Author’s response to reviews

Title: Are community-living and institutionalized dementia patients cared for differently? Evidence on service utilization and costs of care from German insurance claims data

Authors:

Larissa Schwarzkopf (l.schwarzkopf@helmholtz-muenchen.de)
Petra Menn (petra.menn@helmholtz-muenchen.de)
Reiner Leidl (leidl@helmholtz-muenchen.de)
Elmar Gräßel (elmar.graessel@uk-erlangen.de)
Rolf Holle (holle@helmholtz-muenchen.de)

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Author’s response to reviews: see over
Dear Ms Calumpita,

enclosed please find the revised version of the manuscript **MS 7204078507928477** entitled

*Are community-living and institutionalized dementia patients cared for differently? Evidence on service utilization and costs of care from German insurance claims data*

We thank our reviewers for their valuable comments and suggestions which significantly improved both clarity and precision compared with the initial version of the manuscript.

All modifications made in the revised manuscript (clean version) are addressed within the attached point-to-point response. To also ensure the detailed traceability of the changes, please kindly note a tracked version of the manuscript that is provided in addition.

As recommended by the journal editors, we also sought the assistance of an English language editor who carefully adapted the manuscript. Here special emphasis was paid to the abstract. We think these corrections prevent potentials for misconception due to an inadequate use of English language best possible and foster the quality of the submitted paper.

We are convinced that the reworked manuscript addresses all previous points of concern in a satisfying manner and thus resubmit our paper to “BMC Health Services Research”.

We would be glad if you consider the manuscript for publication.

Yours sincerely,

Larissa Schwarzkopf

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Enclosed:

- Manuscript (BMC_HSR_ms 7204078507928477_revised_tracked.doc)
- Manuscript (BMC_HSR_ms 7204078507928477_revised_clean.doc)
- Point-to-point Response (point_to_point_response_ms 7204078507928477.doc)

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Please address correspondence to

Larissa Schwarzkopf
Helmholtz Zentrum München/ Institute of Health Economics and Health Care Management
Ingolstädter Landstrasse 1
85764 Neuherberg
Germany

Phone.: ++49-89-3187-3994
Fax: ++48-89-3187-3375
Email: l.schwarzkopf@helmholtz-muenchen.de
Point to point Response MS 7204078507928477

Reviewer: Ramon Luengo-Fernandez

Major Compulsory Revisions

1) Abstract, Results section, last sentence. It should be stated explicitly that these amounts are per patient per year.

The last sentence of the results section was reformulated as follows (see p 2):

- “Altogether, institutional care required additional \textit{yearly per capita} expenses of ca. €200 in health and of ca. €11,200 in long-term care sector.”

2) Abstract, Conclusion section, 2nd sentence. The sentence starting "After corre-
sponding...." is very difficult to understand. For example, what is corresponding adjustment, is it adjustment by care levels, age-gender, co-morbidity etc...

As argued by reviewer 2, the existence of baseline differences between community-
living and institutionalized dementia patients is rather a precondition for than a finding of our study. Thus, it was suggested not to mention this commonplace within the conclusion of the abstract. Following this recommendation we dropped the initial sentence and replaced it by a reflection on the economic advantage of community-based care. Doing so, it was no longer necessary to refer to the performed adjustments at the beginning of sentence two, which is now reworded (see p 2):

- "\textit{Health care spending is comparable but community-living and institutional-
ized individuals present characteristic service utilization patterns}”.

3) Methods, page 5, paragraph 3, last sentence. At this point the authors should define the different levels of care.

We now briefly mention the three care levels of interest within the subchapter “data source and sample selection”. To do so, an additional sentence was added but the detailed description for the requirements of care level assignment remained within the subchapter “LTCI services” (see page 6).

- \textit{Within the German long-term care system, the need for care is reflected by three care levels, which account for the daily support required in ADL. Care level 1 reflects mild dependency, care level 2 moderate dependency and care level 3 severe dependency.}
4) Results comment applicable throughout the section. My major criticism of this study is the way in which results are presented. Throughout the results section, I thought there could have been a better connection between the results presented in the tables and in the text.

For example, when providing written commentary of the results reported in Table 3, the authors could have made better use of the results presented in the table (e.g. institutionalised patients had over 50 GP visits per year compared with 35 for community-dwelling patients, p<0.0001 etc...) This not only highlights major findings, but also makes reading the paper much easier.

