Author’s response to reviews

Title: Caregiving associated with selected cancer risk behaviors and screening utilization among women: results of the 2009 BRFSS

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Author’s response to reviews: see over
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Jiqisha Patel
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Dear Dr. Patel,

Thank you for your feedback regarding our recently submitted manuscript. We appreciate the two reviewers’ helpful comments and careful review of our manuscript. We have made most of their suggested changes, and believe that the manuscript has been strengthened as a result. Below, we present each comment, followed by how we revised the text.

Reviewer #1

Major compulsory revisions:

1. “The study can benefit from a conceptual model to undergird the research question and the discussion of the findings and potential study limitations. …”
   - The Caregiving Stress Process Model (Pearlin et al, 1990) outlines how various aspects of the caregiving situation could contribute to adverse psychological and physical health outcomes in caregivers. We have included a sentence and reference to this model to how caregivers, as a result of chronic stress, demands of caregiving, or as a coping mechanism, could engage in health risk behaviors and not maintain cancer screening behaviors.

2. “The study employs backwards elimination to select covariates for each of the separate model estimates. … Also, the results section presents point estimates and confidence intervals using models that include different covariate sets, meaning that the point estimates are not comparable across models. But the estimates are presented as being comparable. This should be addressed in the manuscript. The set of variables included in the models would be most useful if they were based on theoretical and conceptual understandings rather than a computer-generated method. I would therefore recommend using an alternative method to justify covariate selection.”
   - Regarding selection of variables, we first identified a set of variables likely to be relevant and based on our conceptual understanding of the research questions. Backwards elimination was then used to identify a parsimonious statistical model based on this subset of variables. We prefer to continue to use this model building strategy, although we have revised our model building strategy to adjust for a common set of variables within each disease (i.e. one set of variables for breast cancer-related outcomes and another set for cervical cancer-related outcomes). The models for the health behavior outcomes were already adjusted for a common set of variables.

3. “The study relies upon breast and cervical cancer screening guidelines proposed by the American Cancer Society (ACS). It would be useful to discuss recent changes to the ACS guidelines in the discussion section and not just in the introduction, as well as to incorporate those changes into the analysis. Accordingly, in the discussion section, the sentence, “Our definition of meeting guidelines as
having a Pap test within the previous three years is likely to be overly conservative,” is not necessarily correct. Also, 21% of the study sample of caregivers was over age 65 and the ACS guidelines for women in this age range recommend no cervical cancer screening for women with regular testing and normal results. 84% of caregivers received cervical cancer screening within guidelines, suggesting that potentially most caregivers were screened according to guidelines. Perhaps presentation of information regarding the proportion of women ≥65 could clear up this issue. Finally, it might be useful to present information regarding guidelines presented by the U.S. Preventive Services Task Force (USPSTF), which recommends biennial mammography for women ≥50 (including what percentage of caregivers in this study would have followed guidelines), or justify why ACS guidelines were chosen for this study.”

- The reviewer makes good comments here. However, since the BRFSS survey took place in 2009, we prefer to base our determination of “within guidelines” based on the guidelines in place at the time of the survey. Recent changes to ACS and USPSTF guidelines are thus not relevant to the analysis, but do deserve comment in the Discussion section, which we have added.
- We do believe that our statement regarding the possibility of our classification of Pap testing being overly conservative is correct. The ACS guidelines for cervical cancer screening recommend more frequent screening depending on HPV status and history of previous Pap test results. Thus it is likely that there is a sizeable proportion of women for whom screening is recommended at a frequency greater than once every three years.
- Additionally, the ACS guidelines in 2009 did not specifically recommend against screening for age ≥65, but rather indicated that women age ≥70 with a history of normal tests “may choose to stop cervical cancer screening.” (American Cancer Society. Cancer Facts & Figures, 2009)
- We chose ACS guidelines as they are likely to be better-known to the general public than those of other organizations. For simplicity, we chose to use only a single set of guidelines, though we recognize that screening guidelines may differ across organizations. We have added a discussion of this issue to the text.

Minor Essential Revisions:

Introduction:
1. In the first paragraph, citation #5 is incorrect—it does not refer to caregivers. I think you may perhaps be citing a report by the National Alliance for Caregiving? And, if so, is there possibly a factual error with the figures listed in the first sentence of the second paragraph?
   - We appreciate the reviewer catching this error, and we have provided the correct reference in the revised manuscript.

2. Second sentence: the “health effects of caregiving are…”
   - This has been revised as suggested.

3. In the second sentence of the fourth paragraph, it is preferable not to have such a precise number (209,060) with the modifier, “approximately”.
   - This number is estimated cases, not actual cases, and are therefore based on statistical prediction, which has some uncertainty. However, we see the reviewer’s point. We have substituted the word “estimated” for “approximately.”

