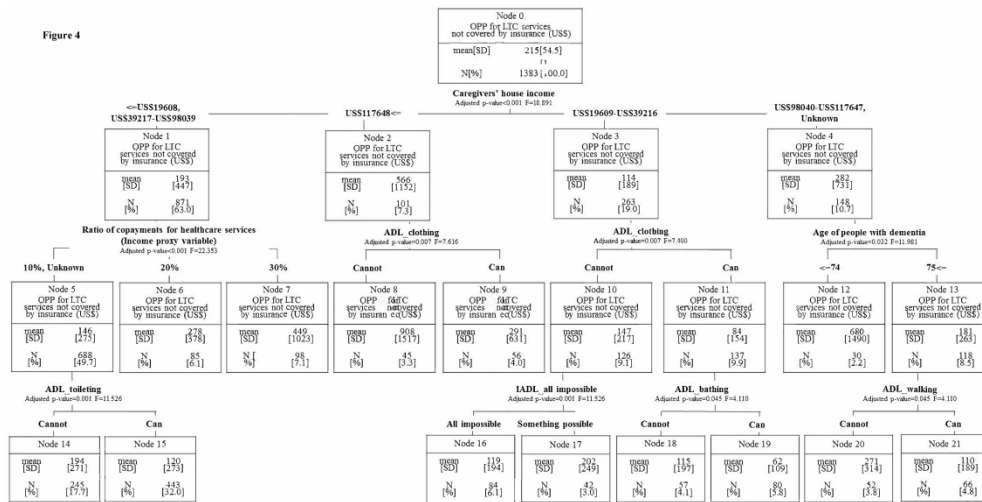


Figure 4: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services not covered by insurance
The dendrogram illustrates the combinations of independent variables to clarify who need more LTC services without insurance.
Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - p.1-2 (b) Provide in the abstract an informative and balanced summary of what was done and what was found – p.2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – p.4-5
Objectives	3	State specific objectives, including any prespecified hypotheses – p.5
Methods		
Study design	4	Present key elements of study design early in the paper – p.5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – p.6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants – p.6 and p.10
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – p.6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group – p.6, 9
Bias	9	Describe any efforts to address potential sources of bias – p.18-19
Study size	10	Explain how the study size was arrived at – p.6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – p.11-12
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding – p.11-12 (b) Describe any methods used to examine subgroups and interactions – p.11-12 (c) Explain how missing data were addressed-p.10 (d) If applicable, describe analytical methods taking account of sampling strategy – Non applicable (e) Describe any sensitivity analyses – Non applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – p.12-13 (b) Give reasons for non-participation at each stage – Non applicable (c) Consider use of a flow diagram - Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – p.13 and Table 1 (b) Indicate number of participants with missing data for each variable of interest – Non applicable
Outcome data	15*	Report numbers of outcome events or summary measures – Table 2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included –p.12-13

		(b) Report category boundaries when continuous variables were categorized – Non applicable
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – Non applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses – p.13, Figure2-4
Discussion		
Key results	18	Summarise key results with reference to study objectives - p,14-15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – p.18-19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – p.15-18
Generalisability	21	Discuss the generalisability (external validity) of the study results –p.18-19
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - p.21

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Classification tree model of the personal economic burden of dementia care by related factors of both people with dementia and caregivers in Japan: A cross-sectional online survey

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9 2 dementia care by related factors of both people with dementia and
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12 3 caregivers in Japan: A cross-sectional online survey
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57 18 Word counts: 3750 words
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6 19 **Abstract**

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8 20 **Objective:**

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11 21 The purpose of this study was to clarify the micro-level determinants of the economic
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14 22 burden of dementia care at home in Japanese community settings by classifying them into
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17 23 subgroups of factors related to people with dementia and their caregivers.

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20 24 **Methods**

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23 25 A cross-sectional online survey was conducted from March 7 to March 14, 2016. For the
24
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26 26 calculation of informal care costs, the average wage stratified by sex and age group was
27
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29 27 used as the opportunity cost. We conducted a chi-square automatic interaction detection
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32 28 analysis to identify the factors related to each cost divided into sub categories.

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35 29 **Results**

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38 30 From 4313 respondents, only 1383 caregivers in community-settings were included in
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41 31 this analysis. In the resultant classifications, informal care cost was mainly related to
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44 32 caregivers' employment status. When caregivers acquired family care leave, informal
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47 33 care costs were the highest. On the other hand, out-of-pocket payments for long-term care
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49
50 34 were related to care-need levels and family economic status. ADL and IADL functions
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53 35 such as bathing, toileting, and cleaning were related to all costs.

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56 36 **Conclusion**

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6 37 This study clarified the difference in dementia care costs between classified subgroups
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9 38 by considering the combination of the situations of both people with dementia and their
10
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12 39 caregivers. Informal care costs were related to caregivers' employment and cohabitation
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15 40 status rather to the situations of people with dementia. On the other hand, out-of-pocket
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18 41 payments for long-term care services were related to care-need levels and family
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21 42 economic status. These classifications will be useful in understanding which situation
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24 43 represents a greater economic burden, and helpful in improving the sustainability of the
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27 44 dementia care system in Japan.
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46 **Strengths and limitations of this study**

47 ● This study clarified the difference in dementia care costs between classified
48 subgroups by considering the combination of the situations of both people with
49 dementia and their caregivers.

50 ● The chi-square automatic interaction detection dendograms provide a visual
51 depiction of criteria and predictor variable interactions that might not be detected in
52 traditional analytic procedures.

53 ● The sample may therefore not be representative of all caregivers because the sample
54 is limited to those who have access to the Internet and are registered with an Internet
55 research company.

56 ● We only assessed objective burden of dementia care such as informal care time or
57 costs, then we didn't consider the subjective burden of care and depressive symptoms.

58

1. Introduction

In the aging society of Japan, it is estimated that there are approximately 4.7 million people living with dementia and that there will be approximately 7 million people with dementia in 2025 [1]. Given that it is also estimated that the total number of people with dementia throughout the world will double every 20 years [2], we need to reconsider how to prepare for dementia care in the community.

Long-term care (LTC) services in Japan used by people with dementia in home care can be classified into three main types: (1) LTC insurance services, (2) LTC services not covered by insurance, and (3) informal care as mutual assistance by family members.

When a person with dementia uses the LTC insurance service, the user bears 10% or 20% of the service expenses as out-of-pocket payments depending on the person's income (Article 49-2 of the Long-Term Care Insurance Act). Aside from such copayments, when LTC services not covered by insurance or exceeding the LTC insurance limit amount are used, people must pay the full amount. Furthermore, it has been pointed out that informal care is an important component of home care, yet it places a burden on caregivers [3,4]. Nevertheless, given the estimates of the societal costs of dementia care throughout the world, the impact of informal care is essential [5,6].

The Japanese government recommends policies to shift to patient-centered and home-centered care to reduce the fiscal burden of the insurance system on community-based

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6 78 integrated systems. While micro level of impact of dementia care has not been
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9 79 insufficiently understood[7], to construct a sustainable dementia care system, we clarified
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12 80 the personal economic burden of dementia care for different residence types and
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15 81 demonstrated that the cost at home in a community setting was equal to or higher than in
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18 82 various institutions[8]. Sustainable dementia care systems should be provided not only to
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21 83 benefit the government or insurance system but also to benefit people with dementia and
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24 84 their caregivers. Furthermore, although there are increasing dementia care costs related
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27 85 to the severity of dementia [9–12], it can be seen that the cost of dementia care increases
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30 86 through the interaction of characteristics or situations of people with dementia and their
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33 87 caregivers. Given this interaction, it is necessary to understand the actual conditions by
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36 88 classifying cases where the greatest economic burdens in dementia care are felt.

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39 89 Therefore, the purpose of this study is to clarify the micro-level determinants of the
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42 90 economic burden of dementia care at home in community settings by classifying them
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45 91 into subgroups of factors related to people with dementia and their caregivers.

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49 93 **2. Methods**

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52 94 This study was a cross-sectional study, based on a self-rated, online questionnaire
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55 95 survey. The economic burden of dementia care in this study is roughly divided into
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58 96 informal care costs as opportunity costs and out-of-pocket payments that people actually
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9 98 *2.1. Online survey for data collection on people with dementia and their caregivers*

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12 99 In this cross-sectional study, we conducted an online questionnaire survey from March
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15 100 3 to March 14, 2016 in cooperation with a commercial research company (Automatic
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18 101 Internet Research System, Macromill, Inc., Japan). Potential participants fulfilled the
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21 102 following criteria: (1) aged 30 years or older, (2) non-professional caregiver of someone
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24 103 with dementia, (3) caring for only one person with dementia, and (4) having no conflicts
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27 104 of interest with advertising or marketing research entities. A total of 3,600 participants
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30 105 were recruited from the research company's registrants and divided into different age
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33 106 groups (850 participants each in the groups aged in 30's, 40's, 50's, and 60's; 200
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36 107 participants in the group aged ≥ 70 years). We excluded caregivers under 29 years of age
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39 108 because, in Japan, they are estimated to represent only 2% of all caregivers [13].

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42 109 *2.2. Questionnaire*

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44
45 110 Resource Utilization in Dementia (RUD) [14,15] is a widely used tool to collect data
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48 111 about resource use in persons with dementia and their caregivers [15]. RUD is available
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51 112 in more than 60 languages and it is widely used throughout the world. In this study, we
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54 113 used RUD (Japanese version) items related to the characteristics of people with dementia
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57 114 and their caregivers, informal care time, employed situation of caregivers, residential
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6 115 types of people with dementia, and resource use of nursing care services. We added items
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9 116 related to LTC services and residential types. The questionnaire components were divided
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12 117 into four categories: (1) characteristics of people with dementia, (2) caregivers' situations
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15 118 (e.g., employment and cohabitation status), (3) informal care duration and (4) frequency
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18 119 of utilization of LTC services.

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21 120 In this project, we could not get information about severity of dementia data because it
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24 121 was regarded as too difficult for caregivers to estimate that. However, we asked for
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27 122 substantial information about care-needs levels. Care needs reflect function, which is a
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30 123 stronger explanatory factor for costs than cognition [16]. Care-needs levels (Support-
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33 124 needs levels 1-2, Care-needs levels 1-5) determine whether a person is qualified to apply
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36 125 for LTC insurance (Article 27 and 32 of the Long-Term Care Insurance Act). Once an
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39 126 insured person applies to use any LTC service, their mental and physical status is first be
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42 127 assessed by certified researchers using a basic checklist. Based on this checklist, care-
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45 128 need times are estimated using an evidence-based computer algorithm. This algorithm
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48 129 was created from the data on how much LTC services were required in 48 hours for more
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51 130 than 3,000 elderly people as a one-minute time study [17]. After estimating the care-needs
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54 131 time, care-needs levels were determined by an expert panel to indicate the amount of care
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57 132 required by each person while taking into consideration their symptoms and functional
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6 133 capability. High care-needs levels indicate increasing dependency and requirement for
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9 134 LTC services [18]. Care-need levels also affect the base amount of the maximum payment
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12 135 for LTC services allowance categories covered by insurance.
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15 136 *2.3. Informal care time*

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18 137 In the questionnaire, informal care time was divided in three domains; support for
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21 138 Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and
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24 139 Supervision [15]. We asked for the mean caregiving time per day and mean caregiving
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27 140 days per week in the past 30 days. We then multiplied the mean daily caregiving time and
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30 141 caregiving days per week to calculate both weekly and monthly informal care time.
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33 142 Supervision time was excluded in calculating informal care time and costs because
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36 143 supervision could be done simultaneously when caregiving for ADL and IADL functions,
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39 144 or in other housekeeping for people without dementia and other family members.
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42 145 *2.4. Cost estimation*

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45 146 In this study, we identified three costs as follows: informal care costs, out-of-pocket
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48 147 payments for LTC services covered by insurance (copayments), and out-of-pocket
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51 148 payments for LTC services not covered by insurance. To calculate the informal care costs,
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53
54 149 there are two methods that are frequently used: the “opportunity cost” and “replacement
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57 150 cost” approaches [19–21]. With the opportunity cost approach it is assumed that there is
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6 151 an alternative use of caregiving time (such as paid work) and thus estimates the costs due
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9 152 to this lost opportunity, whereas the replacement cost approach assumes that informal
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12 153 care services can be valued similarly to home care services provided by professional
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15 154 caregivers. Even though many previous studies on the economic valuation of informal
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18 155 care have used the replacement cost approach [20], the ‘opportunity cost approach’ is
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21 156 recommended by the developers of RUD for estimating informal care costs [2,5,22]. We
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24 157 used the opportunity cost approach to assess informal care time as forgone wages for
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27 158 caregivers [2,5,9]. We used caregivers’ monthly mean wages stratified by sex and age to
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30 159 value informal care. We assessed informal care costs for caregivers who were not working
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33 160 or who were over 65 years of age at 30% of the mean wage of employed caregivers [23–
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35
36 161 26]. A maximum daily informal care time of 16 hours was assumed, in order to allow for
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39 162 other activities such as cooking for other family members and sleep [12,27,28].
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42 163 Caregivers were asked to state their contribution to the total informal care in 5-point scale
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45 164 of 20%. In order to treat all caregivers as primary caregivers and estimate the costs
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48 165 associated with all informal care provided to a patient, we adjusted the informal care time
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51 166 by dividing its time by the median of these contribution levels, according to RUD
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54 167 instructions. This adjustment of informal care time was done only when calculating the
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57 168 informal care costs.
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7 169 Out-of-pocket payments for LTC services both covered and not covered by insurance
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10 170 were included in the questionnaire. We asked for these out-of-pocket payments through
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13 171 categories that were easy to answer (no payments, under JPY9,999, JPY10,000–24,999,
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16 172 JPY25,000–49,999, JPY50,000–74,999, JPY75,000–99,999, JPY100,000–124,999,
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19 173 JPY125,000–149,999, JPY150,000–299,999, JPY300,000–499,999, and over
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22 174 JPY500,000). We adjusted the answers by capping the upper limit of the limit amount
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24
25 175 (Care-needs level 1; JPY166,920, Care-needs level 5; JPY 360,650) depending on each
26
27
28 176 care-needs level or each ratio of copayment (10% or 20%) if the answers were over it.
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31 177 These costs were substituted by a median of each category, and we calculated the
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34 178 weighted average as the following formula:
$$\frac{\sum_{i=0}^k (\text{median of category}_i) * n_i}{\sum n}$$

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37 179 All costs were converted from Japanese yen to US dollars using the purchasing power
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40 180 parity rate in 2016 (¥102 = \$1) provided by the Organization for Economic Cooperation
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43 181 and Development.

44 45 182 *2.5. Inclusion and exclusion criteria*

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48 183 With respondents, we only focused on community settings for people with dementia
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51 184 who lived in their own home. We excluded respondents based on the following criteria:
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54 185 (1) people with dementia who were hospitalized or lived in nursing home, (2) lack of data
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57 186 about out-of-pocket payments for LTC services or care-needs levels, (3) contradictions
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6 187 in relationships between caregivers and people with dementia, and (4) contradictions in
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9 188 care time (over 24 hours). When the age difference was less than 15 years and the person
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12 189 with dementia was a parent or child (not in-law), these cases were identified as
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14
15 190 contradictions.

18 191 *2.6. Statistical analysis*

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21 192 We conducted descriptive analysis for characteristics of people with dementia and
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24 193 caregivers. We then stratified the informal care time and dementia care costs by the care-
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27 194 needs level and cohabitation to test our hypothesis that high care-needs level or people
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30 195 who lives with caregivers need more informal care time. In this description, we didn't
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33 196 adjusted informal care time by caregivers' contribution rate.