Following on from this point, I found the text detailing Table 4 difficult to follow. The authors report "Analysing trends across care levels the LTCI expenditures rose by ca. EUR 7,800 in the community and by ca. EUR 4,600 in nursing homes." However, this is not directly discernible from the table: If I compare Care level 2 to Care level 1 the difference is EUR 2,782 for insitutionalised patients and EUR 3,995 for community patients. If I compare Care Level 3 to Care Level 2 the difference is EUR 1,864 for insitutionalised patients and EUR 3,761 for community patients. And finally, if I compare Care Level 3 to Care Level 1 the difference is EUR 5,939 for institutionalised patients and EUR 9,390 for community patients.

None of these comparisons matches the results presented in the text.

Within the initial version of the manuscript we tried to avoid a duplication of text information and table information. Thus it seemingly has been difficult to follow the results. Within the reworked manuscript we more precisely refer to the services and care levels of interest within the text. To ease the readability of the paper we also decided on naming the tables of interest always at the beginning of a sentence and not at the end of it.

However, we did not follow the suggestion to report exact utilization figures and p-values within the manuscript. This was considered to be a sensitive issue because corresponding figures by trend are not valid across all three care levels. For example referring to the authors reflections on GP visits in table 3, the statement is correct for care level 2 and care level 3 but not for care level 1.

Given the complexity of information which includes different care levels and different settings, we thought it would be more helpful to point out general utilization trends than to stress some – arbitrarily chosen – services in detail. Referring to the reviewer’s example the revised paragraph is:
“Table 3 focuses on the intensity of per capita service utilization and shows that nursing home residents assigned to care levels 1 or 2 used general practitioners, medical specialists, non-physician services, medical aids and drugs more frequently than their community-living counterparts, who on the other hand required anti-dementia drugs, hospital treatment and rehabilitation on a larger scale. In care level 3, the utilization of hospital treatment, anti-dementia drugs and non-physician services was comparable in both settings. Similar to care levels 1 and 2, physician visits and medical aid prescriptions were higher in nursing homes but, in contrast to the lower care levels, drug intake was increased in the community.”

We consider these modifications to be well suited to accentuate the main findings of our study and draw a comprehensive picture on the current structures of health care service provision. Regarding the reviewer’s comments on table 4, the figures reported within the manuscript always refer to a comparison between care level 1 and care level 3. These points of reference are now included (see page 13):

• “From care level 1 to care level 3, the LTCI expenditures rose by ca. €7,800 in the community and by ca. €4,600 in nursing homes”.

The reviewer mentions spending differences of EUR 5,939 for institutionalized patients and EUR 9,390 for community-living patients and remarks that corresponding figures do not occur within the manuscript. These figures refer to the entire cost of care for the social security system, i.e. the difference in SHI plus the difference in LTCI. We now refer to them at the beginning of the discussion section (see page 14).

• Comparing mildly dependent patients with severely dependent ones, the increase – including, again, SHI and LTCI – is ca. €9,400 (+104%) in the community and ca. €5,900 (+35%) in nursing homes.

Adding the SHI difference (ca. €1,300) and the LTCI difference (ca. €4,600) for nursing home residents given on page 13 results in ca. €5,900. However, within the community-living population the addition of the corresponding differences (€7,800 LTCI; €1,300 SHI) just sums up to ca. €9,100 and not to ca. €9,400. This is due to the fact that the overall spending of the social security system as presented in table 4 results from a model estimation and yields therefore slightly different figures than the addition of expenses across the different categories. This artefact is stated in the footnote of table 4 and within the statistics section on page 10. A monetary difference of ca. €300 equals a percentage difference by less than 3% which we consider to be tolerable. Therefore we refer to the model based cost figures within the discus-
sion section.

All figures presented refer to a GLM-model and - despite a careful specification - model imprecision cannot be fully excluded. Therefore we intentionally reported all figures rounded because from our point of view giving exact figures might mask estimation errors and pretend an unfounded level of accuracy.

5) Discussion, page 13, sentence starting "However, comparable SHI expenditures...." This sentence does not make sense. It is my impression that something has been left out.

We intended to express that community-living and institutionalized dementia patients incur comparable expenditures in the health care sector but that the underlying service utilization patterns are different. The most interesting differences in service utilization are then further described in the following paragraphs. To avoid misunderstanding we reformulated the corresponding sentence less ambiguously (see page 14).

- “Despite the fact that overall health care expenses for community-living and institutionalized dementia patients are comparable, the underlying utilization patterns show some notable differences. “

6) Discussion, page 15. This is extremely dense, with the paragraph taking an entire page. To aid readers, please break into paragraphs and condense text.

