PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	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
AUTHORS	Nakabe, Takayo; Sasaki, Noriko; Uematsu, Hironori; Kunisawa, Susumu; Wimo, Anders; Imanaka, Yuichi

VERSION 1 - REVIEW

REVIEWER	Dr. Aida Adlimoghaddam St.Boniface Hospital Research Centre- Canada
REVIEW RETURNED	19-Oct-2018

GENERAL COMMENTS	This report investigates the difference in dementia care costs between classified groups by considering the combination of the situations of both individuals with dementia and their caregivers. Informal care costs were related to the employment status of caregiver's rather to the situations of individuals with dementia. These classifications will be beneficial in understanding which situation represents a greater economic burden, and useful in improving the sustainability of the dementia care system in Japan. The article is well written, and the aims of the study are important. This manuscript would make a significant contribution to the field. It is the opinion of this reviewer that the manuscript be accepted for publication after the incorporation of the minor revisions stated below. Authors need to mention and discuss the types of dementia in their statistics analysis. This is important to understand the broader impact of caregivers on different types of dementia including the assessments of time that caregiver spend and how caregiver experience is influenced by dementia severity and compare it with other forms of assistance (such as private care and insurance). Also, authors need to discuss if other countries find similar results.

REVIEWER	Gail B. Rattinger School of Pharmacy and Pharmaceutical Sciences Binghamton University United States
REVIEW RETURNED	16-Nov-2018

GENERAL COMMENTS	1. Study design is problematic in that the use of one-third income in those caregivers who were not employed outside the home seems arbitrary; as well of course costs will be higher for those caregivers who earn more outside of the home. The opportunity cost is a societal perspective while the micro-factors are from a personal perspective. This needs to be sorted out more objectively; perhaps by performing the decision tree models from each perspective separately. 2. There are missing values in Table 1 for employment status and age. 3. The paper is difficult to follow and would benefit from working with a native English speaker/writer to make the content and its presentation clearer. The results explanations are particularly difficult to follow; it would be helpful if more of the information were in the tables. 4. The authors employed a market research firm to perform the study and there is not sufficient mention/details of IRB approval for the study. 5. The findings regarding men being the majority caregivers seem very biased and the authors should investigate the underlying reasons for this lopsided participation in their survey. 6. The authors should do a more thorough literature search and consider including the findings from the Hurd 2013 paper which was based on a long-standing cohort - this addresses the opportunity and replacement cost issues by "bracketing" both situations. 7. The discussion should make mention of other work in the field and the limitations of using the opportunity cost approach.

REVIEWER	David Cantarero Prieto Department of Economics-The University of Cantabria
REVIEW RETURNED	07-Jan-2019

GENERAL COMMENTS	First of all, this paper could be written more convincingly and there are many edition issues that need to be improved and corrected. Moreover, the topic is clear. The authors explore the micro level determinants of the economic burden of dementia care at home in cmmunity settings to explore the question of which subgroup of factors are related to people with dementia and their caregivers, but there is no single focus of the paper. In abstract the authors indicate that they conducted a chi-square automatic interaction detection analysis although it is usually identified in marketing research.

Nevertheless, in page 4 there is a huge limitation of the study: that the sample may therefore not be representative. So, what is the real solution?.

In page 7 the authors argue that potential participants fulfilled the criteria (4) having no conflicts of interest with advertising or marketing research entities but it could be useful to consider who tell this?

In page 8 please remove the paragraph about the algorithm to other section of the draft or provide a clear explanation indicating how it gets information.

Much of the literature reviewed is not very suitable to the main focus of the paper and I think there should be other studies done on this body of literatura, so please check it.
In page 10 please extend the informal care costs for caregivers and máximum daily informal care time argument in the paper and not only in one paragraph. The same it could be applied to page 11 to the paragraph on adjusting the answers for the out of pocket payments. Moreover, it could be useful to get an estimation of out of pocket payments for LTC services or care needs levels

There are no clear summary statistics and empirical results provided. Besides,authors should use other income proxy variables than the ratio of copayments for healthcare services and ethical considerations it could be located in another page (page 13).