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36 197 Also, we used chi-square automatic interaction detection (CHAID) analysis to identify
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39 198 the characteristics of people with dementia and caregivers who needed more care services.
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42 199 In CHAID analysis, the dependent variable would be divided into sub-groups by the most
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45 200 explanatory independent variables. These groups could be formed by any possible
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48 201 combination with all independent variables. Especially, we conducted an exhaustive
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51 202 CHAID analysis that repeats the trial until it finds the optimal combination of all
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54 203 independent variables. The CHAID dendograms provide a visual depiction of criteria and
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57 204 predictor variable interactions that might not be detected in traditional analytic procedures.
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6 205 We set informal care costs, out-of-pocket payments for LTC services covered by
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9 206 insurance and out-of-pocket payments for LTC services not covered by insurance as
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12 207 dependent variables. Then, we used the characteristics of people with dementia (age, sex,
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15 208 care-need level, dementia types, ADL and IADL functions, and primary disease as the
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18 209 reason for care), the characteristics of caregivers (age, sex, marital status, children,
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21 210 cohabitation with people with dementia, visiting time, relationship to people with
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23
24 211 dementia, and occupation), and economic factors (the ratio of copayments for healthcare
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27 212 services and family income of caregivers). We treated the ratio of copayments for
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30 213 healthcare services as income proxy variable because this ratio was decided by income of
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32
33 214 people with dementia. We set the following criteria: tree depth was limited to three levels,
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36 215 no group smaller than 100 was split, no group smaller than 30 was formed, and the p-
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39 216 value for all statistical tests was under 0.05.

41
42 217 All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan Inc.,
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44
45 218 Tokyo, Japan).

48 219 *2.6. Ethical considerations and consents*

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51 220 This study was approved by the Ethics committee of Kyoto University Graduate School
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54 221 of Medicine (R0487). All participants were volunteers and they were informed that there
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57 222 was no obligation to participate in the study, and only people who consented to this study
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6 223 completed the questionnaire.
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9 224 *2.7. Patient and public involvement*
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12 225 Patients were not formally involved in this study; however, their caregivers participated
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15 226 in our online-based questionnaire survey. Caregivers, who constituted the online panel,
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18 227 were sent the invitation by the Internet research company. Patients and their caregivers
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21 228 can view the results of this study when it is published in a peer-reviewed journal.
22
23

24 229 **3. Results**
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26

27 230 *3.1. Characteristics of people with dementia and their caregivers*
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29

30 231 A total of 3,916 caregivers answered the questionnaire. We focused only on people
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33 232 with dementia who lived in their own home (n=2277). However, we excluded the data
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36 233 according to the criteria and the final sample comprised 1,383 respondents (Figure 1).
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38

39 234 Table 1 shows the characteristics of people with dementia and their caregivers. More
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42 235 than half of the people with dementia were female (66.7%), and the mean age was 81.8
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45 236 years. In contrast, more than half of the caregivers were male (61.7%), and the mean age
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48 237 was 52.2 years. 1,233 people (89.2%) responded that ADL functions such as meals and
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51 238 toilet use could be managed by themselves, while IADL functions such as cleaning and
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54 239 shopping could be done by one person in the same way. There were only 788 people
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57 240 (57.0%) who did the latter by themselves.
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7 241 *3.2. Informal care time and costs of dementia care*

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9 242 The mean daily informal care time was 9.36 hours in total. The time for only ADL was
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12 243 4.97 hours and for only IADL was 4.39 hours. On the other hand, monthly informal care
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15 244 time (ADL+IADL) was 166.32 hours. Table 2 shows the differences in daily informal
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18 245 care time and personal cost of dementia care among the care-need levels. In this table, we
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21 246 didn't adjust by contribution rate. Informal care times increased with care-needs levels,
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24 247 especially in ADL. Out-of-pocket payments for LTC services were less than informal
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27 248 care costs in all of the care-needs levels.

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32 250 *3.3. Classification with classification trees*

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34
35 251 Figure 2 shows the results of CHAID analysis for informal care costs. Informal care
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38 252 costs were related to caregivers' employment status, cohabitation, age, and care-needs
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41 253 levels or ADL function of people with dementia. When the caregiver acquired family care
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44 254 leave, informal care cost was the highest (node 2). For the caregivers who were between
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47 255 43-52 years old (node 12) and worked outside the home as well as cohabited with people
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50 256 with dementia, informal care costs were high, similar to caregivers who acquired family
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52
53 257 care leave (node 2). Even if the caregiver did not work, informal care costs were higher
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56 258 with high care-needs levels (node 6-8). The costs for cohabiting caregivers (node 5) were
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59 259 higher than for those not cohabiting (node 4). For those not cohabiting and the person
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6 260 with dementia could not walk without assistance (node 9), informal care costs were higher
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9 261 than for those that could walk (node 10) .
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12 262 Out-of-pocket payments for LTC services covered by insurance were related to care-
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15 263 need levels, ADL or IADL functions, sex (both the people with dementia and caregivers)
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18 264 and caregivers' household incomes (Figure 3). Especially, if the people with dementia
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21 265 could bathe or use the toilet by themselves, out-of-pocket payments would be about 65%
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24 266 lower (nodes 9-10, 15-18). On the other hand, if out-of-pocket payments were not covered
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27 267 by insurance, they were related to caregivers' household incomes, income proxy variable,
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30 268 ADL or IADL functions of people with dementia, and age of people with dementia
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33 269 (Figure 4). Both the out-of-pocket payments that were covered by insurance and those
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36 270 that were not were related to caregivers' house hold income or ADL functions which
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39 271 affected the ability to pay and service use volume.
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42 43 44 273 **4. Discussion**

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47 274 In this study, we first demonstrated that informal care time for ADL or IADL functions
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50 275 increased with high care-needs levels as our hypothesis stipulated (Care-need level 1:
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53 276 2.2hours, level 3: 3.4 hours. level 5: 4.6 hours). Second, we established that the
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56 277 combination of characteristics of both people with dementia and their caregivers were
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59 278 related to dementia care costs through the classification tree analysis. Caregivers'
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6 279 employment and cohabitation status were mainly related to informal care costs, and the
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9 280 costs were the highest when caregivers took nursing care leave, which caregivers leave
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12 281 work due to caregiving. Furthermore, when caregivers worked at an occupation and lived
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15 282 separately, or the people with dementia could not walk, the costs doubled. Out-of-pocket
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18 283 payments for LTC services covered by insurance were mainly related to care-need levels
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21 284 and ADL and IADL functions. In the case of low care-needs levels, where care was
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24 285 needed for toileting or bathing, high out-of-pocket payments were required for LTC
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27 286 insurance services. On the other hand, out-of-pocket payments were related to caregivers'
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30 287 household income levels or income proxy variable. Caregivers with high annual incomes
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33 288 (more than \$117,648 US) made out-of-pocket payments for dementia care of full amounts
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36 289 that were two to five times more than others.

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39 290 Informal care costs were mainly related to caregivers' characteristics such as
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42 291 employment or cohabitation status in the classification tree, which illustrated related
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45 292 factors by order of precedence. In many previous studies, ADL functions or dementia
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48 293 severity were explained as related factors in regression models [9–12]. Some studies
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51 294 showed caregivers' characteristics such as employment status were related to informal
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54 295 care costs [9,29,30], but few studies considered all of the caregivers' characteristics. Thus,
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57 296 caregiver factors may be as important as factors related to people with dementia are.
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6 297 Furthermore, we considered the combination of characteristics of both people with
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9 298 dementia and their caregivers. For example, informal care costs doubled when caregivers
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12 299 lived separately and people with dementia could not walk. Many previous studies
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15 300 established the determinants by regression analysis[9,12,31–34]. Although it is possible
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18 301 to understand the influence on the objective variable adjusted in the multivariate by
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21 302 regression analysis, the combinations between explanatory variables have not been
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24 303 clarified. CHAID analysis provided the classification only for related characteristics in
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27 304 the outcome. Such combinations suggest that support should be provided to caregivers
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30 305 who cannot live with people with dementia or caregivers who are not employed (Figure
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33 306 2, Node 3-4).

36 307 The association between out-of-pocket payments for LTC services covered by
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39 308 insurance and care-need levels is reasonable because the benefit limit standard amounts
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42 309 for formal care services at home are decided in relation to care-need levels[35]. In
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45 310 addition, when people with dementia had a high care-needs level and their caregiver's
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48 311 household income was high, out-of-pocket payments were high. Because the
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51 312 determination of service usage within the limit amount is a free contract, people with
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54 313 dementia and their caregivers may decide how they use formal care services depending
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57 314 on how much they can pay for services. High care-needs levels [36], age[10,34,36,37]
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6 315 and sex[10,36] were related to the high costs of LTC services. Even for low care-needs
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9 316 levels, the cost may be high when people with dementia need assistance with bathing or
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12 317 toileting. This was affected by LTC insurance services providing specific substitutions,
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15 318 such as bath assistance, and also Ku et al.'s or Dodel et al.'s ADL functions were related
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18 319 to the social care costs[9,30].
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21 320 Similarly, economic variables such as household income and income proxy variable
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24 321 were mainly related to out-of-pocket payments for LTC services not covered by insurance
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27 322 (Figure 4). This is because people must pay the full amount if they use LTC services
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30 323 without insurance. In the United States, high copayments are required for the use of LTC
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33 324 services; however, these copayments were related to age, sex, and comorbidities in the
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36 325 cohort study [37]. A part of the result of Hurd et al. was similar to our results in the case
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39 326 of the payments that were covered by insurance for the use of LTC services. Out-of-
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42 327 pocket payments not covered by insurance might occur for over the limit standard
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45 328 amounts or the use of LTC services not covered by insurance (e.g. feeding service[38]).
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48 329 According to the questionnaire responses, people tended to pay for expendables such as
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51 330 diapers, employment of housekeepers, and home repair such as handrail installation as
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54 331 out-of-pocket payments not covered by LTC insurance. Furthermore, except when
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57 332 caregivers' income was high, the cost did not change significantly due to differences in
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6 333 ADL and IADL functions as it did for the payments that were covered by insurance.
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9 334 These application examples were not really affected by ADL or IADL functions.
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12 335 From the viewpoint of independent variables, if people with dementia lacked some
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15 336 ADL function, then costs might be higher but in the case of IADL functions this was
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18 337 reversed. There is a possibility that some services are used to support the independent
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21 338 lives of people with dementia. Some people with dementia who can do housework by
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24 339 themselves might move or walk around more, and therefore use more LTC services like
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27 340 commuting for care (day service) or commuting for rehabilitation. Also, care-need levels
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30 341 were not related to out-of-pocket payments not covered by insurance. The above
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33 342 application examples were also not related to care-needs levels. The relationship of
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36 343 cohabitation or employment status was the same as in previous studies [9,29,32]. While
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39 344 differences of burden of dementia care depended on the dementia types that existed and
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42 345 were pointed out [24], dementia types were not related to any other factors in this study.
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45 346 In our CHAID analysis, family caregivers' economic status or severity (care-needs levels)
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48 347 might have been more important than dementia types to dementia care costs. In creating
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51 348 policy for LTC services in an aging society, we must understand the actual conditions
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54 349 from not only a societal but also a personal perspective. This is true even if from a societal
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57 350 viewpoint, the societal cost of dementia care in the community has been established by
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6 351 other countries to be greater than that in institutional care [39]. Furthermore, we need a
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9 352 wide range of perspectives of stakeholders to discuss the dementia care system, while
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12 353 almost all studies of economic burden of dementia stood on societal or payers'
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15 354 viewpoint[7,19–21]. Then, as a first step, we need to understand what people with
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18 355 dementia and their family caregivers are already spending too much money on. We need
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21 356 to recognize the complicated combination of characteristics associated with people with
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24 357 dementia and their caregivers. To this point, the results of this classification could be
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27 358 useful to understanding which situation requires more resources depending on cost types.
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30 359 Our results may suggest that a sustainable dementia care system in Japan should be
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33 360 reconstructed from a personal viewpoint.

36 361 There are some limitations to this study. First, we conducted an online questionnaire
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39 362 survey with caregivers of people with dementia. Traditionally, respondents who use the
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42 363 Internet tend to be male and relatively young, reflecting the general characteristics of
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45 364 online research [40–42]. The sample may therefore not be representative of all caregivers
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48 365 because the sample is limited to those who have access to the Internet and are registered
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51 366 with an Internet research company [43]. Certainly, we cannot extrapolate the
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54 367 representative value in each node of the CHAID tree to the population as a whole.
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57 368 However, this study focused on finding a combination of independent variables related to
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6 369 the dependent variables (informal care cost and financial burden), taking into account the
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9 370 interaction between multiple independent variables. The significance of subgroups made
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12 371 by combinations of variables may not change significantly even if the population changes.
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15 372 Therefore, in this study, influence due to the difference between this sample and general
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18 373 public is not considered to be a practical problem. However, further research (e.g. a
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21 374 paper-based questionnaire survey mailed to the family caregivers association) to collect
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24 375 representative samples might be needed in the future. Second, we didn't consider the
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27 376 subjective burden of care and depressive symptoms. These mental burdens are considered
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30 377 to be important factors in explaining the actual state of care costs, and many previous
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33 378 studies in Japan have covered subjective costs [44–46]. In the future, in addition to the
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36 379 burden of time and money, it would be preferable to measure subjective burdens. Third,
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39 380 we estimated informal care costs only by the opportunity cost approach. Some studies
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42 381 indicated results estimated by both opportunity cost approach and replacement cost
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45 382 approach. The opportunity cost approach might be underestimated in comparison to the
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48 383 replacement approach[9,37]

51 384

54 385 **Conclusions**

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6 386 This study clarified the difference in dementia care costs between classified subgroups
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9 387 by considering the combination of the situations of both people with dementia and their
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12 388 caregivers. Informal care costs were related to caregivers' employment and cohabitation
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15 389 status rather to the situation of people with dementia. On the other hand, out-of-pocket
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18 390 payments for long-term care services were related to care-needs levels and family
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21 391 economic status. These classifications will be useful in understanding which situation
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24 392 represents a greater economic burden, and helpful in improving the sustainability of the
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27 393 dementia care system in Japan.