The discussion was fundamentally restructured with regard to the order of paragraphs as recommended by the second reviewer. In this context we also subdivided the text into shorter paragraphs to ensure smooth reading of the text.

Minor Essential Revisions

1) The use of respectively is sometimes used inappropriately, e.g. "per capita expenditures were estimated on ca. EUR 4,500 (community) respectively EUR 15,300 (nursing-home)...." and "dementia-specific ICD-10-Code respectively with at least one....".

The revised manuscript was proofread by an English language editor. The term ‘respectively’ is now replaced by ‘versus’ wherever it was required.

2) ADL is never defined in full.

We thank our reviewer for this remark and no define ADL as ‘activities of daily living’ (see page 5).
3) It is my belief than when setting statistical significance is being set the use of $p<0.05$ is customary, rather than 5%.

As far as we are able to judge, this remark refers to the last sentence of the “statistics” section. As per our knowledge the use of $p<0.05$ instead of 5% is quite common regarding the presentation of results but this is not necessarily the case within the methods section. Therefore we decided on keeping the previous version.

4) Page 13, last paragraph, 2nd sentence. Rather than this results corresponds, it would be better use of language to report this result is similar to, or has been also observed etc…

We are grateful for the reviewer’s suggestion. Within the reworked manuscript the corresponding sentence is reworded (see page 14)

- “Our result is similar to the findings of two US-based studies which reported more frequent hospital admissions in community-living elderly”.

5) idem to above in page 14, paragraph 3, 2nd sentence.

The sentence was reworded within the revised manuscript (see page15):

- “The minor relevance of anti-dementia drug therapy was also stated within another recent German claims data analysis.”

Reviewer: Hilde Verbeek

Major Compulsory Revisions:

1) Abstract: Please reformulate the conclusion as presented in the abstract. The conclusions drawn in the abstract do not follow the aim, methods and result as described in the abstract. In addition, what do the authors mean with that both settings are not per se interchangeable? It is already known that overall, characteristics of people living in the community are different from those living in a nursing home and therefore it is strange that this is a conclusion from the current data. However, what is interesting is why some people with dementia have similar characteristics (e.g. level of care needed) but some live at home and others in the nursing home. This should be addressed in the paper as the authors have studied this.
We agree with our reviewer, that different demographic and clinical characteristics between institutionalized individuals and community-living individuals are rather a precondition than a conclusion. Thus we dropped the corresponding sentences within the conclusion part of the abstract. Instead we refer to the preferability of community-based care when adopting a payer perspective (see page 2):

• “Community-based dementia care is cost saving from the payer perspective due to substantially lower long-term care expenditures.”

We also share the reviewer’s opinion that it would have been desirable to further analyse why – despite shared clinical and demographic characteristics – some dementia patients are cared for in nursing homes and some dementia patients are cared for at home. However, the data of this study unfortunately do not provide any basis for a direct analysis of this issue:

Claims data do not include socio-economic and qualitative information and therefore we can only hypothesize the potential explanations. From our point of view, the most convincing factor is the density of the informal care network available.

To address the need for additional research in this end, the discussion of the revised manuscript ends with the following sentences:

• “Future research combining primary and secondary data could account for these manifold aspects of dementia care. This would allow a more comprehensive judgement on the preferability of both settings and help to understand why – despite shared clinical and demographic characteristics — some dementia patients are cared for in the community and others in nursing homes.”

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2) Overall, the paper needs more structured background and context information on the paying system. The authors use abbreviations SHI and LTCI throughout the study and only address the content of these financing systems very briefly in the method section. This terminology is highly specific for German context, and needs therefore clarification. For example, what sources provide money for these systems? And how can this be transferred to other countries? Is it like social care versus medical care? Please explain some more background info so readers outside Germany can relate to the context as well. Furthermore, try to relate the sources of funding to people living in the community and living in a nursing home: who pays for what in Germany? It is written in several parts throughout the manuscript, but it would be helpful to cluster it more.

We thank our reviewer for this valuable comment. The important issue how the Ger-
man health and long-term care system is structured is now addressed in brief within some additional paragraphs (see pages 6 and 7):

- “In Germany, health and long-term care insurance are a legal obligation, and about 85% of the resident population is insured within statutory funds. These are characterized by pay-as-you-go financing and income-dependent but risk-independent contributions.