Page 14: Mean age was 81.8 but where? In Table 1? What about currently employed?
It could be useful to show in a Table the information on informal care time and costs of dementia care.

Page 15: Please clarify if covered and not covered are similar. And when the authors argue that "When the caregiver acquired family care leave, informal care cost was the highest" please explain if it is similar to other groups.

Page 17: Please check the second paragraph because there are some arguments that are similar to other previously explained. Page 18: please explain that this information is similar to the Figure 4

For example, Tables should be reduced because there is information that it is not very useful.

In page 20 the authors argue that “Certainly, we cannot extrapolate our results to the population as a whole”. Please explain this assumption.

In this regard, for the results section, there is not much discussion why the authors argue the main paragraphs

Besides, there is no explanation of how the main findings are related to the main focus of the paper.

Table 1: what is the age mean? Table 2: what about the hours? The information of the Figures is confusing and numbers vary a lot

Finally, I recommend consider minor revision in this paper.

VERSION 1 – AUTHOR RESPONSE

Responses to reviewers' comments

Reviewer: 1

#1 Authors need to mention and discuss the types of dementia in their statistics analysis. This is important to understand the broader impact of caregivers on different types of dementia including the assessments of time that caregiver spend and how caregiver experience is influenced by dementia severity and compare it with other forms of assistance (such as private care and insurance).

Thank you for your suggestion. We already added dementia types as an independent variable in the CHAID analysis (Page 13, line 207); however, it was not related to any other factors, including the costs, in our results; therefore, we did not include it in Table 1. Subsequently, we revised Table 1 and added some information about dementia types (Page 20, line 340-344).

#2 Also, authors need to discuss if other countries find similar results.

As suggested, we added some information on the comparison of the situation with other countries (Page 18-19).

Reviewer: 2

#3 Study design is problematic in that the use of one-third income in those caregivers who were not employed outside the home seems arbitrary; as well of course costs will be higher for those caregivers who earn more outside of the home. The opportunity cost is a societal perspective while the micro-factors are from a personal perspective. This needs to be sorted out more objectively; perhaps by performing the decision tree models from each perspective separately.

We considered the opportunity cost approach based on the caregivers' labor value. This is why we used average wage, stratified by sex and age. Furthermore, concerning whether we considered caregivers who were employed, we treated their caregiving time as leisure time. Therefore, we assessed their opportunity cost as one-third compared to that of the caregivers who earned more outside the home.

Opportunity cost approach is a method of calculating unpaid care by the labor value of each caregiver. If we estimated societal costs of dementia care, including informal care costs, it would have meant that we relied on societal perspective. However, in this study, we only estimated each caregiver's informal care costs or out-of-pocket payments from a personal perspective. Therefore, dividing the perspectives in order to perform the decision tree models might have been beyond the scope of our study.

#4 There are missing values in Table 1 for employment status and age.

Thank you for your comment. We have included the missing data in Table 1.

#5 The paper is difficult to follow and would benefit from working with a native English speaker/writer to make the content and its presentation clearer. The results explanations are particularly difficult to follow; it would be helpful if more of the information were in the tables.

Thank you for your comment. We added more useful guides in the result section about Figures (e.g., node XX).

#6 The authors employed a market research firm to perform the study and there is not sufficient mention/details of IRB approval for the study.

We only mentioned the approval from the Ethics committee of Kyoto University Graduate School of Medicine (R0487). In the same paragraph, we added information about the informed consent that was received from the respondents (Page 13, line 220-222).

#7 The findings regarding men being the majority caregivers seem very biased and the authors should investigate the underlying reasons for this lopsided participation in their survey.

Generally, caregivers tend to be female or older people; however, in this study, more young and male caregivers responded to the survey questions, similar to a previous study that used the Internet research method (Fujihara et al., 2018). In this study, we conducted stratified sampling of caregivers. Subsequently, it was beyond the scope of this study to compare the differences in the distribution of caregiver variables, such as sex or age.

