

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Likelihood that Expectations of Informal Care will be Met at Onset of Caregiving Need: A Retrospective Study of Older Adults in the United States
AUTHORS	Abrahamson, Kathleen; Hass, Zachary; Sands, Laura

VERSION 1 – REVIEW

REVIEWER	John Pastor Ansah Duke-NUS Medical School. Singapore
REVIEW RETURNED	07-Jul-2017

GENERAL COMMENTS	<ol style="list-style-type: none">1. It is important to know if the potential caregivers unable to provide care are contributing financial resources to ensure that the care recipient is cared for.2. The authors did not define what caregiving means in this paper. Those caregiving means physically providing all the ADL/IADL needs or the respondents? Any indication of the care hours provided?3. What was the employment status of the potential caregivers prior to the development of the ADL and after the development of ADL needs? Those employment status affect the likelihood of becoming caregiver among the potential caregivers?4. Table 1 baseline characteristics shows average ADL at baseline is 2. However, in the “analytic sample” the authors indicated that respondents were independent in their ADL tasks in the initial interviews. Can the authors clarify this inconsistency?5. If the potential caregiver listed is paying for the care the elderly is receiving, is that considered as providing care?6. Can the authors compare health outcomes of the elderly receiving needed care to those not receiving needed care to understand the likely impact of unmet care needs.7. What are the reasons for the potential caregiver’s inability to provided care?
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REVIEWER	Yoshihisa Hirakawa Nagoya University Graduate School of Medicine, Japan
REVIEW RETURNED	16-Aug-2017

GENERAL COMMENTS	This paper deal with important topic. However, the difinitions of the key words such as "need" is too abstract to accept the paper as a scientific one. This research fail to collect enough data to examine the research questions.
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REVIEWER	Yan Li The New York Academy of Medicine
REVIEW RETURNED	03-Oct-2017
GENERAL COMMENTS	The manuscript addresses an important question in long-term care policy research. It is very well written. The analysis is fairly straightforward, but it is clearly presented and well justified. I would recommend acceptance of the manuscript in its current form.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1:

1. Reviewer 1 commented that it is important to know if the potential caregivers that are unable to provide care are contributing financial resources to ensure that the care recipient is cared for through formal services.

Response: We agree that examining the expected caregiver's provision of financial resources in lieu of physical or instrumental care would be important. The HRS contains variables asking if care is received from a formal service, and who pays for that service (insurance, public financing, family). There are also questions asking if the respondent has received financial assistance (not specified to care), and from whom. However, the HRS data regarding is provision of payment is not specific enough to link any payment for care back to the expected caregiver, nor is it able to link any financial resources provided from a family member specifically to caregiving, and therefore we are unable to determine whether the expected caregiver is paying another to provide needed care. The focus of this paper is expectations of care from specified individuals and whether those expectations have been met. Because our research question specifically addressed whether expected care was received from the expected caregiver, we (manuscript p. 5) define paid services as an unmet expectation, which is important because it informs the importance of frequently discussing plans for future care needs. This important point has been added to the limitations section of the manuscript (p.10).

2. Reviewer 1 commented that the authors did not define what caregiving means in this paper. Those caregiving means physically providing all the ADL/IADL needs or the respondents? Any indication of the care hours provided?

Response: It has now been added to p. 5 of the manuscript that care is defined as personal assistance with any ADL/IADL need. The total hours of help per day by caregiving status are:

Unmet Expectations: Avg = 7.8, SD = 8.7

From Expected Caregiver: Avg = 6.9, SD = 8.3

Met Expectations Total: Avg = 7.2, SD = 9.0

We defined any level of care assistance from the expected caregiver as receipt of care from the expected person. We have added these numbers to the findings section of the manuscript.

3. Reviewer 1 asked: What was the employment status of the potential caregivers prior to the development of the ADL and after the development of ADL needs and whether the employment status of the chosen caregiver affected the likelihood of becoming caregiver among the potential caregivers?

Response: We agree that employment status of potential caregivers would be important to know. However, this is not available in the data. We have added this to the limitations section of the manuscript (p.10).

4. Reviewer 1 commented that Table 1 baseline characteristics shows average ADL at baseline is 2.

Response: However, in the “analytic sample” the authors indicated that respondents were independent in their ADL tasks in the initial interviews. Can the authors clarify this inconsistency? Table 1 has been edited for clarity.

5. Reviewer 1 asked: If the potential caregiver listed is paying for the care the elderly is receiving, is that considered as providing care? Not unless they are also providing some level of personal care.

Response: Please see the response to Reviewer 1, comment 1.

6. Reviewer 1 asked if the authors are able to compare health outcomes of the elderly receiving needed care to those not receiving needed care to understand the likely impact of unmet care needs.

Response: We appreciate this suggestion as our prior work shows the reviewer is correct in the assumption that unmet expectations for disability care is associated with poor health outcomes. We did not duplicate this work partly because it would require the acquisition of linked CMS data. Our relevant publications include:

Xu H, Covinsky KE, Stallard E, Thomas III J, Sands LP. Insufficient help for ADL disabilities and risk for all-cause hospitalization. *Journal of the American Geriatrics Society*, 60:927-933, 2012, doi: 10.1111/j.1532-5415.2012.03926.x.

Hass Z*, DePalma G, Craig BA, Xu H, Sands LP. Unmet need for help with activities of daily living disabilities and emergency department admissions among older Medicare recipients. *The Gerontologist*, Online 2015, doi: 10.1093/geront/gnv142.

He S, Craig BA, Xu H, Covinsky KE, Stallard E, Thomas J, Hass Z, Sands LP. Unmet need for ADL assistance is associated with mortality among older adults with mild disability. *Journals of Gerontology: Medical Sciences*, 70(9): 1128-1132. 2015. doi:10.1093/gerona/glv028

7. Reviewer 1 asked: What are the reasons for the potential caregiver's inability to provided care?

Response: We agree that this is an interesting question, and one that should be addressed in future studies. The current HRS data does not have reasons that expected care is not received as a variable. We linked the data longitudinally to match expectations to caregiving, and a specific question regarding unmet expectations is not asked. We have noted in the Discussion section that future qualitative research is needed to further in-depth on this topic.

Reviewer 2:

Reviewer 2 commented that the paper deals with important topic. However, the definitions of the key words such as "need" are too abstract to accept the paper as a scientific one, and that the research fails to collect enough data to examine the research questions.

Response: We have defined need as the respondent's self-report that they require assistance with any ADL/IADL task. This is a standard term used in geriatric literature. We have defined care as the personal provision of assistance with any ADL/IADL task. We defined expectation as an expressed statement from the respondent that if they needed assistance in the future the named individual would provide that needed assistance. Although our data has limitations, as noted above, it remains a unique source of expressed expectations of caregiving, over time, for a nationally representative sample of aging adults in the United States. We appreciate the Reviewers' comment, and hope that we have addressed these concerns.

VERSION 2 – REVIEW

REVIEWER	John Pastor Ansah Duke-NUS Medical School, Singapore
REVIEW RETURNED	23-Oct-2017
GENERAL COMMENTS	The authors have addressed all the issues and I believe the paper is ready for publication.