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33 395 **Footnotes**

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36 396 *Abbreviations*

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39 397 LTC: Long-Term Care

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42 398 RUD: Resource Utilization in Dementia

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45 399 ADL: Activities of Daily Life

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48 400 IADL: Instrumental Activities of Daily Life

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51 401 CHAID analysis: chi-square automatic interaction detection analysis

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54 402 *Authors' contribution*

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57 403 TN, SN and YI designed the study. All authors discussed for preparing the questionnaire.
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6 404 TN mainly analyzed all data, and HU, SK, AW and YI advised for analysis. TN prepared
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9 405 the draft of the manuscript, then all authors contributed to rewrite it. All authors read and
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12 406 approved the final manuscript.
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30 412 in the study design, data collection and analysis, decision to publish, or preparation of the
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33 413 manuscript.
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36 414 *Competing interest*
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48 418 *Conflicts of interest*
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54 420 *Data sharing statement*
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57 421 No additional data are available.
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7 **Figure 1: Selection process for the analysis**

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9 This diagram shows the flow of participants who we focused on.
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12 **Figure 2: Classification tree of chi-square automatic interaction detection for**
13 **informal care costs**
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17 The dendogram illustrates the combinations of independent variables to clarify who need
18 or provide more informal care.
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22 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
23 Living; SD, Standard deviation; LTC, Long-term care
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30 **Figure 3: Classification tree of chi-square automatic interaction detection for out-**
31 **of-pocket payments for LTC services covered by insurance**
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35 The dendogram illustrates the combinations of independent variables to clarify who need
36 more LTC insurance services.
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40 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
41 Living; SD, Standard deviation; LTC, Long-term care
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48 **Figure 4: Classification tree of chi-square automatic interaction detection for out-**
49 **of-pocket payments for LTC services not covered by insurance**
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53 The dendogram illustrates the combinations of independent variables to clarify who need
54 more LTC services without insurance.
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6 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
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Table 1 Characteristics of people with dementia and caregivers

People with Dementia		N=1383
Age, mean±SD, y		81.8±10.3
Sex, n (%)		
Female		922 (66.7)
Male		461 (33.3)
Care-needs level, n (%)		
Support-Needs Level 1-2		253 (18.3)
Care-Needs Level 1		310 (22.4)
Care-Needs Level 2		335 (24.2)
Care-Needs Level 3		258 (18.7)
Care-Needs Level 4		122 (8.8)
Care-Needs Level 5		105 (7.6)
ADL/IADL functional capabilities		
ADL score (0-6), mean±SD		3.2±2.0
IADL score (0-7), mean±SD		1.3±1.6
Ratio of copayments for healthcare services, n(%)		
10%		961 (69.5)
20%		137 (9.9)
30%		157 (11.4)
Unknown		128 (9.3)
Types of Dementia, n(%)		
Alzheimer's disease		751 (54.3)
Caregivers		
Age, mean ± SD		52.2±13.1
Sex, n (%)		
Female		530 (38.3)
Male		853 (61.7)
Relationship, n (%)		
Mother		575 (41.6)
Mother-in-law		169 (12.2)
Father		288 (20.8)
Father-in-law		90 (6.5)
Spouse		99 (7.2)
Sibling		11 (0.8)
Child		10 (0.7)
Friend		5 (0.4)
Other (including grandparents)		136 (9.8)
Contribution level for caregiving, n (%)		
1-20%		395 (28.6)
21-40%		355 (25.7)
41-60%		241 (17.4)
61-80%		166 (12.0)
81-100%		226 (16.3)
Currently employed, n (%)		532 (38.5)

SD: Standard deviation, ADL: Activities of Daily Living, IADL: Instrumental Activities

of Daily Living

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570 **Table 2 Daily informal care time and personal costs of dementia care sorted by care-needs levels**

			Support- required level	Care-need level 1	Care-need level 2	Care-need level 3	Care-need level 4	Care-need level 5
Informal care time (hours/day)	ADL	Mean [SD]	2.56 [3.23]	2.23 [2.54]	2.92 [2.90]	3.44 [2.90]	3.99 [2.40]	4.60 [3.85]
		Median [IQR]	1.67 [2.00]	1.50 [2.50]	2.00 [3.00]	3.00 [3.50]	4.00 [3.00]	3.33 [4.00]
	IADL	Mean [SD]	2.35 [2.62]	2.46 [3.05]	2.88 [3.26]	2.82 [2.92]	3.03 [2.59]	3.45 [3.77]
		Median [IQR]	2.00 [2.00]	1.50 [2.00]	2.00 [2.00]	2.00 [2.50]	2.00 [3.13]	2.00 [4.00]
Personal cost of dementia care (US\$)	Informal care cost	Mean [SD]	1518 [2017]	1271 [1526]	1754 [1982]	2181 [2220]	2112 [2104]	2672 [2314]
		Median [IQR]	747 [1646]	709 [1440]	1090 [1697]	1366 [2459]	1535 [1466]	1939 [2240]
	OPP for LTC services covered by insurance	Mean [SD]	148 [190]	158 [174]	244 [209]	313 [217]	301 [202]	318 [218]
		Median [IQR]	49 [172]	49 [123]	172 [319]	368 [441]	368 [196]	368 [441]
	OPP for care services not covered by insurance	Mean [SD]	158 [336]	95 [156]	278 [695]	303 [543]	241 [579]	352 [998]
		Median [IQR]	49 [172]	49 [172]	49 [368]	172 [319]	49 [368]	49 [368]

571 ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, SD: Standard deviation, IQR: Interquartile range

572 OPP: Out-of-pocket payments LTC: Long-term care

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Figure 1

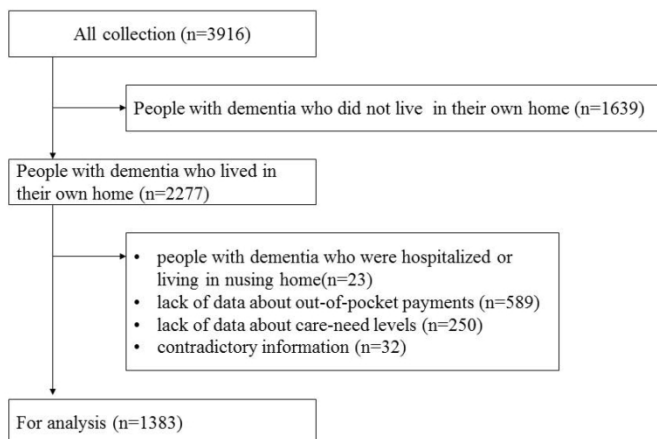


Figure 1: Selection process for the analysis
This diagram shows the flow of participants who we focused on.

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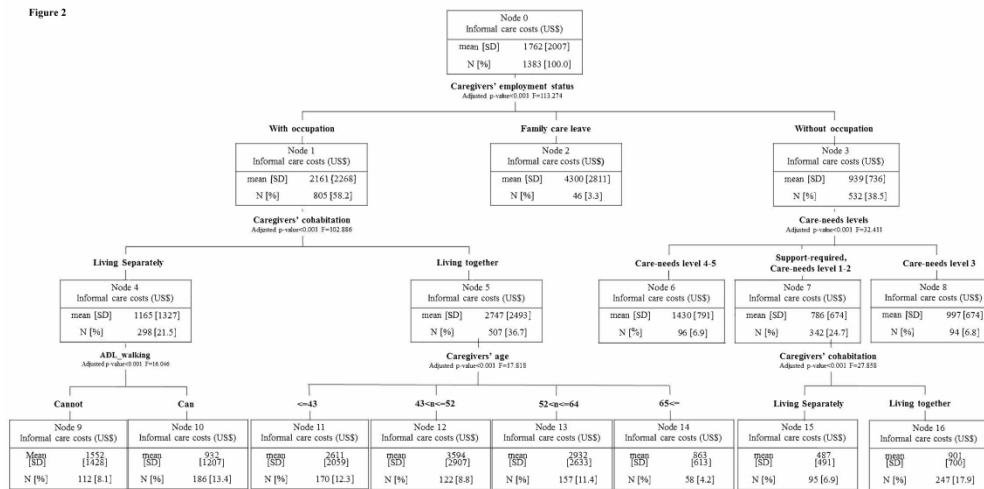


Figure 2: Classification tree of chi-square automatic interaction detection for informal care costs
 The dendrogram illustrates the combinations of independent variables to clarify who need or provide more informal care.

Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

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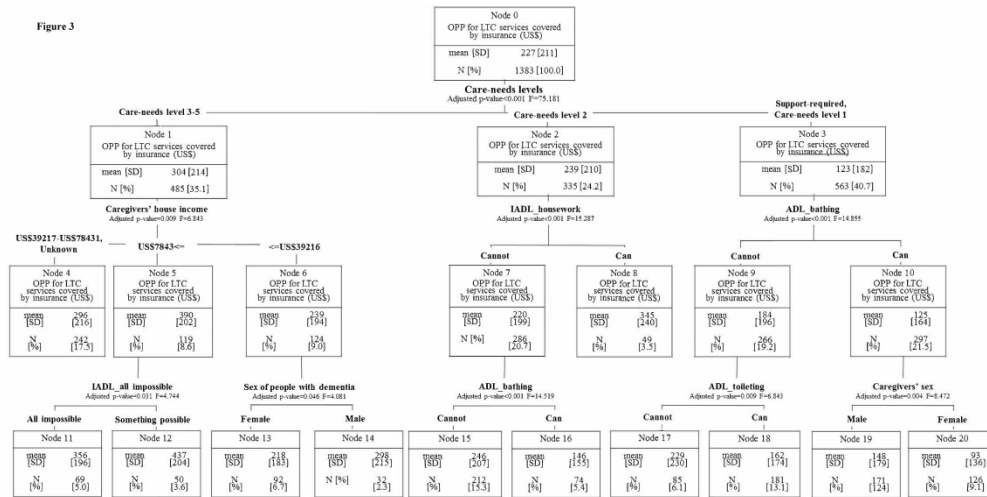


Figure 3: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services covered by insurance
 The dendrogram illustrates the combinations of independent variables to clarify who need more LTC insurance services.
 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

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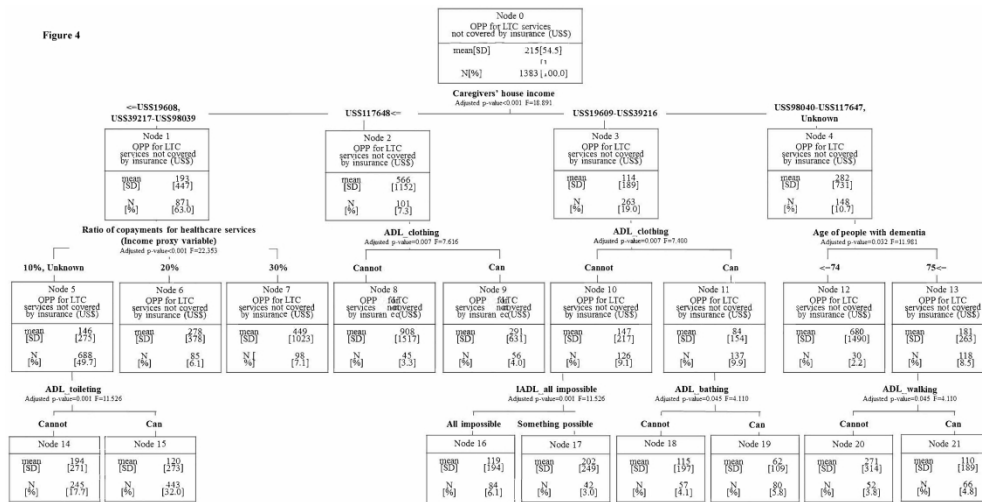


Figure 4: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services not covered by insurance
The dendrogram illustrates the combinations of independent variables to clarify who need more LTC services without insurance.
Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - p.1-2 (b) Provide in the abstract an informative and balanced summary of what was done and what was found – p.2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – p.4-5
Objectives	3	State specific objectives, including any prespecified hypotheses – p.5
Methods		
Study design	4	Present key elements of study design early in the paper – p.5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – p.6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants – p.6 and p.10
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – p.6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group – p.6, 9
Bias	9	Describe any efforts to address potential sources of bias – p.18-19
Study size	10	Explain how the study size was arrived at – p.6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – p.11-12
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding – p.11-12 (b) Describe any methods used to examine subgroups and interactions – p.11-12 (c) Explain how missing data were addressed-p.10 (d) If applicable, describe analytical methods taking account of sampling strategy – Non applicable (e) Describe any sensitivity analyses – Non applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – p.12-13 (b) Give reasons for non-participation at each stage – Non applicable (c) Consider use of a flow diagram - Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – p.13 and Table 1 (b) Indicate number of participants with missing data for each variable of interest – Non applicable
Outcome data	15*	Report numbers of outcome events or summary measures – Table 2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included –p.12-13

		(b) Report category boundaries when continuous variables were categorized – Non applicable
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – Non applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses – p.13, Figure2-4
Discussion		
Key results	18	Summarise key results with reference to study objectives - p,14-15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – p.18-19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – p.15-18
Generalisability	21	Discuss the generalisability (external validity) of the study results –p.18-19
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - p.21

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Classification tree model of the personal economic burden of dementia care by related factors of both people with dementia and caregivers in Japan: A cross-sectional online survey

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Primary Subject Heading:	Public health
Secondary Subject Heading:	Health economics
Keywords:	Informal care, RUD, Cost, Classification, Japan

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18 5 Takayo Nakabe^a, Noriko Sasaki^a, Hironori Uematsu^a, Susumu Kunisawa^a, Anders Wimo^b,
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57 18 Word counts: 3750 words
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6 19 **Abstract**

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8 20 **Objective:**

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11 21 The purpose of this study was to clarify the micro-level determinants of the economic
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14 22 burden of dementia care at home in Japanese community settings by classifying them into
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17 23 subgroups of factors related to people with dementia and their caregivers.

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20 24 **Methods**

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23 25 A cross-sectional online survey was conducted from March 7 to March 14, 2016.
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26 26 Participants were recruited through the panels of Japanese research company. For the
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29 27 calculation of informal care costs, the average wage stratified by sex and age group was
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32 28 used as the opportunity cost. We conducted a chi-square automatic interaction detection
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35 29 analysis to identify the factors related to each cost (informal care costs and out-of-pocket
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38 30 payments for long-term care services) divided into sub categories.

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41 31 **Results**

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44 32 From 4313 respondents, only 1383 caregivers in community-settings were included in
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47 33 this analysis. In the resultant classifications, informal care cost was mainly related to
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50 34 caregivers' employment status. When caregivers acquired family care leave, informal
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53 35 care costs were the highest. On the other hand, out-of-pocket payments for long-term care
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56 36 were related to care-need levels and family economic status. ADL and IADL functions
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59 37 such as bathing, toileting, and cleaning were related to all costs.
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6 **38 Conclusion**
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9 **39** This study clarified the difference in dementia care costs between classified subgroups
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12 **40** by considering the combination of the situations of both people with dementia and their
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15 **41** caregivers. Informal care costs were related to caregivers' employment and cohabitation
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18 **42** status rather to the situations of people with dementia. On the other hand, out-of-pocket
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21 **43** payments for long-term care services were related to care-need levels and family
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24 **44** economic status. These classifications will be useful in understanding which situation
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27 **45** represents a greater economic burden, and helpful in improving the sustainability of the
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30 **46** dementia care system in Japan.
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48 **Strengths and limitations of this study**

49 ● This study clarified the difference in dementia care costs between classified
50 subgroups by considering the combination of the situations of both people with
51 dementia and their caregivers.

52 ● The chi-square automatic interaction detection dendograms provide a visual
53 depiction of criteria and predictor variable interactions that might not be detected in
54 traditional analytic procedures.

55 ● The sample may therefore not be representative of all caregivers because the sample
56 is limited to those who have access to the Internet and are registered with an Internet
57 research company.

58 ● We only assessed objective burden of dementia care such as informal care time or
59 costs, then we didn't consider the subjective burden of care and depressive symptoms.

60

61 **1. Introduction**

62 In the aging society of Japan, it is estimated that there are approximately 4.7 million
63 people living with dementia and that there will be approximately 7 million people with
64 dementia in 2025 [1]. Given that it is also estimated that the total number of people with
65 dementia throughout the world will double every 20 years [2], we need to reconsider how
66 to prepare for dementia care in the community.

67 Long-term care (LTC) services in Japan used by people with dementia in home care
68 can be classified into three main types: (1) LTC insurance services, (2) LTC services not
69 covered by insurance, and (3) informal care as mutual assistance by family members.

70 When a person with dementia uses the LTC insurance service, the user bears 10% or 20%
71 of the service expenses as out-of-pocket payments depending on the person's income
72 (Article 49-2 of the Long-Term Care Insurance Act). Aside from such copayments, when
73 LTC services not covered by insurance or exceeding the LTC insurance limit amount are
74 used, people must pay the full amount. Furthermore, it has been pointed out that informal
75 care is an important component of home care, yet it places a burden on caregivers [3,4].
76 Nevertheless, given the estimates of the societal costs of dementia care throughout the
77 world, the impact of informal care is essential [5,6].