There are no different funding sources for community-living and nursing home-based individuals, but the responsibility of SHI versus LTCI is defined by the type of service required: SHI covers acute health care needs and temporary nursing needs (e.g. household support after a fracture). It is designed as full coverage insurance providing almost free access to a broad range of medical services. In contrast, LTCI accounts for durable ADL impairment and has only a supportive character. Hence, long-term care services are only reimbursed up to a fixed ceiling amount, which depends, first, on the type of service utilized and, second, on the patient’s ‘care level’ (ADL dependency group).

LTCI data and SHI data are managed under one umbrella, but the corresponding services are financed by either LTCI contributions or SHI contributions.”

3) It is unclear what the authors mean with a ‘payer perspective’ (e.g. as used in the abstract, introduction, discussion). The authors address this briefly in the discussion section but the paper would benefit if it was presented earlier (e.g. in the introduction)

The term ‘payer perspective’ is common in health economic literature and accounts for the bodies which reimburse the services used. In our paper it refers to the German Statutory Health Insurance (SHI) together with the Compulsory Long-Term Care Insurance (LTCI). The combination of both insurance branches is referred to as “the social security system”.

For further clarification, the term ‘payer perspective’ is now defined in the abstract and within the manuscript.

- ABSTRACT (see page 2):

  “Adopting the perspective of the German social security system, which combines Statutory Health Insurance and Compulsory Long-Term Care Insurance (payer perspective), our study aimed to compare community-living and in-
institutionalized dementia patients regarding their health care service utilization profiles and to contrast the respective expenditures.”

• INTRODUCTION (see page 4):

“According to the Federal Statistical Office, the German social security system, represented by the Statutory Health Insurance (hereafter SHI) together with the Compulsory Long-Term Care Insurance (hereafter LTCI), spent ca. €10.5 billion on treating dementia disorders in 2008. This equals ca. 8.4% of the entire public health and long-term care spending on individuals aged 65 and older. Dementia is a substantial economic burden for the public health sector and, from this payer perspective, professional long-term care in an institutional setting is the crucial expense factor.”

4) The discussion needs major rewriting. Please restructure the discussion and start with answering your research question. What are your main results? It is not that the two samples differ since that has been reported before. Please start with your conclusions on costs of care and whether these are different for community and nursing home. For example, in my opinion the first three to four paragraphs of the discussion are unnecessary and should be deleted. For example, what is the point the authors are trying to make in the second paragraph? At first this appears a methodological reflection on the German system of measuring care level. Why is this relevant? Everybody would agree that care level and need for care is not captured by ADL only. But how does this influence your results? And why is the discussion on need for care relevant at this point?

We share the reviewer’s opinion that the main finding of our study is not that community-living and institutionalized dementia patients have different baseline characteristics (see comment on remark 1). Therefore we dropped the first paragraph of the discussion section dealing with the necessity of performing adjustment for clinical and demographic differences. Instead the discussion starts now with a brief summary on the differing health and long-term care expenses as recommended by the reviewer (see pages 13 and 14).

In addition we shortened reflective paragraphs on the German health and long-term care system wherever it seemed appropriate to better abstract away from a national level and to further increase the international relevance of our findings.

However, we believe that it is necessary to keep the contents of the third and the fourth paragraph of the discussion section which deal with the strengths and limita-
tions of claims data-based research. We consider corresponding information to be indispensable to judge the informative value of the study results. In this context we now even describe each restriction in a separate paragraph. In order to ensure a smooth reading of the manuscript the corresponding paragraphs were shifted to the middle of the discussion section and follow now the interpretation of the results on page 16.

We also incorporated the discussion on care levels which was referred to in the second paragraph again but reworked the text slightly. The underlying idea is that care levels can serve as a rough proxy for dementia severity, with higher care levels indicating more advanced cognitive decline.

The assumption that individuals with more severe cognitive impairment are less likely to be found in lower care levels is based on experiences of a previous own study which revealed the following care level distribution among the 319 community-living participants:

- Patients with mild dementia (18 ≤ MMSE ≤ 24): No care level: 63.5%, care level 1: 21.8%, care level 2: 13.7%, care level 3: 1.0%.
- Patients with moderate dementia (10 ≤ MMSE ≤ 17): No care level: 23.2%, care level 1: 37.0%, care level 2: 31.6%, care level 3: 9.3%.

Thus, despite lacking explicit clinical information on the patients’ cognitive status, claims data-based studies can at least partially account for corresponding information by proxy variables (see page 16).

