

## 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

<b>TITLE (PROVISIONAL)</b>	Characteristics and well-being of urban informal home care providers during COVID-19 pandemic: a population-based study
<b>AUTHORS</b>	Chan, Emily; Lo, Eugene; Huang, Zhe; Kim, Jean; Hung, Heidi; Hung, Kevin KC; Wong, Eliza LY; Wong, Samuel; Gobat, Nina

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Birgitte Schoenmakers University of Leuven, Belgium Dept of Public Health and Primary Care
<b>REVIEW RETURNED</b>	24-Jun-2020

<b>GENERAL COMMENTS</b>	<p>Dear Author</p> <p>This is a very well developed study. all my comments are included in the PDF version of this manuscript. My major concern are the inclusion criteria and the definition of the studied group (informal caregivers). You really need to clarify this. As it is described now, I can not confirm or endorse the results.</p> <p>Kind regards, Birgitte</p> <p>The reviewer provided a marked copy with additional comments. Please contact the publisher for full details.</p>
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<b>REVIEWER</b>	Dr Kerrie Noonan Adjunct Research Fellow, Western Sydney University
<b>REVIEW RETURNED</b>	19-Jul-2020

<b>GENERAL COMMENTS</b>	<p>This article provides insights into the needs of informal caregivers. It provides a good review of the literature in the field and how this research adds to it. The limitations are also dealt with well. It provides further evidence about the needs of informal caregivers, particularly during COVID.</p>
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### VERSION 1 – AUTHOR RESPONSE

1<sup>st</sup> (Line 98 – 104)

**Sentence with reviewer's comment:** *"The quarantine policy had resulted in 13,649 individuals under compulsory home quarantine from 13 Mar to 26 Mar 2020. In such a public health emergency which non-essential service were cut down to minimize the infection possibility, informal care may be the only care option for people in need. There have been no published studies of informal care providers during extreme events or during population-level health emergencies. Hence, the impacts on informal*

*home care providers from the closure of community services and limited access to healthcare services during the COVID-19 are yet unknown.*

**Reviewer's Comment:** "I lost the clue here: do you mean that within this group there are many informale caregivers that are not able to provide care or do you mean that there are many care receivers who are left without home care?"

**Reply:** *"Thanks for your comment. We mean that many care receivers who are left without home care. An additional sentence is put to make it more clear. "*

**Action:** *Adding a new sentence – "In such a public health emergency, informal care may be the only care option for people in need"*

2<sup>nd</sup> (Line 106)

**Sentence with reviewer's comment:** *" children aged under "*

**Reviewer's Comment:** *"needing home care? Or in another way involved or affecting home care?"*

**Reply:** *"Thanks for your comment. They were needing home care. We have revised the next sentence to make it more clear."*

**Action:** *Change this sentence "Combined, these households accounted for 27.2% of the whole Hong Kong population..." → "Combined, these households were particularly in need of home care even in ordinary setting, accounting for 27.2% of the whole Hong Kong population..."*

3<sup>rd</sup> (Line 130)

**Sentence with reviewer's comment:** *" A self-reported, semi-structured Chinese questionnaire"*

**Reviewer's Comment:** *"why didn't you use a burden scale as this is most reliable predictor of stress and depression?"*

**Reply:** *"Thanks for your comment. Unfortunately, we did not use burden scale in this study. This study explored wide topics related to COVID-19 pandemic. An additional sentence is put for further details about the questionnaire."*

**Action:** No action taken

4<sup>th</sup> (Line 130)

**Sentence with reviewer's comment:** *" 141 questions" (already deleted in the revised version)*

**Reviewer's Comment:** *"really, 141 questions? How long did the phone call take?"*

**Reply:** *"Thanks for your comment. Yes, each phone call took about 30 to 40 mins."*

**Action:** *"The '141 questions' is deleted"*

5<sup>th</sup> (Line 134-136)

**Sentence with reviewer's comment:** "care providers were identified through one of the questions in the questionnaire "Do you currently need to look after member(s) of your family and relatives' daily needs"

**Reviewer's Comment:** "so only provision of care within the household in quarantine? That is not clear from your introduction, see also comment there. The definition and scope of informal caregiver go further than care provision in house.

*Until now, it is unclear for me what exactly the output/impact of this research will be: delivering informal home care is a heavy job and causes burden and stress. I am not sure if by the inclusion strategy you use now, you will reach the right group of caregivers"*

**Reply:** "Thanks for your comment. Since this study aimed at identifying the patterns of informal home care, we would like to conduct a population-wide telephone survey in order to figure out the percentage of care provider in Hong Kong. So that our sample population included those who were 18 years old or older, and speak Cantonese.