78 The Japanese government recommends policies to shift to patient-centered and home-
79 centered care to reduce the fiscal burden of the insurance system on community-based
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6 80 integrated systems. While micro level of impact of dementia care has not been
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9 81 insufficiently understood[7], to construct a sustainable dementia care system, we clarified
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12 82 the personal economic burden of dementia care for different residence types and
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15 83 demonstrated that the cost at home in a community setting was equal to or higher than in
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18 84 various institutions[8]. Sustainable dementia care systems should be provided not only to
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21 85 benefit the government or insurance system but also to benefit people with dementia and
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24 86 their caregivers. Furthermore, although there are increasing dementia care costs related
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27 87 to the severity of dementia [9–12], it can be seen that the cost of dementia care increases
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30 88 through the interaction of characteristics or situations of people with dementia and their
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33 89 caregivers. Given this interaction, it is necessary to understand the actual conditions by
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36 90 classifying cases where the greatest economic burdens in dementia care are felt.

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39 91 Therefore, the purpose of this study is to clarify the micro-level determinants of the
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45 93 into subgroups of factors related to people with dementia and their caregivers.

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49 95 **2. Methods**

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52 96 This study was a cross-sectional study, based on a self-rated, online questionnaire
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9 100 *2.1. Online survey for data collection on people with dementia and their caregivers*

101 In this cross-sectional study, we conducted an online questionnaire survey from March
102 3 to March 14, 2016 in cooperation with a commercial research company (Automatic
103 Internet Research System, Macromill, Inc., Japan). Potential participants fulfilled the
104 following criteria: (1) aged 30 years or older, (2) non-professional caregiver of someone
105 with dementia, (3) caring for only one person with dementia, and (4) having no conflicts
106 of interest with advertising or marketing research entities. A total of 3,600 participants
107 were recruited from the research company's registrants and divided into different age
108 groups (850 participants each in the groups aged in 30's, 40's, 50's, and 60's; 200
109 participants in the group aged ≥ 70 years). We excluded caregivers under 29 years of age
110 because, in Japan, they are estimated to represent only 2% of all caregivers [13].

111 *2.2. Questionnaire*

112 Resource Utilization in Dementia (RUD) [14,15] is a widely used tool to collect data
113 about resource use in persons with dementia and their caregivers [15]. RUD is available
114 in more than 60 languages and it is widely used throughout the world. In this study, we
115 used RUD (Japanese version) items related to the characteristics of people with dementia
116 and their caregivers, informal care time, employed situation of caregivers, residential

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6 117 types of people with dementia, and resource use of nursing care services. We added items
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9 118 related to LTC services and residential types. The questionnaire components were divided
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12 119 into four categories: (1) characteristics of people with dementia, (2) caregivers' situations
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15 120 (e.g., employment and cohabitation status), (3) informal care duration and (4) frequency
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18 121 of utilization of LTC services.

21 122 In this project, we could not get information about severity of dementia data because it
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24 123 was regarded as too difficult for caregivers to estimate that. However, we asked for
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27 124 substantial information about care-needs levels. Care needs reflect function, which is a
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30 125 stronger explanatory factor for costs than cognition [16]. Care-needs levels (Support-
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33 126 needs levels 1-2, Care-needs levels 1-5) determine whether a person is qualified to apply
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36 127 for LTC insurance (Article 27 and 32 of the Long-Term Care Insurance Act). Once an
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39 128 insured person applies to use any LTC service, their mental and physical status is first be
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42 129 assessed by certified researchers using a basic checklist. Based on this checklist, care-
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45 130 need times are estimated using an evidence-based computer algorithm. This algorithm
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48 131 was created from the data on how much LTC services were required in 48 hours for more
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51 132 than 3,000 elderly people as a one-minute time study [17]. After estimating the care-needs
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54 133 time, care-needs levels were determined by an expert panel to indicate the amount of care
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57 134 required by each person while taking into consideration their symptoms and functional
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6 135 capability. High care-needs levels indicate increasing dependency and requirement for
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9 136 LTC services [18]. Care-need levels also affect the base amount of the maximum payment
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11
12 137 for LTC services allowance categories covered by insurance.
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15 138 *2.3. Informal care time*

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18 139 In the questionnaire, informal care time was divided in three domains; support for
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20
21 140 Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and
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23
24 141 Supervision [15]. We asked for the mean caregiving time per day and mean caregiving
25
26
27 142 days per week in the past 30 days. We then multiplied the mean daily caregiving time and
28
29
30 143 caregiving days per week to calculate both weekly and monthly informal care time.
31
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33 144 Supervision time was excluded in calculating informal care time and costs because
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36 145 supervision could be done simultaneously when caregiving for ADL and IADL functions,
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39 146 or in other housekeeping for people without dementia and other family members.
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42 147 *2.4. Cost estimation*

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45 148 In this study, we identified three costs as follows: informal care costs, out-of-pocket
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48 149 payments for LTC services covered by insurance (copayments), and out-of-pocket
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51 150 payments for LTC services not covered by insurance. To calculate the informal care costs,
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53
54 151 there are two methods that are frequently used: the “opportunity cost” and “replacement
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57 152 cost” approaches [19–21]. With the opportunity cost approach it is assumed that there is
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6 153 an alternative use of caregiving time (such as paid work) and thus estimates the costs due
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9 154 to this lost opportunity, whereas the replacement cost approach assumes that informal
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12 155 care services can be valued similarly to home care services provided by professional
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15 156 caregivers. Even though many previous studies on the economic valuation of informal
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18 157 care have used the replacement cost approach [20], the ‘opportunity cost approach’ is
19
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21 158 recommended by the developers of RUD for estimating informal care costs [2,5,22]. We
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23
24 159 used the opportunity cost approach to assess informal care time as forgone wages for
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27 160 caregivers [2,5,9]. We used caregivers’ monthly mean wages stratified by sex and age to
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29
30 161 value informal care. We assessed informal care costs for caregivers who were not working
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32
33 162 or who were over 65 years of age at 30% of the mean wage of employed caregivers [23–
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35
36 163 26]. A maximum daily informal care time of 16 hours was assumed, in order to allow for
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39 164 other activities such as cooking for other family members and sleep [12,27,28].
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42 165 Caregivers were asked to state their contribution to the total informal care in 5-point scale
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44
45 166 of 20%. In order to treat all caregivers as primary caregivers and estimate the costs
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47
48 167 associated with all informal care provided to a patient, we adjusted the informal care time
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51 168 by dividing its time by the median of these contribution levels, according to RUD
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54 169 instructions. This adjustment of informal care time was done only when calculating the
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57 170 informal care costs.
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7 171 Out-of-pocket payments for LTC services both covered and not covered by insurance
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10 172 were included in the questionnaire. We asked for these out-of-pocket payments through
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13 173 categories that were easy to answer (no payments, under JPY9,999, JPY10,000–24,999,
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15
16 174 JPY25,000–49,999, JPY50,000–74,999, JPY75,000–99,999, JPY100,000–124,999,
17
18
19 175 JPY125,000–149,999, JPY150,000–299,999, JPY300,000–499,999, and over
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21
22 176 JPY500,000). We adjusted the answers by capping the upper limit of the limit amount
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24
25 177 (Care-needs level 1; JPY166,920, Care-needs level 5; JPY 360,650) depending on each
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27
28 178 care-needs level or each ratio of copayment (10% or 20%) if the answers were over it.

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31 179 These costs were substituted by a median of each category, and we calculated the
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34 180 weighted average as the following formula:
$$\frac{\sum_{i=0}^k (\text{median of category}_i) * n_i}{\sum n}$$

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36
37 181 All costs were converted from Japanese yen to US dollars using the purchasing power
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40 182 parity rate in 2016 (¥102 = \$1) provided by the Organization for Economic Cooperation
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42
43 183 and Development.

44 45 184 *2.5. Inclusion and exclusion criteria*

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48 185 With respondents, we only focused on community settings for people with dementia
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51 186 who lived in their own home. We excluded respondents based on the following criteria:
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54 187 (1) people with dementia who were hospitalized or lived in nursing home, (2) lack of data
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57 188 about out-of-pocket payments for LTC services or care-needs levels, (3) contradictions
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6 189 in relationships between caregivers and people with dementia, and (4) contradictions in
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9 190 care time (over 24 hours). When the age difference was less than 15 years and the person
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12 191 with dementia was a parent or child (not in-law), these cases were identified as
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15 192 contradictions.

18 193 *2.6. Statistical analysis*

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21 194 We conducted descriptive analysis for characteristics of people with dementia and
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24 195 caregivers. We then stratified the informal care time and dementia care costs by the care-
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26
27 196 needs level and cohabitation to test our hypothesis that high care-needs level or people
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30 197 who lives with caregivers need more informal care time. In this description, we didn't
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32
33 198 adjusted informal care time by caregivers' contribution rate.

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36 199 Also, we used chi-square automatic interaction detection (CHAID) analysis to identify
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39 200 the characteristics of people with dementia and caregivers who needed more care services.

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42 201 In CHAID analysis, the dependent variable would be divided into sub-groups by the most
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45 202 explanatory independent variables. These groups could be formed by any possible
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48 203 combination with all independent variables. Especially, we conducted an exhaustive
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51 204 CHAID analysis that repeats the trial until it finds the optimal combination of all
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54 205 independent variables. The CHAID dendograms provide a visual depiction of criteria and
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57 206 predictor variable interactions that might not be detected in traditional analytic procedures.
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6 207 We set informal care costs, out-of-pocket payments for LTC services covered by
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9 208 insurance and out-of-pocket payments for LTC services not covered by insurance as
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12 209 dependent variables. Then, we used the characteristics of people with dementia (age, sex,
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15 210 care-need level, dementia types, ADL and IADL functions, and primary disease as the
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18 211 reason for care), the characteristics of caregivers (age, sex, marital status, children,
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21 212 cohabitation with people with dementia, visiting time, relationship to people with
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24 213 dementia, and occupation), and economic factors (the ratio of copayments for healthcare
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27 214 services and family income of caregivers). We treated the ratio of copayments for
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30 215 healthcare services as income proxy variable because this ratio was decided by income of
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33 216 people with dementia. We set the following criteria: tree depth was limited to three levels,
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36 217 no group smaller than 100 was split, no group smaller than 30 was formed, and the p-
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39 218 value for all statistical tests was under 0.05.

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42 219 All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan Inc.,
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45 220 Tokyo, Japan).

48 221 *2.6. Ethical considerations and consents*

51 222 This study was approved by the Ethics committee of Kyoto University Graduate School
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54 223 of Medicine (R0487). All participants were volunteers and they were informed that there
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57 224 was no obligation to participate in the study, and only people who consented to this study
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6 225 completed the questionnaire.
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9 226 *2.7. Patient and public involvement*
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12 227 Patients were not formally involved in this study; however, their caregivers participated
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15 228 in our online-based questionnaire survey. Caregivers, who constituted the online panel,
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18 229 were sent the invitation by the Internet research company. Patients and their caregivers
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21 230 can view the results of this study when it is published in a peer-reviewed journal.
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24 231 **3. Results**
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27 232 *3.1. Characteristics of people with dementia and their caregivers*
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30 233 A total of 3,916 caregivers answered the questionnaire. We focused only on people
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33 234 with dementia who lived in their own home (n=2277). However, we excluded the data
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36 235 according to the criteria and the final sample comprised 1,383 respondents (Figure 1).
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39 236 Table 1 shows the characteristics of people with dementia and their caregivers. More
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42 237 than half of the people with dementia were female (66.7%), and the mean age was 81.8
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45 238 years. In contrast, more than half of the caregivers were male (61.7%), and the mean age
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48 239 was 52.2 years. 1,233 people (89.2%) responded that ADL functions such as meals and
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51 240 toilet use could be managed by themselves, while IADL functions such as cleaning and
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54 241 shopping could be done by one person in the same way. There were only 788 people
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57 242 (57.0%) who did the latter by themselves.
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6 243 *3.2. Informal care time and costs of dementia care*
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9 244 The mean daily informal care time was 9.36 hours in total. The time for only ADL was
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12 245 4.97 hours and for only IADL was 4.39 hours. On the other hand, monthly informal care
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15 246 time (ADL+IADL) was 166.32 hours. Table 2 shows the differences in daily informal
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18 247 care time and personal cost of dementia care among the care-need levels. In this table, we
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21 248 didn't adjust by contribution rate. Informal care times increased with care-needs levels,
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23
24 249 especially in ADL. Out-of-pocket payments for LTC services were less than informal
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27 250 care costs in all of the care-needs levels.
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32 252 *3.3. Classification with classification trees*
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35 253 Figure 2 shows the results of CHAID analysis for informal care costs. Informal care
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38 254 costs were related to caregivers' employment status, cohabitation, age, and care-needs
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41 255 levels or ADL function of people with dementia. When the caregiver acquired family care
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44 256 leave, informal care cost was the highest (node 2). For the caregivers who were between
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46
47 257 43-52 years old (node 12) and worked outside the home as well as cohabited with people
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49
50 258 with dementia, informal care costs were high, similar to caregivers who acquired family
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53 259 care leave (node 2). Even if the caregiver did not work, informal care costs were higher
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56 260 with high care-needs levels (node 6-8). The costs for cohabiting caregivers (node 5) were
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59 261 higher than for those not cohabiting (node 4). For those not cohabiting and the person
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6 262 with dementia could not walk without assistance (node 9), informal care costs were higher
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9 263 than for those that could walk (node 10) .
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12 264 Out-of-pocket payments for LTC services covered by insurance were related to care-
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15 265 need levels, ADL or IADL functions, sex (both the people with dementia and caregivers)
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18 266 and caregivers' household incomes (Figure 3). Especially, if the people with dementia
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21 267 could bathe or use the toilet by themselves, out-of-pocket payments would be about 65%
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24 268 lower (nodes 9-10, 15-18). On the other hand, if out-of-pocket payments were not covered
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27 269 by insurance, they were related to caregivers' household incomes, income proxy variable,
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30 270 ADL or IADL functions of people with dementia, and age of people with dementia
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33 271 (Figure 4). Both the out-of-pocket payments that were covered by insurance and those
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36 272 that were not were related to caregivers' house hold income or ADL functions which
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39 273 affected the ability to pay and service use volume.
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43 44 275 **4. Discussion**

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47 276 In this study, we first demonstrated that informal care time for ADL or IADL functions
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50 277 increased with high care-needs levels as our hypothesis stipulated (Care-need level 1:
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53 278 2.2hours, level 3: 3.4 hours. level 5: 4.6 hours). Second, we established that the
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56 279 combination of characteristics of both people with dementia and their caregivers were
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59 280 related to dementia care costs through the classification tree analysis. Caregivers'
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6 281 employment and cohabitation status were mainly related to informal care costs, and the
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9 282 costs were the highest when caregivers took nursing care leave, which caregivers leave
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12 283 work due to caregiving. Furthermore, when caregivers worked at an occupation and lived
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15 284 separately, or the people with dementia could not walk, the costs doubled. Out-of-pocket
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18 285 payments for LTC services covered by insurance were mainly related to care-need levels
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21 286 and ADL and IADL functions. In the case of low care-needs levels, where care was
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24 287 needed for toileting or bathing, high out-of-pocket payments were required for LTC
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27 288 insurance services. On the other hand, out-of-pocket payments were related to caregivers'
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30 289 household income levels or income proxy variable. Caregivers with high annual incomes
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33 290 (more than \$117,648 US) made out-of-pocket payments for dementia care of full amounts
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36 291 that were two to five times more than others.