- “First, claims data lack information on cognitive status. (…) If accepting a relation between cognitive and physical decline, the care level strata can serve as a rough proxy for disease severity and at least partially reflect how worsening symptoms of dementia affect health and long-term care expenditures in both settings.”

5) Discussion, p.13 paragraph ‘Contrary to LTCI…LTCI services. This section provides rather technical information and is difficult to understand for readers outside Germany. Please try to make it more understandable and relating it to more general funding sources or put it in international relevant context.

Within the mentioned paragraph, the intermediate position of home health care is maybe explained in a too sophisticated manner. To avoid confusion, the paragraph was condensed (see page 14):

- “Comparing the health care expenditures between both settings, it has to be
kept in mind that SHI services include ‘home health care’, which accounts for short-term medical nursing and temporary household support in community-living individuals. These services are by definition not available for nursing home residents.”

Minor essential revisions

1) Method, p.4. I don’t understand what you mean with dementia quarters. Furthermore, why have the authors included patients based on dementia drugs to diagnose? What do you mean with dementia drugs? It would be helpful if you could define this this using ATC classification coding system. And do all patients with a dementia diagnoses have access to these drugs? From the literature it is known that this may not be the case. Furthermore, why is a diagnoses based on physician judgment in itself not sufficient?

Within the German SHI system physician report their diagnoses on a quarterly base. As a consequence the exact date of a diagnosis is unknown and the quarter of the year is the most exact point of reference. The concept of dementia quarters is explained in detail in:


Basically, a ‘dementia quarter’ is each quarter with at least one diagnosis of dementia defined by the ICD 10 codes ‘F00’, ‘F01’, ‘F02’, ‘F03’ and ‘G30’ and/or at least one filled prescription on cholinesterase inhibitors (ATC code N06DA) or memantine (ATC code N06DX01). The corresponding ICD-10 codes and ATC codes are now added (see page 5).

We decided on regarding prescriptions of these drugs as on par with an explicit diagnosis, since in Germany cholinesterase inhibitors and memantine are licensed for the treatment of Alzheimer’s dementia only. Thus, a person receiving a corresponding drug has for sure dementia even an explicit diagnosis is missing within the corresponding quarter.

There were several reasons for combining inpatient and outpatient diagnoses with anti-dementia drug prescriptions to identify our patients: 1) Due to billing purposes a dementia diagnoses might be documented with some delay 2) Outpatient diagnoses of dementia might not be tracked regularly after the incident diagnosis, especially if a pa-
tient contacts the physician for other reasons than dementia. 3) For some physicians dementia is still a sensitive issue and they might avoid an explicit diagnosis but nevertheless they still ‘treat’ the condition.

The included anti-dementia drugs are theoretically available for all patients because the German SHI reimburses cholinesterase inhibitors and memantine. However, the factual access to these drugs depends on the individual physician’s attitude towards anti-dementia drug therapy.

2) Method, p.5. please explain what you mean with an institutional setting. Is this nursing home care specifically or does it also include residential care or sheltered housing?

We are grateful for this valuable remark of the reviewer. Indeed, institutional care does explicitly address nursing-home residents. This patient group is now defined unambiguously by rewording the corresponding sentence (see page 6):

- “This sample was classified as community-living or institutionalized in a nursing home based on a distinct component of long-term care insurance called ‘institutional care’”.

3) Results, p.10 ‘focusing on…community setting’. Please rephrase. Looking at table 3 statement appears only true for care level 1, and 2 (except for 1 service); care level three picture is much more mixed with many ns values for nursing home residents as well.

Within the reworked manuscript this paragraph was reworded and refers now explicitly to the care levels concerned (see pages 11 and 12).

- “Table 3 focuses on the intensity of per capita service utilization and shows that nursing home residents assigned to care levels 1 or 2 (…). In care level 3, (…)”.

4) Results, p.10. What do the authors mean with the sentence ‘the observed patterns…service users only?’

Our tables refer to mean utilization per capita. Hence the denominator includes both service users and non-users. Therefore the presented figures are first influenced by the intensity of service use by service users and second by the user quota. For example a high user quota could compensate for a low intensity of service use (e.g. 85% and 8 visits per user 7 visits per capita) and vice versa (e.g. 20% and 35 visits per user 7 visits per capita). To judge the impact of the user quota we also looked at the mean per
capita utilization of service users only. Here we of course observed a higher intensity of service utilization but the relation between community-living and the institutionalized individuals was comparable to the previous analysis which also included the non-users.

To avoid confusion we dropped this sentence.