However, we did not focus on obtaining the representativeness of caregivers' distribution, rather, we focused on the characteristics of subgroups. We also focused on finding the combination of independent variables related to the dependent variables (informal care cost and financial burden), taking into account the interaction between multiple independent variables. Therefore, in this study, influence due to the difference between the sample and the general public is not considered as a practical problem (Page 21, line 363-372).

#8 The authors should do a more thorough literature search and consider including the findings from the Hurd 2013 paper which was based on a long-standing cohort - this addresses the opportunity and replacement cost issues by "bracketing" both situations.

#9 The discussion should make mention of other work in the field and the limitations of using the opportunity cost approach.

Thank you for your comment. We revised our discussion to compare our results with other works, both in Japan and foreign countries (Page 18-19). Also, we added the limitations of using the opportunity cost approach (Page 22, line 376-380).

Reviewer: 3

#10 In abstract the authors indicate that they conducted a chi-square automatic interaction detection analysis although it is usually identified in marketing research.

Nevertheless, in page 4 there is a huge limitation of the study: that the sample may therefore not be representative. So, what is the real solution?.

Generally, caregivers tend to be female or older people; however, in this study, more young and male caregivers responded to the survey questions, similar to a previous study that used the Internet research method (Fujihara et al., 2018).

In this study, we conducted stratified sampling of caregivers. Subsequently, it was beyond the scope of this study to compare the differences in the distribution of caregiver variables, such as sex or age.

However, we did not focus on obtaining the representativeness of caregivers' distribution, rather, we focused on the characteristics of subgroups. We also focused on finding the combination of independent variables related to the dependent variables (informal care cost and financial burden), taking into account the interaction between multiple independent variables. Therefore, in this study, influence due to the difference in sample variable distribution is not considered as a practical problem (Page 21, line 363-372).

#11 In page 7 the authors argue that potential participants fulfilled the criteria (4) having no conflicts of interest with advertising or marketing research entities but it could be useful to consider who tell this?

This criteria was set by the Internet research company, Automatic Internet Research System, Macromill, Inc., Japan. (https://monitor.macromill.com/agreement/sub.html).

#12 In page 8 please remove the paragraph about the algorithm to other section of the draft or provide a clear explanation indicating how it gets information.

We added and organized some information about the collection of data with regards to the assessment of the care-needs levels (Page 8, line 123-132).

#13 Much of the literature reviewed is not very suitable to the main focus of the paper and I think there should be other studies done on this body of literatura, so please check it. In page 10 please extend the informal care costs for caregivers and máximum daily informal care time argument in the paper and not only in one paragraph. The same it could be applied to page 11 to the paragraph on adjusting the answers for the out of pocket payments. Moreover, it could be useful to get an estimation of out of pocket payments for LTC services or care needs levels.

Thank you for your comment. We added some studies in our paper. We divided the sections into informal care time (2-3) and informal care costs (2-4). In calculating informal care costs, to set the maximum informal care time, we were careful not to double count the housekeeping or sleeping time. That is why the description of the maximum informal care time was included in the informal care costs' paragraph. This setting is similar to previous studies (Farré et al., 2016; Rattinger et al., 2015; Gustavsson et al., 2011). On the other hand, we also set the upper limits of out-of-pocket payments for LTC services covered by insurance; consequently, we added some information about the maximum account amounts (Page 11, line 174-176).

#14There are no clear summary statistics and empirical results provided. Besides, authors should use other income proxy variables than the ratio of copayments for healthcare services and ethical considerations it could be located in another page (page 13).

We only have data about caregivers' individual or home income. We did not collect data of the income of people with dementia (Nakabe et al., 2018, Table 1). Therefore, we used the ratio of copayments for healthcare services as a proxy variable. This copayment ratio was decided by their age and income.

Copayment ratio		Income	
		-JPY 3,700,000	over JPY 3,700,000
Age	over 75	10%	30%
Age	70-74	20%	30%
Age	-70	30%	30%

#15 Page 14: Mean age was 81.8 but where? In Table 1? What about currently employed?

It could be useful to show in a Table the information on informal care time and costs of dementia care.

