## 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)** | What older adults and their caregivers need for making better health-related decisions at home: a participatory mixed methods protocol |
| **AUTHORS** | Lai, Claudia; Holyoke, Paul; Plourde, Karine; Décary, Simon; Légaré, France |

## VERSION 1 – REVIEW

| | |
|---|---|
| **REVIEWER** | Frances Bunn<br>University of Hertfordshire, UK |
| **REVIEW RETURNED** | 12-May-2020 |

| | |
|---|---|
| **GENERAL COMMENTS** | 1. There is a lack of evidence on SDM for older adults and so this study has the potential to further knowledge in this area. However, the way in which the study is presented feels rather superficial and does not draw enough on what is already known about SDM for older adults. For example, see Bunn et al BMC Geriatrics 2018, 18:165. They need to draw more on what we already know about barriers and facilitators to decision making for older people.<br><br>2. I would like to see them draw more on the literature on interprofessional SDM. Legare is an author on this study but they don't seem to have drawn on this literature as much as I would have expected. I think the literature on interprofessional SDM is important because this study seems to focus on a range of professionals including nurses and OTs.<br><br>3. The study is focused on older adults. However, older adults are a heterogeneous group and so the needs among different groups of older people may vary a great deal. For example, decision making may be very different for people with complex physical needs and/or dementia. This isn't addressed in the protocol.<br><br>4. Are they addressing issues such as advanced care planning and end of life care? This is not addressed in the protocol<br><br>5. I would have liked more detail about the focus of the qualitative interviews. At present it seems rather vague - it doesn't draw enough on what we already know about SDM. They say that they will look at what participants view as their decisional needs. But what about other issues such as whether people feel involved in decision making, how they feel decisions are negotiated, how different perspectives (e.g. patient, carer, caregiver) are negotiated? Also how is SDM affected by complex and changing health needs? What about how decisions are recorded and communicated? All of these are important issues. |

| | |
|---|---|
| | 6. p12 - when describing participants why does it say aged 18 and over? I thought the focus was on older adults. What do they mean by older adults?<br><br>7. The participant advisory group is very small. |

| | |
|---|---|
| **REVIEWER** | Anja Bieber<br>Institute of Health and Nursing Science<br>Medical Faculty<br>Martin Luther University Halle-Wittenberg<br>Germany |
| **REVIEW RETURNED** | 20-May-2020 |

| | |
|---|---|
| **GENERAL COMMENTS** | Comments on manuscript bmjopen-2020-039102<br>Thank you for the invitation to peer review the manuscript, which deals with needs of older adults and their caregivers for health-related decisions at home. Therefore, a participatory mixed method protocol was developed.<br>I have some minor comments.<br>Abstract<br>P.4 line 40: Qualitative and quantitative results will be triangulated. A short explanation should be added to inform about the triangulation method.<br>Methods and Analysis<br>Design and setting<br>P. 9 line 3: The CHERRIES checklist should be described.<br>Theoretical framework<br>P. 10 line 0-8: It would be interesting to know, whether there are experiences in the use of the Ottawa Decision Support Framework for older adults receiving home care.<br>Participants and recruitment<br>P. 11 line 28: Participants aged 18 and over will be included. This does not seem to be correct with regard to the aim of including older patients in the investigation.<br>P. 11 line 35: Patients and professionals of the SE Health were recruited. An information should be added, whether the SE Health organization has rules or guidelines to support decision-making by patients and caregivers. Perhaps this could influence the results of the study.<br>Older adults and their caregivers<br>P.12 line 1: The duration of professional home care of the participants could be another interesting aspect.<br>Interdisciplinary health and social care providers<br>P.12 line 14: An information should be added about the position of the included health and social care professionals, whether they are in constant contact with patients or working at the organizational level of services.<br>Data collection<br>P.14 line 0-15: The supplementary files is categorized in the Sections A-C. These categories should be used here.<br>Ethics<br>P.17 line 3: A sentence should be added, whether an information sheet was used to inform study participants.<br>P.17 line 19: The Tier 1 SMD and KT team should be described.<br>Figure 1<br>P.26 line 18: Some details should be added to the last step of the study: “Integrate qualitative and quantitative findings”. |

## VERSION 1 – AUTHOR RESPONSE

Dear BMJ reviewer #1,

Thank you for your thoughtful comments on the paper. Please see the following comments and revisions made to the paper in response to your comments.