*People in need of home care were not limited to those under quarantine, but healthy children due to the closure of schools for example.*

*We have also revised the sentence in the manuscript"*

**Action:** Adding the sentence prior to the highlighted part – "Since the home care recipients could include a wide range of different groups (e.g. healthy children due to the closure of schools)"

6<sup>th</sup> (Line 141 – 142)

**Sentence with reviewer's comment:** "(defined as inability to maintain activities of daily living without care provider assistance )."

**Reviewer's Comment:** "did you confirm this by using an objective care measurement instrument? Katz? Lawton&Brody?"

**Reply:** "Thanks for your comment. Unfortunately, this study did not use objective care measurement instrument. This was a self-reported question."

**Action:** No action taken

7<sup>th</sup> (Line 147 – 149)

**Sentence with reviewer's comment:** "and other related health impact (ranging from 1= no impact to 5= maximum impact). Respondents were asked about their home care experience, risks perception, household capacity to provide care and home care challenges that they experienced."

**Reviewer's Comment:** "is it correct that the informal caregivers included here were not caregivers before lockdown but became caregiver out of necessity?"

**Reply:** "Thanks for your comment. This study did not investigate if the informal care providers during COVID-19 were caregivers before the lockdown. We have observed this limitation and we will include this question into the next stage of our study."

**Action:** No action taken

8<sup>th</sup> (Line 188-189)

**Sentence with reviewer's comment:** *"children represented 55.2% (being taken care of by parents)"*

**Reviewer's Comment:** *"in what way children do need care? Are these chronically ill children or children with particular care needs?"*

**Reply:** *"Thanks for your comment. These children usually receive the daily care in school. Due to the closure of schools, they were in need of home care. Their chronic condition or particular need were not specified."*

**Action:** No action taken

9<sup>th</sup> (Line 192)

**Sentence with reviewer's comment:** *"isolation requirements"*

**Reviewer's Comment:** *"what do you mean by that."*

**Reply:** *"Thanks for your comment. It is revised."*

**Action:** Changed 'isolation requirement' into 'had to stay at home'

10<sup>th</sup> (Line 194)

**Sentence with reviewer's comment:** *"completely care dependent"*

**Reviewer's Comment:** *"during or due to this lockdown or also before?"*

**Reply:** *"Thanks for your comment. This care dependent state implies "during" the epidemic. Further description of the state is added in the sentence."*

**Action:** We have added "during the epidemic" in the sentence.

11<sup>th</sup> (Line 217 – 218)

**Sentence with reviewer's comment:** *"Nearly one in five of informal home care providers reported that they had to take personal leave from work or school to take care of their families"*

**Reviewer's Comment:** *"because there was no formal care available? Brings me back to one of my first comments"*

**Reply:** *"Thanks for your comment. In normal days, the informal care recipients were taken care in community service center or school. But during the COVID-19 pandemic, with the closure of these facilities, the informal home care providers had to take up the responsibilities."*

**Action:** Adding "during this COVID-19 pandemic" in the beginning

12<sup>th</sup> (Line 234 – 236)

**Sentence with reviewer's comment:** "More than half of the informal home care providers were responsible for caring for more than one individual and nearly 20% (36/192) of respondents reporting that they needed to provide care to 3 or more household members"

**Reviewer's Comment:** "What is the definition of caregiving here? Or is there a sudden increase in care need due to the lockdown? I think this issues and confusion all has to do with the inclusion criteria, the definition of caregiving and the unclear scope of the research"

**Reply:** "Thanks for your comment. The definition of caregiving did not change in this study. The definition is as same as previous described."

*In this paragraph, we described the characteristics informal home care providers in Hong Kong, which was one of our study objectives. We found that about 20% of the population reported that they needed to provide care to 3 or more household members. We did not imply if this is related to the sudden increase in care need."*

**Action: No action taken**

13<sup>th</sup> (Line 278-279)

**Sentence with reviewer's comment:** "however, showed that these perceptions were not associated with age, sex and education attainment nor the number of care recipient"

**Reviewer's Comment:** "in general this is related to the perceived level of burden and coping strategies of the caregiver. Did you measure that?"

**Reply:** "Thanks for your comment. This study did not measure the burden and the coping strategy of the care providers directly. But we agreed that having a dependent care recipient and having to take personal leave to provide care contribute to a higher burden of care."

**Action: No action taken**

14<sup>th</sup> Line (323 -324)

**Sentence with reviewer's comment:** "During large-scale public health emergencies, home care may be the only viable method of providing continuous health care due to disruption of services and transportation."