Thank you for your comment. We added some data to Table 1. Also, we included information on informal care time and costs in Table 2.

#16 Page 15: Please clarify if covered and not covered are similar. And when the authors argue that "When the caregiver acquired family care leave, informal care cost was the highest" please explain if it is similar to other groups.

We clarified the common factors between out-of-pocket payments that were covered by insurance and those that were not (Page 16, line 268-269). Also, we added some explanations about similar groups in which caregivers acquired family care leave (Page 15, line 253-256).

#17 Page 17: Please check the second paragraph because there are some arguments that are similar to other previously explained.

#18 Page 18: please explain that this information is similar to the Figure 4.

For example, Tables should be reduced because there is information that it is not very useful.

We added some information about the difference between our results and those of other studies in Page 17. Furthermore, we added information about Figure 4 to discuss the factors related to out-of-pocket payments for LTC services not covered by insurance.

#19 In page 20 the authors argue that “Certainly, we cannot extrapolate our results to the population as a whole”. Please explain this assumption. In this regard, for the results section, there is not much discussion why the authors argue the main paragraphs. Besides, there is no explanation of how the main findings are related to the main focus of the paper.

Generally, caregivers tend to be female or older people; however, in this study, more young and male caregivers responded to the survey questions, similar to a previous study that used the Internet research method (Fujihara et al., 2018).

In this study, we conducted stratified sampling of caregivers. Subsequently, it was beyond the scope of this study to compare the differences in the distribution of caregiver variables, such as sex or age. This study focused on finding the combination of independent variables related to the dependent variables (informal care cost and financial burden), taking into account the interaction between multiple independent variables. The significance of subgroups made by combinations of variables may not change significantly even if the population changes. Therefore, in this study, influence due to the difference in sample variable distribution is not considered as a practical problem. However, we might need to conduct further research (e.g., paper-based questionnaire survey mailed to the entire family caregivers association) to collect representative samples in the future (Page 21, line 363-372).

Furthermore, to find a suitable combination of independent variables is the objective of this study. Subsequently, we discussed about this combination and its relation to other factors from the second to sixth paragraph in the discussion section. In the seventh paragraph of the discussion section, we also mentioned about the implications of our findings with regards to the combination of independent variables.

#20 Table 1: what is the age mean? Table 2: what about the hours? The information of the Figures is confusing and numbers vary a lot

We added some data to Table 1. A CHAID tree always includes an F value or other numbers in every branch point (e.g., Naruse et al., 2012; Igarashi et al., 2014).

VERSION 2 – REVIEW

REVIEWER	David cantarero The University of Cantabria-Spain
REVIEW RETURNED	23-Apr-2019

GENERAL COMMENTS	The main objective of this paper is to know the microeconomic determinants that affect the economic weight of senile dementia household care in community settings in Japan. The methods are based on cross-sectional study, based on a self-evaluated online questionnaire. The economic burden of care for dementia in this study is divided into informal care costs such as opportunity costs and direct (out-of-pocket) payments that people made; the opportunity cost was calculated as the average wage of caregivers stratified in sex and age group. A descriptive analysis of the characteristics of people with dementia and caregivers was carried out. Then, informal care time and dementia care costs were stratified by level of need for care and coexistence. In addition, chi-square automatic interaction detection (CHAID) analysis was used to identify the characteristics of people with dementia and caregivers who needed. The proportion of co-payments for health services was treated as a proxy proxy variable. The main findings are that the costs of informal care were related to the employment and living conditions of caregivers and not to the situation of people with dementia. While disbursement payments for long-term care services were related to levels of care needs and family economic situation. These classifications are useful to understand which situation represents a greater economic burden and to improve the sustainability of the dementia care in Japan

	Moreover, it is a very specific study, since it only focuses on one country (Japan) when it is a problem that affects globally. Please, explain more in detail for other countries Many patients suffering from this disease are excluded, since they only refer to the domestic environment; for example, people with dementia who were hospitalized or living in nursing homes. What are the limitations? The sample is not representative of all the caregivers because it is limited to those who have access to the Internet and are registered in a specific research company, in order to complete the online questionnaire. What are the implications of this decision? No data are collected on direct (out-of-pocket) payments stratified by long-term care services or levels of care needs. Why? Please explain it Other interesting variables, but difficult to achieve or measure, could be the severity of the figures on dementia (estimated through the caregivers), since the article refers to the fact that they can be an influencing factor; or the existing contradictions in the relationships between caregivers and people with dementia. Why? Please explain it Only the objective burden of dementia care is evaluated but the subjective part of attention and depressive symptoms are not considered. What are the limitations?