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39 292 Informal care costs were mainly related to caregivers' characteristics such as
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42 293 employment or cohabitation status in the classification tree, which illustrated related
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45 294 factors by order of precedence. In many previous studies, ADL functions or dementia
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48 295 severity were explained as related factors in regression models [9–12]. Some studies
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51 296 showed caregivers' characteristics such as employment status were related to informal
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54 297 care costs [9,29,30], but few studies considered all of the caregivers' characteristics. Thus,
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57 298 caregiver factors may be as important as factors related to people with dementia are.
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6 299 Furthermore, we considered the combination of characteristics of both people with
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9 300 dementia and their caregivers. For example, informal care costs doubled when caregivers
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12 301 lived separately and people with dementia could not walk. Many previous studies
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15 302 established the determinants by regression analysis[9,12,31–34]. Although it is possible
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18 303 to understand the influence on the objective variable adjusted in the multivariate by
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21 304 regression analysis, the combinations between explanatory variables have not been
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24 305 clarified. CHAID analysis provided the classification only for related characteristics in
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27 306 the outcome. Such combinations suggest that support should be provided to caregivers
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30 307 who cannot live with people with dementia or caregivers who are not employed (Figure
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33 308 2, Node 3-4).

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36 309 The association between out-of-pocket payments for LTC services covered by
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39 310 insurance and care-need levels is reasonable because the benefit limit standard amounts
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42 311 for formal care services at home are decided in relation to care-need levels[35]. In
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45 312 addition, when people with dementia had a high care-needs level and their caregiver's
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48 313 household income was high, out-of-pocket payments were high. Because the
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51 314 determination of service usage within the limit amount is a free contract, people with
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54 315 dementia and their caregivers may decide how they use formal care services depending
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57 316 on how much they can pay for services. High care-needs levels [36], age[10,34,36,37]
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6 317 and sex[10,36] were related to the high costs of LTC services. Even for low care-needs
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9 318 levels, the cost may be high when people with dementia need assistance with bathing or
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12 319 toileting. This was affected by LTC insurance services providing specific substitutions,
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15 320 such as bath assistance, and also Ku et al.'s or Dodel et al.'s ADL functions were related
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18 321 to the social care costs[9,30].
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21 322 Similarly, economic variables such as household income and income proxy variable
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24 323 were mainly related to out-of-pocket payments for LTC services not covered by insurance
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27 324 (Figure 4). This is because people must pay the full amount if they use LTC services
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29
30 325 without insurance. In the United States, high copayments are required for the use of LTC
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33 326 services; however, these copayments were related to age, sex, and comorbidities in the
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36 327 cohort study [37]. A part of the result of Hurd et al. was similar to our results in the case
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39 328 of the payments that were covered by insurance for the use of LTC services. Out-of-
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42 329 pocket payments not covered by insurance might occur for over the limit standard
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45 330 amounts or the use of LTC services not covered by insurance (e.g. feeding service[38]).
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48 331 According to the questionnaire responses, people tended to pay for expendables such as
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51 332 diapers, employment of housekeepers, and home repair such as handrail installation as
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54 333 out-of-pocket payments not covered by LTC insurance. Furthermore, except when
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57 334 caregivers' income was high, the cost did not change significantly due to differences in
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6 335 ADL and IADL functions as it did for the payments that were covered by insurance.
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9 336 These application examples were not really affected by ADL or IADL functions.
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12 337 From the viewpoint of independent variables, if people with dementia lacked some
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15 338 ADL function, then costs might be higher but in the case of IADL functions this was
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18 339 reversed. There is a possibility that some services are used to support the independent
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21 340 lives of people with dementia. Some people with dementia who can do housework by
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24 341 themselves might move or walk around more, and therefore use more LTC services like
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27 342 commuting for care (day service) or commuting for rehabilitation. Also, care-need levels
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30 343 were not related to out-of-pocket payments not covered by insurance. The above
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33 344 application examples were also not related to care-needs levels. The relationship of
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36 345 cohabitation or employment status was the same as in previous studies [9,29,32]. While
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39 346 differences of burden of dementia care depended on the dementia types that existed and
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42 347 were pointed out [24], dementia types were not related to any other factors in this study.
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45 348 In our CHAID analysis, family caregivers' economic status or severity (care-needs levels)
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48 349 might have been more important than dementia types to dementia care costs. In creating
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51 350 policy for LTC services in an aging society, we must understand the actual conditions
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54 351 from not only a societal but also a personal perspective. This is true even if from a societal
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57 352 viewpoint, the societal cost of dementia care in the community has been established by
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6 353 other countries to be greater than that in institutional care [39]. Furthermore, we need a
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9 354 wide range of perspectives of stakeholders to discuss the dementia care system, while
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12 355 almost all studies of economic burden of dementia stood on societal or payers'
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15 356 viewpoint[7,19–21]. Then, as a first step, we need to understand what people with
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18 357 dementia and their family caregivers are already spending too much money on. We need
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21 358 to recognize the complicated combination of characteristics associated with people with
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24 359 dementia and their caregivers. To this point, the results of this classification could be
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27 360 useful to understanding which situation requires more resources depending on cost types.
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30 361 Our results may suggest that a sustainable dementia care system in Japan should be
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33 362 reconstructed from a personal viewpoint.

36 363 There are some limitations to this study. First, we conducted an online questionnaire
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39 364 survey with caregivers of people with dementia. Traditionally, respondents who use the
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42 365 Internet tend to be male and relatively young, reflecting the general characteristics of
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45 366 online research [40–42]. The sample may therefore not be representative of all caregivers
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48 367 because the sample is limited to those who have access to the Internet and are registered
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51 368 with an Internet research company [43]. Certainly, we cannot extrapolate the
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54 369 representative value in each node of the CHAID tree to the population as a whole.
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57 370 However, this study focused on finding a combination of independent variables related to
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6 371 the dependent variables (informal care cost and financial burden), taking into account the
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9 372 interaction between multiple independent variables. The significance of subgroups made
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12 373 by combinations of variables may not change significantly even if the population changes.
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15 374 Therefore, in this study, influence due to the difference between this sample and general
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18 375 public is not considered to be a practical problem. However, further research (e.g. a
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21 376 paper-based questionnaire survey mailed to the family caregivers association) to collect
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24 377 representative samples might be needed in the future. Second, it was impossible to
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27 378 measure the response rate in this study. Samples were collected from an online panel
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30 379 until the target number set in each age category was achieved. Third, we didn't consider
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33 380 the subjective burden of care and depressive symptoms. These mental burdens are
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36 381 considered to be important factors in explaining the actual state of care costs, and many
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39 382 previous studies in Japan have covered subjective costs [44–46]. In the future, in addition
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42 383 to the burden of time and money, it would be preferable to measure subjective burdens.
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45 384 Fourth, we estimated informal care costs only by the opportunity cost approach. Some
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48 385 studies indicated results estimated by both opportunity cost approach and replacement
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51 386 cost approach. The opportunity cost approach might be underestimated in comparison to
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54 387 the replacement approach[9,37]

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6 389 **Conclusions**

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9 390 This study clarified the difference in dementia care costs between classified subgroups
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12 391 by considering the combination of the situations of both people with dementia and their
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15 392 caregivers. Informal care costs were related to caregivers' employment and cohabitation
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18 393 status rather to the situation of people with dementia. On the other hand, out-of-pocket
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21 394 payments for long-term care services were related to care-needs levels and family
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24 395 economic status. These classifications will be useful in understanding which situation
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27 396 represents a greater economic burden, and helpful in improving the sustainability of the
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30 397 dementia care system in Japan.

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36 399 **Footnotes**

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39 400 *Abbreviations*

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42 401 LTC: Long-Term Care

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45 402 RUD: Resource Utilization in Dementia

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48 403 ADL: Activities of Daily Life

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51 404 IADL: Instrumental Activities of Daily Life

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54 405 CHAID analysis: chi-square automatic interaction detection analysis
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6 406 *Authors' contribution*

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9 407 TN, SN and YI designed the study. All authors discussed for preparing the questionnaire.

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12 408 TN mainly analyzed all data, and HU, SK, AW and YI advised for analysis. TN prepared

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14
15 409 the draft of the manuscript, then all authors contributed to rewrite it. All authors read and

16
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18 410 approved the final manuscript.

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34
35
36 416 in the study design, data collection and analysis, decision to publish, or preparation of the

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39 417 manuscript.

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42 418 *Competing interest*

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45 419 None declared.

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51 421 None.

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54 422 *Conflicts of interest*

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57 423 None.

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424 *Data sharing statement*

425 No additional data are available.

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For peer review only

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7 **Figure 1: Selection process for the analysis**

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9 This diagram shows the flow of participants who we focused on.
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12 **Figure 2: Classification tree of chi-square automatic interaction detection for**
13 **informal care costs**
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17 The dendogram illustrates the combinations of independent variables to clarify who need
18 or provide more informal care.
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22 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
23 Living; SD, Standard deviation; LTC, Long-term care
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30 **Figure 3: Classification tree of chi-square automatic interaction detection for out-**
31 **of-pocket payments for LTC services covered by insurance**
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35 The dendogram illustrates the combinations of independent variables to clarify who need
36 more LTC insurance services.
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41 Living; SD, Standard deviation; LTC, Long-term care
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48 **Figure 4: Classification tree of chi-square automatic interaction detection for out-**
49 **of-pocket payments for LTC services not covered by insurance**
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53 The dendogram illustrates the combinations of independent variables to clarify who need
54 more LTC services without insurance.
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Table 1 Characteristics of people with dementia and caregivers

People with Dementia		N=1383
Age, mean±SD, y		81.8±10.3
Sex, n (%)		
Female		922 (66.7)
Male		461 (33.3)
Care-needs level, n (%)		
Support-Needs Level 1-2		253 (18.3)
Care-Needs Level 1		310 (22.4)
Care-Needs Level 2		335 (24.2)
Care-Needs Level 3		258 (18.7)
Care-Needs Level 4		122 (8.8)
Care-Needs Level 5		105 (7.6)
ADL/IADL functional capabilities		
ADL score (0-6), mean±SD		3.2±2.0
IADL score (0-7), mean±SD		1.3±1.6
Ratio of copayments for healthcare services, n(%)		
10%		961 (69.5)
20%		137 (9.9)
30%		157 (11.4)
Unknown		128 (9.3)
Types of Dementia, n(%)		
Alzheimer's disease		751 (54.3)
Caregivers		
Age, mean ± SD		52.2±13.1
Sex, n (%)		
Female		530 (38.3)
Male		853 (61.7)
Relationship, n (%)		
Mother		575 (41.6)
Mother-in-law		169 (12.2)
Father		288 (20.8)
Father-in-law		90 (6.5)
Spouse		99 (7.2)
Sibling		11 (0.8)
Child		10 (0.7)
Friend		5 (0.4)
Other (including grandparents)		136 (9.8)
Contribution level for caregiving, n (%)		
1-20%		395 (28.6)
21-40%		355 (25.7)
41-60%		241 (17.4)
61-80%		166 (12.0)
81-100%		226 (16.3)
Currently employed, n (%)		532 (38.5)

SD: Standard deviation, ADL: Activities of Daily Living, IADL: Instrumental Activities

of Daily Living

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574 **Table 2 Daily informal care time and personal costs of dementia care sorted by care-needs levels**

			Support- required level	Care-need level 1	Care-need level 2	Care-need level 3	Care-need level 4	Care-need level 5
Informal care time (hours/day)	ADL	Mean [SD]	2.56 [3.23]	2.23 [2.54]	2.92 [2.90]	3.44 [2.90]	3.99 [2.40]	4.60 [3.85]
		Median [IQR]	1.67 [2.00]	1.50 [2.50]	2.00 [3.00]	3.00 [3.50]	4.00 [3.00]	3.33 [4.00]
	IADL	Mean [SD]	2.35 [2.62]	2.46 [3.05]	2.88 [3.26]	2.82 [2.92]	3.03 [2.59]	3.45 [3.77]
		Median [IQR]	2.00 [2.00]	1.50 [2.00]	2.00 [2.00]	2.00 [2.50]	2.00 [3.13]	2.00 [4.00]
Personal cost of dementia care (US\$)	Informal care cost	Mean [SD]	1518 [2017]	1271 [1526]	1754 [1982]	2181 [2220]	2112 [2104]	2672 [2314]
		Median [IQR]	747 [1646]	709 [1440]	1090 [1697]	1366 [2459]	1535 [1466]	1939 [2240]
	OPP for LTC services covered by insurance	Mean [SD]	148 [190]	158 [174]	244 [209]	313 [217]	301 [202]	318 [218]
		Median [IQR]	49 [172]	49 [123]	172 [319]	368 [441]	368 [196]	368 [441]
	OPP for care services not covered by insurance	Mean [SD]	158 [336]	95 [156]	278 [695]	303 [543]	241 [579]	352 [998]
		Median [IQR]	49 [172]	49 [172]	49 [368]	172 [319]	49 [368]	49 [368]

575 ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, SD: Standard deviation, IQR: Interquartile range

576 OPP: Out-of-pocket payments LTC: Long-term care

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Figure 1

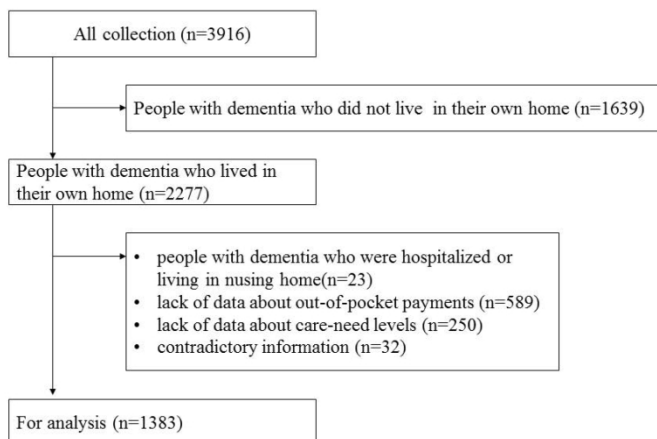


Figure 1: Selection process for the analysis
This diagram shows the flow of participants who we focused on.

338x190mm (300 x 300 DPI)

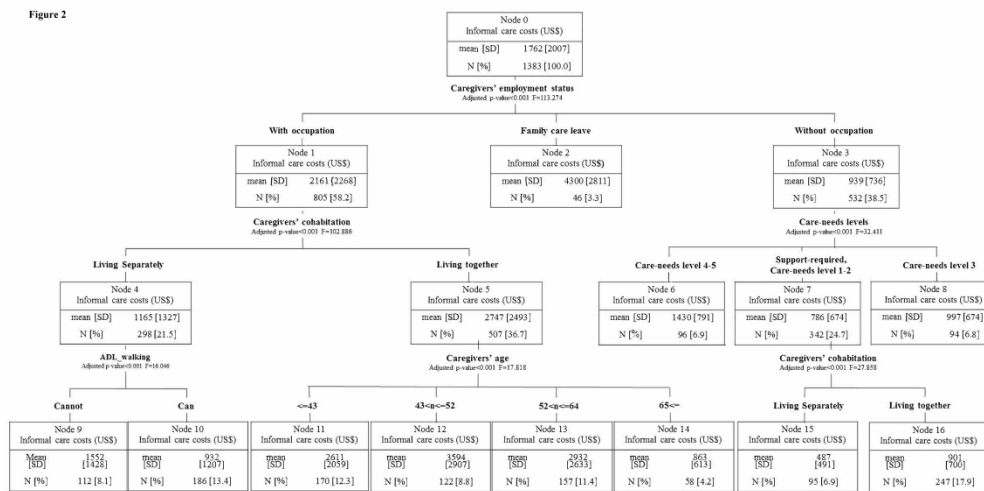


Figure 2: Classification tree of chi-square automatic interaction detection for informal care costs
 The dendrogram illustrates the combinations of independent variables to clarify who need or provide more informal care.

Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

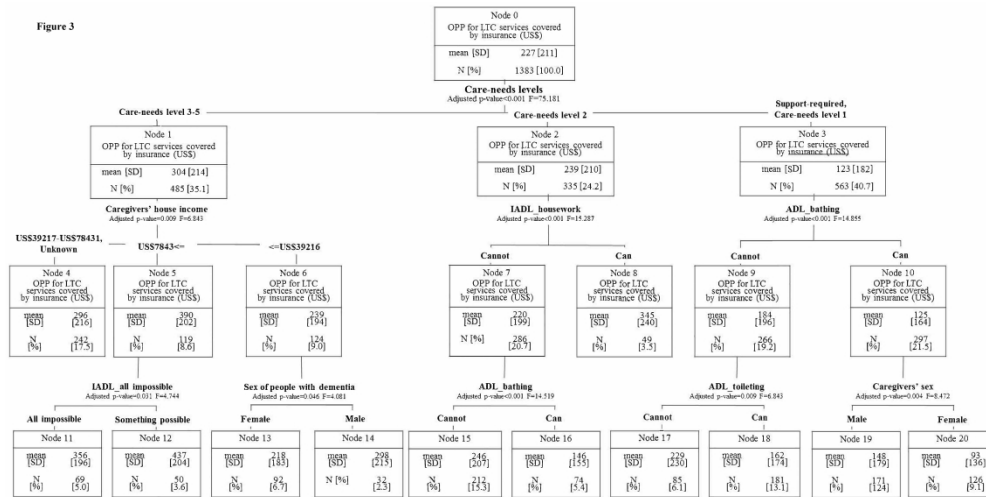


Figure 3: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services covered by insurance
 The dendrogram illustrates the combinations of independent variables to clarify who need more LTC insurance services.
 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

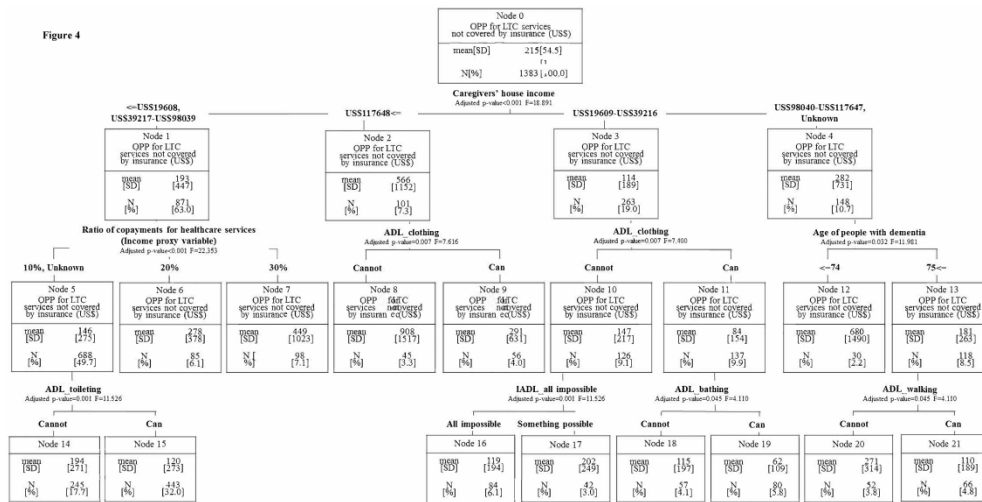


Figure 4: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services not covered by insurance
The dendrogram illustrates the combinations of independent variables to clarify who need more LTC services without insurance.
Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - p.1-2 (b) Provide in the abstract an informative and balanced summary of what was done and what was found – p.2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – p.4-5
Objectives	3	State specific objectives, including any prespecified hypotheses – p.5
Methods		
Study design	4	Present key elements of study design early in the paper – p.5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – p.6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants – p.6 and p.10
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – p.6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group – p.6, 9
Bias	9	Describe any efforts to address potential sources of bias – p.18-19
Study size	10	Explain how the study size was arrived at – p.6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – p.11-12
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding – p.11-12 (b) Describe any methods used to examine subgroups and interactions – p.11-12 (c) Explain how missing data were addressed-p.10 (d) If applicable, describe analytical methods taking account of sampling strategy – Non applicable (e) Describe any sensitivity analyses – Non applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – p.12-13 (b) Give reasons for non-participation at each stage – Non applicable (c) Consider use of a flow diagram - Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – p.13 and Table 1 (b) Indicate number of participants with missing data for each variable of interest – Non applicable
Outcome data	15*	Report numbers of outcome events or summary measures – Table 2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included –p.12-13

		(b) Report category boundaries when continuous variables were categorized – Non applicable
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – Non applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses – p.13, Figure2-4
Discussion		
Key results	18	Summarise key results with reference to study objectives - p,14-15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – p.18-19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – p.15-18
Generalisability	21	Discuss the generalisability (external validity) of the study results –p.18-19
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - p.21

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Classification tree model of the personal economic burden of dementia care by related factors of both people with dementia and caregivers in Japan: A cross-sectional online survey

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9 2 dementia care by related factors of both people with dementia and
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12 3 caregivers in Japan: A cross-sectional online survey
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57 18 Word counts: 3750 words
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6 19 **Abstract**

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8 20 **Objective:**

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11 21 The purpose of this study was to clarify the micro-level determinants of the economic
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14 22 burden of dementia care at home in Japanese community settings by classifying them into
15
16
17 23 subgroups of factors related to people with dementia and their caregivers.

18
19
20 24 **Design:**

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23 25 A cross-sectional online survey.

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25
26 26 **Participants:**

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28 27 4313 panels of Japanese research company who fulfilled the following criteria: (1) aged
29
30
31
32 28 30 years or older, (2) non-professional caregiver of someone with dementia, (3) caring
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34
35 29 for only one person with dementia, and (4) having no conflicts of interest with advertising
36
37
38 30 or marketing research entities.

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41 31 **Primary outcome measures:**

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44 32 Informal care costs and out-of-pocket payments for long-term care services

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47 33 **Results:**

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50 34 From 4313 respondents, only 1383 caregivers in community-settings were included in
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52
53 35 this analysis. We conducted a chi-square automatic interaction detection analysis to
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56 36 identify the factors related to each cost (informal care costs and out-of-pocket payments
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59 37 for long-term care services) divided into sub categories. In the resultant classifications,
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6 38 informal care cost was mainly related to caregivers' employment status. When caregivers
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9 39 acquired family care leave, informal care costs were the highest. On the other hand, out-
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12 40 of-pocket payments for long-term care were related to care-need levels and family
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14
15 41 economic status. ADL and IADL functions such as bathing, toileting, and cleaning were
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17
18 42 related to all costs.
19

20 21 43 **Conclusion**

22
23
24 44 This study clarified the difference in dementia care costs between classified subgroups
25
26
27 45 by considering the combination of the situations of both people with dementia and their
28
29
30 46 caregivers. Informal care costs were related to caregivers' employment and cohabitation
31
32
33 47 status rather to the situations of people with dementia. On the other hand, out-of-pocket
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35
36 48 payments for long-term care services were related to care-need levels and family
37
38
39 49 economic status. These classifications will be useful in understanding which situation
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41
42 50 represents a greater economic burden, and helpful in improving the sustainability of the
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45 51 dementia care system in Japan.
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7 **53 Strengths and limitations of this study**
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9 ● This study clarified the difference in dementia care costs between classified
10 subgroups by considering the combination of the situations of both people with
11 dementia and their caregivers.
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17 ● The chi-square automatic interaction detection dendograms provide a visual
18 depiction of criteria and predictor variable interactions that might not be detected in
19 traditional analytic procedures.
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26 ● The sample may therefore not be representative of all caregivers because the sample
27 is limited to those who have access to the Internet and are registered with an Internet
28 research company.
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35 ● We only assessed objective burden of dementia care such as informal care time or
36 costs, then we didn't consider the subjective burden of care and depressive symptoms.
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66 **1. Introduction**

67 In the aging society of Japan, it is estimated that there are approximately 4.7 million
68 people living with dementia and that there will be approximately 7 million people with
69 dementia in 2025 [1]. Given that it is also estimated that the total number of people with
70 dementia throughout the world will double every 20 years [2], we need to reconsider how
71 to prepare for dementia care in the community.

72 Long-term care (LTC) services in Japan used by people with dementia in home care
73 can be classified into three main types: (1) LTC insurance services, (3) LTC services not
74 covered by insurance, and (3) informal care as mutual assistance by family members.

75 When a person with dementia uses the LTC insurance service, the user bears 10% or 20%
76 of the service expenses as out-of-pocket payments depending on the person's income
77 (Article 49-2 of the Long-Term Care Insurance Act). Aside from such copayments, when
78 LTC services not covered by insurance or exceeding the LTC insurance limit amount are
79 used, people must pay the full amount. Furthermore, it has been pointed out that informal
80 care is an important component of home care, yet it places a burden on caregivers [3,4].
81 Nevertheless, given the estimates of the societal costs of dementia care throughout the
82 world, the impact of informal care is essential [5,6].

83 The Japanese government recommends policies to shift to patient-centered and home-
84 centered care to reduce the fiscal burden of the insurance system on community-based

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6 85 integrated systems. While micro level of impact of dementia care has not been
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9 86 insufficiently understood[7], to construct a sustainable dementia care system, we clarified
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12 87 the personal economic burden of dementia care for different residence types and
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15 88 demonstrated that the cost at home in a community setting was equal to or higher than in
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18 89 various institutions[8]. Sustainable dementia care systems should be provided not only to
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21 90 benefit the government or insurance system but also to benefit people with dementia and
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24 91 their caregivers. Furthermore, although there are increasing dementia care costs related
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27 92 to the severity of dementia [9–12], it can be seen that the cost of dementia care increases
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30 93 through the interaction of characteristics or situations of people with dementia and their
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33 94 caregivers. Given this interaction, it is necessary to understand the actual conditions by
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36 95 classifying cases where the greatest economic burdens in dementia care are felt.

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39 96 Therefore, the purpose of this study is to clarify the micro-level determinants of the
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42 97 economic burden of dementia care at home in community settings by classifying them
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45 98 into subgroups of factors related to people with dementia and their caregivers.

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100 **2. Methods**

101 This study was a cross-sectional study, based on a self-rated, online questionnaire
102 survey. The economic burden of dementia care in this study is roughly divided into
103 informal care costs as opportunity costs and out-of-pocket payments that people actually
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9 105 *2.1. Online survey for data collection on people with dementia and their caregivers*

10 106 In this cross-sectional study, we conducted an online questionnaire survey from March
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12 107 3 to March 14, 2016 in cooperation with a commercial research company (Automatic
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18 108 Internet Research System, Macromill, Inc., Japan). Potential participants fulfilled the
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21 109 following criteria: (1) aged 30 years or older, (2) non-professional caregiver of someone
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24 110 with dementia, (3) caring for only one person with dementia, and (4) having no conflicts
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26
27 111 of interest with advertising or marketing research entities. A total of 3,600 participants
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30 112 were recruited from the research company's registrants and divided into different age
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33 113 groups (850 participants each in the groups aged in 30's, 40's, 50's, and 60's; 200
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36 114 participants in the group aged ≥ 70 years). We excluded caregivers under 29 years of age
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39 115 because, in Japan, they are estimated to represent only 2% of all caregivers [13].

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42 116 *2.2. Questionnaire*

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45 117 Resource Utilization in Dementia (RUD) [14,15] is a widely used tool to collect data
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47
48 118 about resource use in persons with dementia and their caregivers [15]. RUD is available
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51 119 in more than 60 languages and it is widely used throughout the world. In this study, we
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54 120 used RUD (Japanese version) items related to the characteristics of people with dementia
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57 121 and their caregivers, informal care time, employed situation of caregivers, residential
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6 122 types of people with dementia, and resource use of nursing care services. We added items
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9 123 related to LTC services and residential types. The questionnaire components were divided
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12 124 into four categories: (1) characteristics of people with dementia, (2) caregivers' situations
13
14
15 125 (e.g., employment and cohabitation status), (3) informal care duration and (4) frequency
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18 126 of utilization of LTC services.

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21 127 In this project, we could not get information about severity of dementia data because it
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24 128 was regarded as too difficult for caregivers to estimate that. However, we asked for
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27 129 substantial information about care-needs levels. Care needs reflect function, which is a
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30 130 stronger explanatory factor for costs than cognition [16]. Care-needs levels (Support-
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33 131 needs levels 1-2, Care-needs levels 1-5) determine whether a person is qualified to apply
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36 132 for LTC insurance (Article 27 and 32 of the Long-Term Care Insurance Act). Once an
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39 133 insured person applies to use any LTC service, their mental and physical status is first be
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42 134 assessed by certified researchers using a basic checklist. Based on this checklist, care-
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45 135 need times are estimated using an evidence-based computer algorithm. This algorithm
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48 136 was created from the data on how much LTC services were required in 48 hours for more
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51 137 than 3,000 elderly people as a one-minute time study [17]. After estimating the care-needs
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54 138 time, care-needs levels were determined by an expert panel to indicate the amount of care
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57 139 required by each person while taking into consideration their symptoms and functional
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6 140 capability. High care-needs levels indicate increasing dependency and requirement for
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9 141 LTC services [18]. Care-need levels also affect the base amount of the maximum payment
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12 142 for LTC services allowance categories covered by insurance.
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15 143 *2.3. Informal care time*

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18 144 In the questionnaire, informal care time was divided in three domains; support for
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21 145 Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and
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24 146 Supervision [15]. We asked for the mean caregiving time per day and mean caregiving
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26
27 147 days per week in the past 30 days. We then multiplied the mean daily caregiving time and
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30 148 caregiving days per week to calculate both weekly and monthly informal care time.
31
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33 149 Supervision time was excluded in calculating informal care time and costs because
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36 150 supervision could be done simultaneously when caregiving for ADL and IADL functions,
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39 151 or in other housekeeping for people without dementia and other family members.
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42 152 *2.4. Cost estimation*

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45 153 In this study, we identified three costs as follows: informal care costs, out-of-pocket
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48 154 payments for LTC services covered by insurance (copayments), and out-of-pocket
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51 155 payments for LTC services not covered by insurance. To calculate the informal care costs,
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53
54 156 there are two methods that are frequently used: the “opportunity cost” and “replacement
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57 157 cost” approaches [19–21]. With the opportunity cost approach it is assumed that there is
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6 158 an alternative use of caregiving time (such as paid work) and thus estimates the costs due
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9 159 to this lost opportunity, whereas the replacement cost approach assumes that informal
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12 160 care services can be valued similarly to home care services provided by professional
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15 161 caregivers. Even though many previous studies on the economic valuation of informal
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18 162 care have used the replacement cost approach [20], the ‘opportunity cost approach’ is
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21 163 recommended by the developers of RUD for estimating informal care costs [2,5,22]. We
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24 164 used the opportunity cost approach to assess informal care time as forgone wages for
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27 165 caregivers [2,5,9]. We used caregivers’ monthly mean wages stratified by sex and age to
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30 166 value informal care. We assessed informal care costs for caregivers who were not working
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33 167 or who were over 65 years of age at 30% of the mean wage of employed caregivers [23–
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36 168 26]. A maximum daily informal care time of 16 hours was assumed, in order to allow for
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39 169 other activities such as cooking for other family members and sleep [12,27,28].
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42 170 Caregivers were asked to state their contribution to the total informal care in 5-point scale
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45 171 of 20%. In order to treat all caregivers as primary caregivers and estimate the costs
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48 172 associated with all informal care provided to a patient, we adjusted the informal care time
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51 173 by dividing its time by the median of these contribution levels, according to RUD
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54 174 instructions. This adjustment of informal care time was done only when calculating the
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57 175 informal care costs.
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6 176 Out-of-pocket payments for LTC services both covered and not covered by insurance
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9 177 were included in the questionnaire. We asked for these out-of-pocket payments through
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12 178 categories that were easy to answer (no payments, under JPY9,999, JPY10,000–24,999,
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15 179 JPY25,000–49,999, JPY50,000–74,999, JPY75,000–99,999, JPY100,000–124,999,
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18 180 JPY125,000–149,999, JPY150,000–299,999, JPY300,000–499,999, and over
19
20
21 181 JPY500,000). We adjusted the answers by capping the upper limit of the limit amount
22
23
24 182 (Care-needs level 1; JPY166,920, Care-needs level 5; JPY 360,650) depending on each
25
26
27 183 care-needs level or each ratio of copayment (10% or 20%) if the answers were over it.
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30 184 These costs were substituted by a median of each category, and we calculated the
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33 185 weighted average as the following formula:
$$\frac{\sum_{i=0}^k (\text{median of category}_i) * n_i}{\sum n}$$

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36 186 All costs were converted from Japanese yen to US dollars using the purchasing power
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38
39 187 parity rate in 2016 (¥102 = \$1) provided by the Organization for Economic Cooperation
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41
42 188 and Development.