Responses to reviewer #1:
1. There is a lack of evidence on SDM for older adults and so this study has the potential to further knowledge in this area. However, the way in which the study is presented feels rather superficial and does not draw enough on what is already known about SDM for older adults. For example, see Bunn et al BMC Geriatrics 2018, 18:165. They need to draw more on what we already know about barriers and facilitators to decision making for older people.

We have now enriched this section of the Introduction to better take into account what is known about SDM and older adults. Please see our modified introduction (noted in red):

"With our aging population, an increasing number of older adults will be faced with important and often difficult health-related decisions as they grow older in their own homes. [1,2,3] These decisions may be about medication, surgery, safety, care transitions, housing transitions, advance care planning and medical assistance in dying.[4,5,6] However, making health-related decisions may often lead to significant decisional conflict, or the feeling of personal uncertainty over which options are best for a specific individual facing a specific situation. In most real-world scenarios, it is difficult to establish one clear best option, and thus many health-related decisions are preference-sensitive.

Shared decision making (SDM) refers to an interpersonal, interdependent process whereby patients and their health care providers relate to and influence each other as they collaborate in making health-related decisions together.[7,8] SDM has been associated with improving wellbeing, independence, and experiences of the health and social care system.[9,10,11] SDM aims to engage patients play an active role in decisions concerning their health, the ultimate goal of person centered care. SDM rests on the best evidence of the risks and benefits of all the available options. In the case of older adults, such decisions are more complex and often involve caregivers. In fact, when older adults suffer from cognitive deficits, their caregivers may be asked to make decisions for them.[12] Older adults may also experience multimorbidities [5] and polypharmacy,[13,14] resulting in an unmanageable burden of treatment. Moreover, they may be cared for by a large number of healthcare providers. Thus, techniques that enable older adults and caregivers to prioritize main issues and then adequately weigh the risks and benefits associated with treatment choices are all the more important.[5] Equally important is establishing a care culture in which the values and preferences of older adults are sought and their opinions valued. Programs most likely to effectively promote SDM with older people are those that allow them to feel respected and understood, and give them the confidence to engage in SDM.[15]"

2. I would like to see them draw more on the literature on interprofessional SDM. Legare is an author on this study but they don't seem to have drawn on this literature as much as I would have expected. I think the literature on interprofessional SDM is important because this study seems to focus on a range of professionals including nurses and OTs.

Thank you for your comment. In the introduction, we added details on the interprofessional approach to SDM as follows (noted in red):

"In recent years, there has been an increased interest in a team-based approach to SDM.[16] Indeed, health and social care providers, such as personal support workers, physiotherapists, occupational therapists, nurses and other clinicians, can together play an important role in supporting older adults and their caregivers with decision-making. An inter-professional approach to SDM has several advantages: teams contribute different knowledge and skills to the decision-making process, thus producing more feasible and sustainable decisions. From the older adult's standpoint, it fosters engagement in decision-making across the continuum of care. Thus it has the potential to improve the quality of care and specifically of decision support provided as it would be performed in a more integrated manner. Lastly it bridges the gap between professionals from various health disciplines and patients and their families, thereby reducing the silos.[17] Research to demonstrate how inter-professional teams of health and social care providers can collaboratively support decision- making in older adults have shown that an inter-professional approach to SDM is acceptable and feasible in the home care sector.[18, 19] This is crucial evidence as a recent pan-Canadian survey reported that Canadians experienced relatively low levels of SDM.[20] In particular, older adults receiving home care are less likely to experience SDM when faced with health and social care decisions than any other sociodemographic group.[20]

A building block for increasing SDM in the home care aging population is a decisional needs assessment.[21] Understanding and assessing the decisional needs not only of patients, but also of their caregivers and health providers in home care, will inform us about ways to better engage older adults and their caregivers in SDM, and how healthcare providers' can better support them to make decisions together that best reflects their preferences."

3. The study is focused on older adults. However, older adults are a heterogeneous group and so the needs among different groups of older people may vary a great deal. For example, decision making may be very different for people with complex physical needs and/or dementia. This isn't addressed in the protocol.

Thank you for pointing this out. As the focus of our study is older adults in home care, we aim to address the variety of decisions faced by older adults and their caregivers (who may be required to make decisions for them in the case of severe dementia), as well as the different ways they would

need support in decision making (decisional needs). To emphasize the significance of heterogeneity in both these areas, the following text (in red) has been added to the paper under the section "Participants and recruitment, Older adults and their caregivers".