Methods:
4. The manuscript would improve if unweighted estimates (reported in Table 1 and elsewhere) of the study sample were provided. The study would also benefit from clearly identifying the analytic sample size for each logistic model and indicating whether complete-case analysis was used in each model.
The CDC recommends against reporting unweighted numbers in published manuscripts, thus we have not provided them in our revision. We have added more detail on the unweighted numbers in the Methods section, which we feel gives the reader a better sense of the data on which our analyses are based.

Yes, complete-case analysis was used in each model. We have clarified this in the Methods section.

Results:
5. The statement about 30% more likely across several outcomes (in the 2\textsuperscript{nd} paragraph under Cancer Risk Behaviors) could be misleading due to the fact that different adjustments were made across the models.
   - As we stated in the text, each model was adjusted for a common set of factors. Thus we have not made any revisions in response to this comment.

6. It is advisable to avoid use of the word “likely” (throughout the results section) when using logistic regression output, unless you computed relative risks from the ORs.
   - We have revised the text as requested.

7. In the second paragraph of the Cancer Risk Behaviors section, the reference to the interaction term (age x body mass index) was unclear—which of the models is referred to?
   - We have clarified the interaction model referred to in the revised manuscript.

8. Under Cancer Screening Behaviors, what does “trend” refer to? Is this a p-trend? If so, that is not referenced in the results or methods sections.
   - We have revised the Results section for clarification as requested.

Discussion:
9. In the last paragraph of Cancer Screening Behaviors) the associations of obesity, smoking, and physical activity are described as varying by age and race. However, in Tables 3 and 5 there appear to be sizeable overlaps of the CIs for a number of the age- and race- stratified models.
   - We have revised the text to indicate that these associations were not always statistically significant, but were suggestive of differences by age and race.

10. The third sentence of the fourth paragraph is not clear (“…by the health and the relationship…”)
    - We have revised this sentence as requested.

Conclusion:
11. In the 2\textsuperscript{nd} sentence, there appears to be a typo—it should probably read, “approximately one-third of caregivers had not been screened for breast cancer…”
    - We have revised this sentence as requested.

Discretionary Revisions:
Introduction:
1. Citations #9 and #10 were listed as being limited for not being stratified by gender, but those studies were not focused on cancer prevention, but rather general preventive health behaviors so it is not clear if stratification would have been beneficial in the manner the authors suggest.
   - We agree with the reviewer that the Burton et al study and Scharlach et al study were focused on general preventive health behaviors. However, Scharlach et al assessed
screening mammography use, as well as other health promotion activities. These studies also investigated several of the same risky health behaviors that we investigated in the BRFSS, such as alcohol use, smoking status, and weight. We stated that a limitation of these studies was lack of stratification by gender because these behaviors tend to have different distributions in men and women, and may, in fact, have different associations with caregiving in men and women. By not stratifying by gender, the reader cannot tell whether caregiving was associated with these behaviors in women, since women were the focus of our analyses.

2. It may be useful to indicate hypotheses for the stratified analyses.
   - We have revised the text as requested.

3. The study may benefit from defining the terms stress, psychological distress, chronic stress, and chronically high stress in the first and second paragraphs.
   - In the first two paragraphs, we now clarify that caregivers have higher levels of self-reported stress and psychological distress, such as depressive symptoms and anxiety. In several places in the Introduction, we now refer to stress as “feelings of stress” and “self-reported stress.”

4. It might be useful to have a uniform set of either positive or negative health behaviors to provide consistency in interpretation of parameter estimates. For instance, one could use the terms smoking, alcohol use, obesity, sedentary behaviors, insufficient fruit/vegetable consumption, and code accordingly.
   - We thank the reviewer for this suggestion, though we prefer to maintain the comparisons presented in the original manuscript.

Methods:
5. Clarification of the coding of the alcohol use covariate may be useful. Is alcohol use defined as the number of drinks each day (the text indicates per time) that a subject drank, and did you assess consumption per day as \[(\text{days drank in past month} \times \text{drinks per day during days with drinking}) / \text{days per month}\]?
   - The alcohol variable used was one calculated by the BRFSS and included in the downloaded dataset. We have clarified this in the revised manuscript.

6. It may be useful to explain in the body of the manuscript that the study’s health behavior variables, which were outcome variables, were also used as predictors in the models with cancer screening as the outcome.
   - We have revised the text in an attempt to clarify this issue.

7. In the statistical analysis, it could be beneficial to run a sub-analysis including the income covariate (for a limited study population) and compare the results to the other models. Not using income could create residual confounding (if income is related to caregiver status and to a predictor of screening such as insurance or to health knowledge).
   - We agree that there is potential for residual confounding by income, but given the high degree of missing data in this variable, any sub-analysis including only those with income data would be uninformative and potentially from a biased sample. We do, however, adjust for other measures of socioeconomic status (education, employment, health insurance status).
8. It could be useful to describe how vegetable/fruit consumption was measured (was it based upon a portion size conversion, for instance).
   - Again, this variable was calculated by the BRFSS and included in the dataset. We have clarified this in the revised manuscript.