45 189 *2.5. Inclusion and exclusion criteria*

47
48 190 With respondents, we only focused on community settings for people with dementia
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50
51 191 who lived in their own home. We excluded respondents based on the following criteria:
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54 192 (1) people with dementia who were hospitalized or lived in nursing home, (2) lack of data
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57 193 about out-of-pocket payments for LTC services or care-needs levels, (3) contradictions
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6 194 in relationships between caregivers and people with dementia, and (4) contradictions in
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9 195 care time (over 24 hours). When the age difference was less than 15 years and the person
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12 196 with dementia was a parent or child (not in-law), these cases were identified as
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15 197 contradictions.

18 198 *2.6. Statistical analysis*

20
21 199 We conducted descriptive analysis for characteristics of people with dementia and
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23
24 200 caregivers. We then stratified the informal care time and dementia care costs by the care-
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26
27 201 needs level and cohabitation to test our hypothesis that high care-needs level or people
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29
30 202 who lives with caregivers need more informal care time. In this description, we didn't
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32
33 203 adjusted informal care time by caregivers' contribution rate.

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36 204 Also, we used chi-square automatic interaction detection (CHAID) analysis to identify
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39 205 the characteristics of people with dementia and caregivers who needed more care services.
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42 206 In CHAID analysis, the dependent variable would be divided into sub-groups by the most
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45 207 explanatory independent variables. These groups could be formed by any possible
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48 208 combination with all independent variables. Especially, we conducted an exhaustive
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50
51 209 CHAID analysis that repeats the trial until it finds the optimal combination of all
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54 210 independent variables. The CHAID dendograms provide a visual depiction of criteria and
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57 211 predictor variable interactions that might not be detected in traditional analytic procedures.
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6 212 We set informal care costs, out-of-pocket payments for LTC services covered by
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9 213 insurance and out-of-pocket payments for LTC services not covered by insurance as
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12 214 dependent variables. Then, we used the characteristics of people with dementia (age, sex,
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15 215 care-need level, dementia types, ADL and IADL functions, and primary disease as the
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18 216 reason for care), the characteristics of caregivers (age, sex, marital status, children,
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21 217 cohabitation with people with dementia, visiting time, relationship to people with
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24 218 dementia, and occupation), and economic factors (the ratio of copayments for healthcare
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27 219 services and family income of caregivers). We treated the ratio of copayments for
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30 220 healthcare services as income proxy variable because this ratio was decided by income of
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32
33 221 people with dementia. We set the following criteria: tree depth was limited to three levels,
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36 222 no group smaller than 100 was split, no group smaller than 30 was formed, and the p-
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39 223 value for all statistical tests was under 0.05.

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41
42 224 All data were analyzed using IBM SPSS Statistics 23.0 for Windows (SPSS Japan Inc.,
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44
45 225 Tokyo, Japan).

46 47 48 226 *2.6. Ethical considerations and consents*

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51 227 This study was approved by the Ethics committee of Kyoto University Graduate School
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53
54 228 of Medicine (R0487). All participants were volunteers and they were informed that there
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57 229 was no obligation to participate in the study, and only people who consented to this study
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6 230 completed the questionnaire.
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9 231 *2.7. Patient and public involvement*
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12 232 Patients were not formally involved in this study; however, their caregivers participated
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15 233 in our online-based questionnaire survey. Caregivers, who constituted the online panel,
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18 234 were sent the invitation by the Internet research company. Patients and their caregivers
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21 235 can view the results of this study when it is published in a peer-reviewed journal.
22
23

24 236 **3. Results**
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26

27 237 *3.1. Characteristics of people with dementia and their caregivers*
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29

30 238 A total of 3,916 caregivers answered the questionnaire. We focused only on people
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33 239 with dementia who lived in their own home (n=2277). However, we excluded the data
34
35
36 240 according to the criteria and the final sample comprised 1,383 respondents (Figure 1).
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39 241 Table 1 shows the characteristics of people with dementia and their caregivers. More
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41
42 242 than half of the people with dementia were female (66.7%), and the mean age was 81.8
43
44
45 243 years. In contrast, more than half of the caregivers were male (61.7%), and the mean age
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47
48 244 was 52.2 years. 1,233 people (89.2%) responded that ADL functions such as meals and
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51 245 toilet use could be managed by themselves, while IADL functions such as cleaning and
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54 246 shopping could be done by one person in the same way. There were only 788 people
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57 247 (57.0%) who did the latter by themselves.
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6 248 *3.2. Informal care time and costs of dementia care*

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9 249 The mean daily informal care time was 9.36 hours in total. The time for only ADL was
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12 250 4.97 hours and for only IADL was 4.39 hours. On the other hand, monthly informal care
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15 251 time (ADL+IADL) was 166.32 hours. Table 2 shows the differences in daily informal
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17
18 252 care time and personal cost of dementia care among the care-need levels. In this table, we
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21 253 didn't adjust by contribution rate. Informal care times increased with care-needs levels,
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23
24 254 especially in ADL. Out-of-pocket payments for LTC services were less than informal
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27 255 care costs in all of the care-needs levels.

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32 257 *3.3. Classification with classification trees*

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35 258 Figure 2 shows the results of CHAID analysis for informal care costs. Informal care
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38 259 costs were related to caregivers' employment status, cohabitation, age, and care-needs
39
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41 260 levels or ADL function of people with dementia. When the caregiver acquired family care
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44 261 leave, informal care cost was the highest (node 2). For the caregivers who were between
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46
47 262 43-52 years old (node 12) and worked outside the home as well as cohabited with people
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49
50 263 with dementia, informal care costs were high, similar to caregivers who acquired family
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52
53 264 care leave (node 2). Even if the caregiver did not work, informal care costs were higher
54
55
56 265 with high care-needs levels (node 6-8). The costs for cohabiting caregivers (node 5) were
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59 266 higher than for those not cohabiting (node 4). For those not cohabiting and the person
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6 267 with dementia could not walk without assistance (node 9), informal care costs were higher
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9 268 than for those that could walk (node 10) .
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12 269 Out-of-pocket payments for LTC services covered by insurance were related to care-
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15 270 need levels, ADL or IADL functions, sex (both the people with dementia and caregivers)
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17
18 271 and caregivers' household incomes (Figure 3). Especially, if the people with dementia
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20
21 272 could bathe or use the toilet by themselves, out-of-pocket payments would be about 65%
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24 273 lower (nodes 9-10, 15-18). On the other hand, if out-of-pocket payments were not covered
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26
27 274 by insurance, they were related to caregivers' household incomes, income proxy variable,
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30 275 ADL or IADL functions of people with dementia, and age of people with dementia
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33 276 (Figure 4). Both the out-of-pocket payments that were covered by insurance and those
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36 277 that were not were related to caregivers' house hold income or ADL functions which
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39 278 affected the ability to pay and service use volume.
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44 280 **4. Discussion**

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46
47 281 In this study, we first demonstrated that informal care time for ADL or IADL functions
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50 282 increased with high care-needs levels as our hypothesis stipulated (Care-need level 1:
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53 283 2.2hours, level 3: 3.4 hours. level 5: 4.6 hours). Second, we established that the
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56 284 combination of characteristics of both people with dementia and their caregivers were
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59 285 related to dementia care costs through the classification tree analysis. Caregivers'
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6 286 employment and cohabitation status were mainly related to informal care costs, and the
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9 287 costs were the highest when caregivers took nursing care leave, which caregivers leave
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12 288 work due to caregiving. Furthermore, when caregivers worked at an occupation and lived
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15 289 separately, or the people with dementia could not walk, the costs doubled. Out-of-pocket
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18 290 payments for LTC services covered by insurance were mainly related to care-need levels
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21 291 and ADL and IADL functions. In the case of low care-needs levels, where care was
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24 292 needed for toileting or bathing, high out-of-pocket payments were required for LTC
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26
27 293 insurance services. On the other hand, out-of-pocket payments were related to caregivers'
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30 294 household income levels or income proxy variable. Caregivers with high annual incomes
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33 295 (more than \$117,648 US) made out-of-pocket payments for dementia care of full amounts
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36 296 that were two to five times more than others.

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39 297 Informal care costs were mainly related to caregivers' characteristics such as
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42 298 employment or cohabitation status in the classification tree, which illustrated related
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45 299 factors by order of precedence. In many previous studies, ADL functions or dementia
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48 300 severity were explained as related factors in regression models [9–12]. Some studies
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51 301 showed caregivers' characteristics such as employment status were related to informal
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54 302 care costs [9,29,30], but few studies considered all of the caregivers' characteristics. Thus,
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57 303 caregiver factors may be as important as factors related to people with dementia are.
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6 304 Furthermore, we considered the combination of characteristics of both people with
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9 305 dementia and their caregivers. For example, informal care costs doubled when caregivers
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12 306 lived separately and people with dementia could not walk. Many previous studies
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15 307 established the determinants by regression analysis[9,12,31–34]. Although it is possible
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18 308 to understand the influence on the objective variable adjusted in the multivariate by
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21 309 regression analysis, the combinations between explanatory variables have not been
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24 310 clarified. CHAID analysis provided the classification only for related characteristics in
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27 311 the outcome. Such combinations suggest that support should be provided to caregivers
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30 312 who cannot live with people with dementia or caregivers who are not employed (Figure
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33 313 2, Node 3-4).

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36 314 The association between out-of-pocket payments for LTC services covered by
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39 315 insurance and care-need levels is reasonable because the benefit limit standard amounts
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42 316 for formal care services at home are decided in relation to care-need levels[35]. In
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45 317 addition, when people with dementia had a high care-needs level and their caregiver's
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48 318 household income was high, out-of-pocket payments were high. Because the
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51 319 determination of service usage within the limit amount is a free contract, people with
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54 320 dementia and their caregivers may decide how they use formal care services depending
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57 321 on how much they can pay for services. High care-needs levels [36], age[10,34,36,37]
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6 322 and sex[10,36] were related to the high costs of LTC services. Even for low care-needs
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9 323 levels, the cost may be high when people with dementia need assistance with bathing or
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12 324 toileting. This was affected by LTC insurance services providing specific substitutions,
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15 325 such as bath assistance, and also Ku et al.'s or Dodel et al.'s ADL functions were related
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18 326 to the social care costs[9,30].
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21 327 Similarly, economic variables such as household income and income proxy variable
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24 328 were mainly related to out-of-pocket payments for LTC services not covered by insurance
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27 329 (Figure 4). This is because people must pay the full amount if they use LTC services
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30 330 without insurance. In the United States, high copayments are required for the use of LTC
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33 331 services; however, these copayments were related to age, sex, and comorbidities in the
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36 332 cohort study [37]. A part of the result of Hurd et al. was similar to our results in the case
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39 333 of the payments that were covered by insurance for the use of LTC services. Out-of-
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42 334 pocket payments not covered by insurance might occur over the limit standard
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45 335 amounts or the use of LTC services not covered by insurance (e.g. feeding service[38]).
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48 336 According to the questionnaire responses, people tended to pay for expendables such as
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51 337 diapers, employment of housekeepers, and home repair such as handrail installation as
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54 338 out-of-pocket payments not covered by LTC insurance. Furthermore, except when
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57 339 caregivers' income was high, the cost did not change significantly due to differences in
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6 340 ADL and IADL functions as it did for the payments that were covered by insurance.
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9 341 These application examples were not really affected by ADL or IADL functions.
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12 342 From the viewpoint of independent variables, if people with dementia lacked some
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15 343 ADL function, then costs might be higher but in the case of IADL functions this was
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18 344 reversed. There is a possibility that some services are used to support the independent
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21 345 lives of people with dementia. Some people with dementia who can do housework by
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24 346 themselves might move or walk around more, and therefore use more LTC services like
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27 347 commuting for care (day service) or commuting for rehabilitation. Also, care-need levels
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30 348 were not related to out-of-pocket payments not covered by insurance. The above
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33 349 application examples were also not related to care-needs levels. The relationship of
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36 350 cohabitation or employment status was the same as in previous studies [9,29,32]. While
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39 351 differences of burden of dementia care depended on the dementia types that existed and
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42 352 were pointed out [24], dementia types were not related to any other factors in this study.
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45 353 In our CHAID analysis, family caregivers' economic status or severity (care-needs levels)
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48 354 might have been more important than dementia types to dementia care costs. In creating
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51 355 policy for LTC services in an aging society, we must understand the actual conditions
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54 356 from not only a societal but also a personal perspective. This is true even if from a societal
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57 357 viewpoint, the societal cost of dementia care in the community has been established by
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6 358 other countries to be greater than that in institutional care [39]. Furthermore, we need a
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9 359 wide range of perspectives of stakeholders to discuss the dementia care system, while
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12 360 almost all studies of economic burden of dementia stood on societal or payers'
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15 361 viewpoint[7,19–21]. Then, as a first step, we need to understand what people with
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18 362 dementia and their family caregivers are already spending too much money on. We need
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21 363 to recognize the complicated combination of characteristics associated with people with
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24 364 dementia and their caregivers. To this point, the results of this classification could be
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27 365 useful to understanding which situation requires more resources depending on cost types.
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30 366 Our results may suggest that a sustainable dementia care system in Japan should be
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33 367 reconstructed from a personal viewpoint.