VERSION 2 – AUTHOR RESPONSE

Responses to reviewers' comments

Reviewer(s)' Comments to Author:

Reviewer: 3

Reviewer Name: David cantarero

Institution and Country: The University of Cantabria-Spain

Please state any competing interests or state 'None declared': None declared

#1 Moreover, it is a very specific study, since it only focuses on one country (Japan) when it is a problem that affects globally. Please, explain more in detail for other countries.

From the global perspective, we discussed the related factors comparing with previous studies which are globally common as shown in our study (Page 18-20).

#2 Many patients suffering from this disease are excluded, since they only refer to the domestic environment; for example, people with dementia who were hospitalized or living in nursing homes. What are the limitations?

The objective of this study to clarify the micro-level determinants of the economic burden of dementia care “at home” in community setting. In Japan, as the integrated care system, it is the mainstream to care people with dementia at home in the community-setting.

On the other hand, we already compared personal costs of dementia care among the various residence types including institutionalized or hospitalized people in another study(1).

[Reference]

1. Nakabe T, Sasaki N, Uematsu H, Kunisawa S, Wimo A, Imanaka Y. The personal cost of dementia care in Japan: A comparative analysis of residence types. Int J Geriatr Psychiatry. 2018;33(9):1243–52.

#3 The sample is not representative of all the caregivers because it is limited to those who have access to the Internet and are registered in a specific research company, in order to complete the online questionnaire. What are the implications of this decision?

As you pointed out, the respondents might be biased because we recruited the Internet panel in a specific research company. Therefore, in this study, we conducted stratified sampling of caregivers.

Subsequently, it was beyond the scope of this study to compare the differences in the distribution of caregiver variables, such as sex or age. This study focused on finding the combination of independent variables related to the dependent variables (informal care cost and financial burden), taking into account the interaction between multiple independent variables. The significance of subgroups made by combinations of variables may not change significantly even if the population changes. Therefore, in this study, influence due to the difference in sample variable distribution is not considered as a practical problem.

Furthermore, to find a suitable combination of independent variables is the objective of this study. Subsequently, we discussed about this combination and its relation to other factors from the second to sixth paragraph in the discussion section. In the seventh paragraph of the discussion section, we also mentioned about the implications of our findings with regards to the combination of independent variables.

#4 No data are collected on direct (out-of-pocket) payments stratified by long-term care services or levels of care needs. Why? Please explain it

Table 2 clearly shows personal cost (out-of-pocket payments (OPPs)) stratified by care-need levels.

#5 (1) Other interesting variables, but difficult to achieve or measure, could be the severity of the figures on dementia (estimated through the caregivers), since the article refers to the fact that they can be an influencing factor; (2) or the existing contradictions in the relationships between caregivers and people with dementia. Why? Please explain it

(1) In this study, we couldn’t measure the severity of dementia itself (e.g. MMSE score) because it was regarded as too difficult for caregivers to estimate that. However, we obtained the care-need level, which represents the volume of care needed. (Page 8-9, line 122-137). This is considered more influential burden of caregivers than the severity of cognitive function.

(2) There were some contradictions in the response. For example, the mother (not in-law) was only 5-year older than her daughter (caregiver). We excluded such contradicting responses from the analysis (Page11-12, line 188-191).

#6 Only the objective burden of dementia care is evaluated but the subjective part of attention and depressive symptoms are not considered. What are the limitations?

We didn't measure the subjective burden in this study, and we declared this fact as a limitation in Page 22, line 379-382. It is out of the scope of this study. It will be another study in the future to measure subjective burdens.