Results:
9. It may be unnecessary to use the word significant when describing associations in this section. If you are reporting an association, then the reader can infer that the association is significant (unless you specify otherwise).
   - We appreciate the reviewer’s suggestion, but we prefer to specifically note when results are statistically significant.

10. Under Cancer Risk Behaviors, rather than stating that caregivers were more likely to be obese, it could be more accurate to state that they had greater odds compared to non-caregivers of “reporting being obese”.
   - We have revised the text as requested.

Discussion:
11. It may be beneficial to include additional references to literature on caregiver health behavior—there are at least 10 or 15 additional studies not cited in this manuscript—although those studies do not exclusively examine cancer risk behaviors.
   - We agree that there many publications on differences in health behavior between caregivers and non-caregivers but we focused primarily on cancer-related literature in order to provide a concise manuscript and not exceed word limits. We cite the Pinquart and Sorensen (2003) meta-analysis of studies of physical health in caregivers and non-caregivers to cover many studies that we did not cite specifically in this manuscript.

Reviewer #2
Minor essential revisions:
Change the weighted frequencies reported to unweighted numbers. The methods used to achieve the sample may allow inference to be made to the population as a whole, however your analysis was carried out with a sample, and this should be reported. You don’t seem to make any reference to the population as a whole in your discussions, so reporting the weighted frequencies may not be required at all.
   - Please refer to our response above. We prefer to base inference off of the weighted frequencies, as this is what is recommended by the CDC.

Discretionary revisions:
Title – The title would be better with a mention of the major finding of the study.
   - We have revised our title to better-reflect the focus of our study.

Page 4 - “Likewise, they may neglect health promotion activities, such as regular cancer screening, due to chronic stress or the time constraints of caregiving” [REFERENCE?] Are there any studies that investigate the reasons why caregivers may change their health behaviours? For example would those caring for a chronically ill relative over a number of years behave differently to those offering end of life care, with regard to cancer risk behaviours and/or screening; or those who are long term carers v those new to caregiving?
   - This is an interesting question. To our knowledge, most studies that compared caregivers and non-caregivers on health promotion activities did not assess the reason why caregivers changed their health behaviors. However, Burton et al (1997) specifically
asked respondents whether they “forgot to take medications” or delayed or missed a doctor’s appointment.” Forgetting to take medications and not having time for a doctor’s appointment were significantly associated with performing more hours of caregiving activities. We have added the Burton et al reference, as well as references to previous studies that have posed that the time constraints of caregiving interfered with health promotion activities (Kim et al, 2004; McGuire et al, 2010).

Page 4 - “In fact, older caregivers may be healthier than their peers, and may attempt to maintain good health in order to continue providing care to their care recipient.” [REFERENCE?] Is this an assumption, or are there any (qualitative) studies that add weight to this claim?

- We cite Fredman et al (2010) who found that older women caregivers had significantly fewer medical conditions and impairments in activities of daily living than their non-caregiver peers. We do not know of any studies that asked caregivers whether they tried to maintain good health in order to continue providing care for their care recipient. We have revised that sentence to cite this study, and then pose that these health differences may reflect that older caregivers attempt to maintain their health in order to continue providing care to the care recipient.

Page 5 - “Therefore, we used data from female respondents to the 2009, Behavioural Risk Factor Surveillance System (BRFSS) to examine the association between caregiving and modifiable behaviours known to decrease overall cancer risk, such as smoking, alcohol use, obesity, physical activity, and fruit/vegetable consumption and on breast cancer cervical cancer screening.” Should this read increase/decrease?

- We have revised this sentence as requested.

Page 9 – how is the sample stratified?

- Details of the BRFSS sampling strategy are available elsewhere. For our analyses, we performed analyses on the entire study population as well as separate analyses stratified at age 65 and another set of analyses stratified on race.

Page 14 “given their frequent contacts with the health care system due to their roles as caregivers, this is a population subgroup that may be especially amenable to such interventions.” [REFERENCE]. Are there any studies to support this? I could conceivably see the opposite of this occurring.

- We have added a citation to a randomized controlled trial by Connell and Janevic (2009) that succeeded in increasing physical activity and reducing stress in sedentary caregivers to a spouse with dementia.

Is the effect of being a caregiver on cancer risk behaviours and screening utilization permanent or transitory? The question in the BRFSS asks if women have been carers in the past month. This captures those women who are current carers, but could it be true that women who answer no to this question may have changed their behaviour in the past due to their experiences of caregiving? What would this do to the results? (Minimise the differences between groups?).

- We appreciate this important point, and we have added discussion of this issue as a limitation of our analysis.

Thank you for your time and consideration. We look forward to hearing from you regarding our resubmission.
Sincerely,

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