36 368 There are some limitations to this study. First, we conducted an online questionnaire
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39 369 survey with caregivers of people with dementia. Traditionally, respondents who use the
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42 370 Internet tend to be male and relatively young, reflecting the general characteristics of
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45 371 online research [40–42]. The sample may therefore not be representative of all caregivers
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48 372 because the sample is limited to those who have access to the Internet and are registered
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51 373 with an Internet research company [43]. Certainly, we cannot extrapolate the
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54 374 representative value in each node of the CHAID tree to the population as a whole.
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57 375 However, this study focused on finding a combination of independent variables related to
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6 376 the dependent variables (informal care cost and financial burden), taking into account the
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9 377 interaction between multiple independent variables. The significance of subgroups made
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12 378 by combinations of variables may not change significantly even if the population changes.
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15 379 Therefore, in this study, influence due to the difference between this sample and general
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18 380 public is not considered to be a practical problem. However, further research (e.g. a
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21 381 paper-based questionnaire survey mailed to the family caregivers association) to collect
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24 382 representative samples might be needed in the future. Second, it was impossible to
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27 383 measure the response rate in this study. Samples were collected from an online panel
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30 384 until the target number set in each age category was achieved. Third, we didn't consider
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33 385 the subjective burden of care and depressive symptoms. These mental burdens are
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36 386 considered to be important factors in explaining the actual state of care costs, and many
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39 387 previous studies in Japan have covered subjective costs [44–46]. In the future, in addition
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42 388 to the burden of time and money, it would be preferable to measure subjective burdens.
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45 389 Fourth, we couldn't measure the clinical dementia severity data measured by such as Mini
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48 390 Mental State Examination or Nueropsychiatric Inventory questionnaire. However, we
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51 391 used care-needs levels as substantial measurements of the severity data, which indicates
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54 392 individual requirements for amount of care determined by an evidence-based computer
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57 393 algorithm and expert panel. Fifth, we estimated informal care costs only by the
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6 394 opportunity cost approach. Some studies indicated results estimated by both opportunity
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9 395 cost approach and replacement cost approach. The opportunity cost approach might be
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12 396 underestimated in comparison to the replacement approach[9,37]
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18 398 **Conclusions**

21 399 This study clarified the difference in dementia care costs between classified subgroups
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24 400 by considering the combination of the situations of both people with dementia and their
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27 401 caregivers. Informal care costs were related to caregivers' employment and cohabitation
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30 402 status rather to the situation of people with dementia. On the other hand, out-of-pocket
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33 403 payments for long-term care services were related to care-needs levels and family
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36 404 economic status. These classifications will be useful in understanding which situation
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39 405 represents a greater economic burden, and helpful in improving the sustainability of the
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42 406 dementia care system in Japan.
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48 408 **Footnotes**

51 409 *Abbreviations*

54 410 LTC: Long-Term Care

57 411 RUD: Resource Utilization in Dementia

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6 412 ADL: Activities of Daily Life
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9 413 IADL: Instrumental Activities of Daily Life
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12 414 CHAID analysis: chi-square automatic interaction detection analysis
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15 415 *Authors' contribution*
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18 416 TN, SN and YI designed the study. All authors discussed for preparing the questionnaire.
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21 417 TN mainly analyzed all data, and HU, SK, AW and YI advised for analysis. TN prepared
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24 418 the draft of the manuscript, then all authors contributed to rewrite it. All authors read and
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27 419 approved the final manuscript.
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45 425 in the study design, data collection and analysis, decision to publish, or preparation of the
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48 426 manuscript.
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51 427 *Competing interest*
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54 428 None declared.
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12 431 *Conflicts of interest*
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18 433 *Data sharing statement*
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21 434 No additional data are available. When this study was approved by the ethics committee of
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24 435 Kyoto University Graduate School of Medicine (R0487), due to the sensitive issues, the
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27 436 raw data which we collected should not be treated outside of our laboratory.
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7 **Figure 1: Selection process for the analysis**
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9 This diagram shows the flow of participants who we focused on.
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12 **Figure 2: Classification tree of chi-square automatic interaction detection for**
13 **informal care costs**
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16 The dendogram illustrates the combinations of independent variables to clarify who need
17 or provide more informal care.
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20 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
21 Living; SD, Standard deviation; LTC, Long-term care
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24 **Figure 3: Classification tree of chi-square automatic interaction detection for out-**
25 **of-pocket payments for LTC services covered by insurance**
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28 The dendogram illustrates the combinations of independent variables to clarify who need
29 more LTC insurance services.
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32 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily
33 Living; SD, Standard deviation; LTC, Long-term care
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36 **Figure 4: Classification tree of chi-square automatic interaction detection for out-**
37 **of-pocket payments for LTC services not covered by insurance**
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40 The dendogram illustrates the combinations of independent variables to clarify who need
41 more LTC services without insurance.
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Table 1 Characteristics of people with dementia and caregivers

People with Dementia		N=1383
Age, mean±SD, y		81.8±10.3
Sex, n (%)		
Female		922 (66.7)
Male		461 (33.3)
Care-needs level, n (%)		
Support-Needs Level 1-2		253 (18.3)
Care-Needs Level 1		310 (22.4)
Care-Needs Level 2		335 (24.2)
Care-Needs Level 3		258 (18.7)
Care-Needs Level 4		122 (8.8)
Care-Needs Level 5		105 (7.6)
ADL/IADL functional capabilities		
ADL score (0-6), mean±SD		3.2±2.0
IADL score (0-7), mean±SD		1.3±1.6
Ratio of copayments for healthcare services, n(%)		
10%		961 (69.5)
20%		137 (9.9)
30%		157 (11.4)
Unknown		128 (9.3)
Types of Dementia, n(%)		
Alzheimer's disease		751 (54.3)
Caregivers		
Age, mean ± SD		52.2±13.1
Sex, n (%)		
Female		530 (38.3)
Male		853 (61.7)
Relationship, n (%)		
Mother		575 (41.6)
Mother-in-law		169 (12.2)
Father		288 (20.8)
Father-in-law		90 (6.5)
Spouse		99 (7.2)
Sibling		11 (0.8)
Child		10 (0.7)
Friend		5 (0.4)
Other (including grandparents)		136 (9.8)
Contribution level for caregiving, n (%)		
1-20%		395 (28.6)
21-40%		355 (25.7)
41-60%		241 (17.4)
61-80%		166 (12.0)
81-100%		226 (16.3)
Currently employed, n (%)		532 (38.5)

SD: Standard deviation, ADL: Activities of Daily Living, IADL: Instrumental Activities

of Daily Living

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585 **Table 2 Daily informal care time and personal costs of dementia care sorted by care-needs levels**

			Support- required level	Care-need level 1	Care-need level 2	Care-need level 3	Care-need level 4	Care-need level 5
Informal care time (hours/day)	ADL	Mean [SD]	2.56 [3.23]	2.23 [2.54]	2.92 [2.90]	3.44 [2.90]	3.99 [2.40]	4.60 [3.85]
		Median [IQR]	1.67 [2.00]	1.50 [2.50]	2.00 [3.00]	3.00 [3.50]	4.00 [3.00]	3.33 [4.00]
	IADL	Mean [SD]	2.35 [2.62]	2.46 [3.05]	2.88 [3.26]	2.82 [2.92]	3.03 [2.59]	3.45 [3.77]
		Median [IQR]	2.00 [2.00]	1.50 [2.00]	2.00 [2.00]	2.00 [2.50]	2.00 [3.13]	2.00 [4.00]
Personal cost of dementia care (US\$)	Informal care cost	Mean [SD]	1518 [2017]	1271 [1526]	1754 [1982]	2181 [2220]	2112 [2104]	2672 [2314]
		Median [IQR]	747 [1646]	709 [1440]	1090 [1697]	1366 [2459]	1535 [1466]	1939 [2240]
	OPP for LTC services covered by insurance	Mean [SD]	148 [190]	158 [174]	244 [209]	313 [217]	301 [202]	318 [218]
		Median [IQR]	49 [172]	49 [123]	172 [319]	368 [441]	368 [196]	368 [441]
	OPP for care services not covered by insurance	Mean [SD]	158 [336]	95 [156]	278 [695]	303 [543]	241 [579]	352 [998]
		Median [IQR]	49 [172]	49 [172]	49 [368]	172 [319]	49 [368]	49 [368]

586 ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living, SD: Standard deviation, IQR: Interquartile range

587 OPP: Out-of-pocket payments LTC: Long-term care

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Figure 1

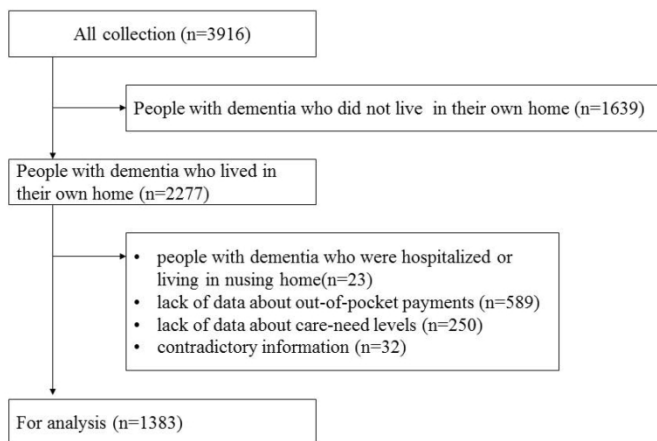


Figure 1: Selection process for the analysis
This diagram shows the flow of participants who we focused on.

338x190mm (300 x 300 DPI)

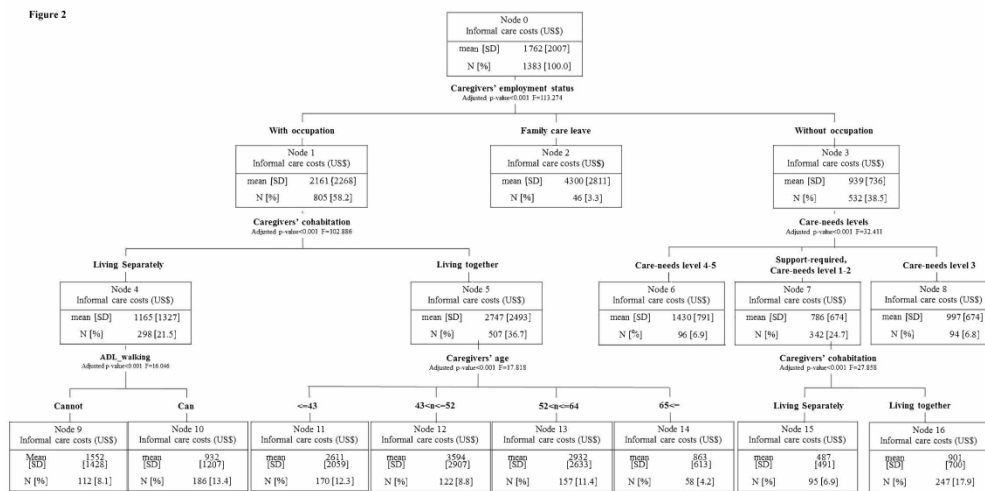


Figure 2: Classification tree of chi-square automatic interaction detection for informal care costs
 The dendrogram illustrates the combinations of independent variables to clarify who need or provide more informal care.

Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

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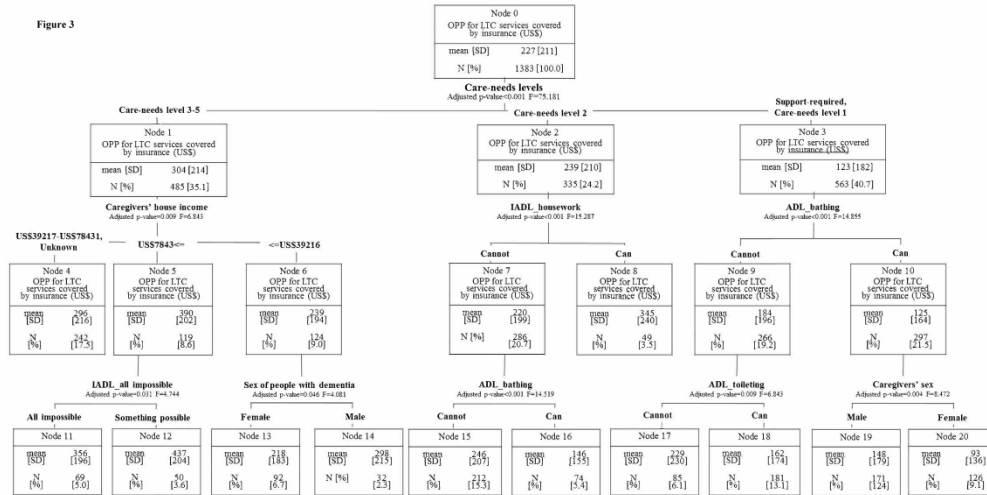


Figure 3: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services covered by insurance
 The dendrogram illustrates the combinations of independent variables to clarify who need more LTC insurance services.
 Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

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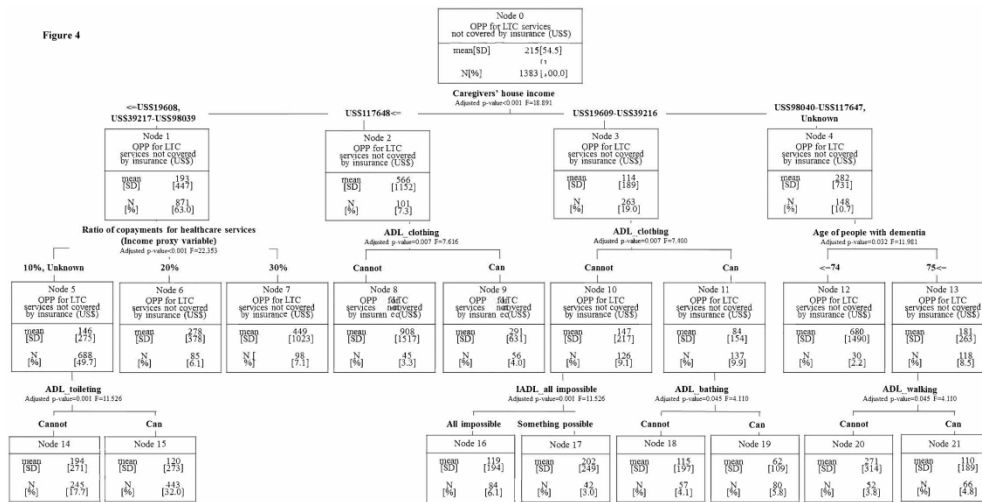


Figure 4: Classification tree of chi-square automatic interaction detection for out-of-pocket payments for LTC services not covered by insurance
The dendrogram illustrates the combinations of independent variables to clarify who need more LTC services without insurance.
Abbreviations: ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; SD, Standard deviation; LTC, Long-term care

600x300mm (300 x 300 DPI)

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract - p.1-2 (b) Provide in the abstract an informative and balanced summary of what was done and what was found – p.2-3
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – p.4-5
Objectives	3	State specific objectives, including any prespecified hypotheses – p.5
Methods		
Study design	4	Present key elements of study design early in the paper – p.5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – p.6
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants – p.6 and p.10
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – p.6-10
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group – p.6, 9
Bias	9	Describe any efforts to address potential sources of bias – p.18-19
Study size	10	Explain how the study size was arrived at – p.6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – p.11-12
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding – p.11-12 (b) Describe any methods used to examine subgroups and interactions – p.11-12 (c) Explain how missing data were addressed-p.10 (d) If applicable, describe analytical methods taking account of sampling strategy – Non applicable (e) Describe any sensitivity analyses – Non applicable
Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – p.12-13 (b) Give reasons for non-participation at each stage – Non applicable (c) Consider use of a flow diagram - Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – p.13 and Table 1 (b) Indicate number of participants with missing data for each variable of interest – Non applicable
Outcome data	15*	Report numbers of outcome events or summary measures – Table 2
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included –p.12-13

		(b) Report category boundaries when continuous variables were categorized – Non applicable
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period – Non applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses – p.13, Figure2-4
Discussion		
Key results	18	Summarise key results with reference to study objectives - p,14-15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – p.18-19
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – p.15-18
Generalisability	21	Discuss the generalisability (external validity) of the study results –p.18-19
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based - p.21

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.