**Reviewer's Comment:** "ok, here it becomes more clear. You really should clarify this in you introduction. Second, you need to specify inclusion parameters and background of the caregiving context"

**Reply:** "Thank for your comment. We have added more information in the Introduction;

*and since we would like to figure out the percentage of care provider in Hong Kong, a population-wide telephone survey was conducted."*

**Action: No action taken**

15<sup>th</sup> (Line 327 – 330)

**Sentence with reviewer's comment:** *"includes not only people caring for those with confirmed or suspected COVID-19; but also care for people with non-COVID-related conditions that may require essential life sustaining care, health maintaining support, or/and additional care during this period.."*

**Reviewer's Comment:** *"how do the caregiving for children fits here? That was not clear? were these all care needing children?"*

**Reply:** *"Thanks for your comment. It is revised according to your comment."*

**Action:** *Changing "...related condition that...." into "...related condition (for example the health maintaining support ,and essential life sustaining care), and their usual care responsibility for their family members"*

16<sup>th</sup> (Line 333 -334)

**Sentence with reviewer's comment:** *"In our general population study sample of Hong Kong adults, approximately one-fourth reported to have provided informal home care during"*

**Reviewer's Comment:** *"how do you explain the high number of care recipients per caregiver?"*

**Reply:** *"Thanks for your comment. In Hong Kong, many of the adults will live with their parents and children in the same household. Hence, the adult would have to take care of their parents and children. The high number of care recipients could be due to the COVID-19 pandemic, which coerced people to stay at home rather than outdoor for a much longer time."*

**Action:** *revised the sentence as "In addition, about 20% among the caregivers reported that they have to provide care to 3 or more care recipients during the pandemic. In Hong Kong, many of the adults will live with their parents and children in the same household. Hence, the adult would have to take care of their parents and children."*

17<sup>th</sup> (Line 349-354)

**Sentence with reviewer's comment:** *"Moreover, those caring for dependent individuals (e.g. fragile elderly and disabled) felt inadequately knowledgeable, possibly due to heavy reliance on existing services for regular management of fragile elderly and people with disabilities by the government. In contrast to the provision of routine informal home care, nearly half of the informal home care providers reported that they had insufficient knowledge to mitigate the additional health risks from the COVID-19 epidemic and these findings were not associated with education or other factors."*

**Reviewer's Comment:** *"this is also in contrast with what we know from regular family caregiving: these informal caregivers tend to be very experienced and self confident as it comes to caregiving tasks and responsibilities. Here comes the problem with the studied population again"*

**Reply:** *"Thanks for your comment. It is because informal home care provides may not possess an appropriate level of health literacy, disease knowledge, psychological readiness, and medical care abilities to provide home care since the roles of caring dependent individuals were took up by community services provided by the government. But the closure of many community services has led to unprecedented reliance on home care."*

**Action: No action taken**

18<sup>th</sup> (Line 365-367)

**Sentence with reviewer's comment:** "Hence, these home care providers with dependent care recipients require additional support services during public health emergencies. Furthermore, more than half of the care recipients were children and teenagers, who added to the caregiving burden during the nearly four-month, territory-wide school closures."

**Reviewer's Comment:** "see above, comment on children"

**Reply:** "Thanks for your comment. These children usually receive the daily care in school. But the closure of many community services has led to unprecedented reliance on home care."

**Action: Action not taken**

19<sup>th</sup> (Line 377)

**Sentence with reviewer's comment:** "There were a few limitations"

**Reviewer's Comment:** "another limitation is that you did not underpin the questionnaire with data from former family caregiving research: burden, coping, perceived wellbeing. These parameters are very strong predictors of the succes/impact of caregiving."

**Reply:** Thanks for your comment. This is revised.

**Action:** Added "Fourthly, our study did not further investigate the burdens, coping method and their perceived wellbeing of the care provider, which were potentially associated with the perceived difficulty of care giving."

## VERSION 2 – REVIEW

<b>REVIEWER</b>	Birgitte Schoenmakers KU Leuven Belgium
<b>REVIEW RETURNED</b>	02-Sep-2020
<b>GENERAL COMMENTS</b>	Dear Thank you for the adjustments you have made to this paper. One minor issue is still pending: could you please clarify who these caregivers were and what their position was before the Quarantine. Were they already caregivers/caring for a relative?

## VERSION 2 – AUTHOR RESPONSE

Thanks for your comment. In Hong Kong, informal home care providers are usually family members. Many of the adults will live with and take care of their parents and children in the same household. During the COVID-19, as mentioned in the manuscript, 53.9% reported that they had experienced additional strain in their care providers' duties. The most commonly cited reasons for additional strains

included COVID-19 health risk concern (40.2%), and increased time spent with care recipient (27.5%).