"We will select participants with different backgrounds (in terms of age, gender, native/non-native English speaking, racial and/or ethnic backgrounds, disability status, and medical conditions ). Thus we will seek maximal variability both in the decisions the older adults find most difficult, and the kind of decision-making support they might need depending on their decision-making contexts, cultures, and preferences.[42,43]"

4. Are they addressing issues such as advanced care planning and end of life care? This is not addressed in the protocol

Thank you. The focus of this study is broad as we are assessing which types of decisions are the most prevalent as well as decisional needs (decision-making needs). It is possible that decisions about ACP will be found to be highly prevalent. We listed the possible issues that might be identified at the beginning of the Introduction:

"With our aging population, an increasing number of older adults are faced with important and often difficult health-related decisions as they grow older in their own homes.[1,2,3] These decisions may be about medication, surgery, safety, care transitions, housing transitions, advance care planning and medical assistance in dying."

5. I would have liked more detail about the focus of the qualitative interviews. At present it seems rather vague - it doesn't draw enough on what we already know about SDM. They say that they will look at what participants view as their decisional needs. But what about other issues such as whether people feel involved in decision making, how they feel decisions are negotiated, how different perspectives (e.g. patient, carer, caregiver) are negotiated? Also how is SDM affected by complex and changing health needs? What about how decisions are recorded and communicated? All of these are important issues.

Thank you for these suggestions, all of which are important issues. Because our study aims to explore the decisional needs of older adults in home care, rather than shared decision making in general, our interview guide will adopt standardized questions guided by the Ottawa Decision Support Framework (ODSF). We have added details about the qualitative interviews and the ODSF in our "Data collection section as follows:

"In Phase 1, qualitative data will be collected from open-ended semi-structured interviews conducted with older adults who have received, or are receiving home care services, and their caregivers. Adopting standardized questions based on the ODSF,[21] the interview guide (Supplementary file 1)

includes questions on what important and difficult decisions they face at home, what makes these decisions difficult, how they feel when making these decisions, and what they feel that they need to make better decisions at home. The questions will be used as probes to encourage discussion. According to the ODSF, decisional needs may be related to decisional conflict, a feeling of lacking knowledge, expectations, values clarity, and a lack of support and/or resources, which can be specific to the type of decision as well as to the characteristics of older adults and their caregivers.[21] As such, our qualitative approach aims to gain an in-depth understand of decision making needs in the home care setting."

6. p12 - when describing participants why does it say aged 18 and over? I thought the focus was on older adults. What do they mean by older adults?

The following statement has been added under the section "Participants and recruitment, Older adults and their caregivers" to clarify:

"As aging is not a uniform process across populations, participants in the older adult group will consist of individuals who self-identify as older adults with home care experience. This approach aims to include individuals who share a worldview as an older adult. Participants under 18 years of age, such as caregivers caring for their grandparents, are excluded from this study as they may have additional concerns that can be further explored in future studies."

7. The participant advisory group is very small.

For our participant advisory group, we sought representation from older adult, caregiver and care provider groups. We engaged committed participants who would provide insightful knowledge and would be able to participate in our research process. To the best of our knowledge, we are not aware of an optional number of advisors for a decisional needs assessment, nor any evidence that would suggest that a large number of advisors would provide better advice for our study.

Dear BMJ reviewer #2,

Thank you for your thoughtful comments on the paper. Please see the following comments and revisions made to the paper in response to your comments.

Abstract

1. P.4 line 40: Qualitative and quantitative results will be triangulated. A short explanation should be added to inform about the triangulation method.

We revised the Results as follows:

"Finally, qualitative and quantitative results will be triangulated (by methods, investigator, theory and source) to develop a comprehensive understanding of decision-making needs from the perspective of older adults, caregivers and health and social care providers."

Methods and Analysis

2. Design and setting

   P. 9 line 3: The CHERRIES checklist should be described.

   We added the following sentence:

   "The items on the CHERRIES checklist was used to design the online survey for phase 2 of the study, including considerations for developing and pre-testing the survey, survey administration, and response rates."

Theoretical framework

3. P. 10 line 0-8: It would be interesting to know, whether there are experiences in the use of the Ottawa Decision Support Framework for older adults receiving home care.

   Thank you for the question. Although the ODSF mentions older adults and has been used studies of older adults, as we mention on page 7, we are not aware of any other studies that assess the decisional needs of older adults receiving home care using the ODSF. We have revised (in red) the paragraph under "Ottawa Decision Support Framework" as follows:

   "A better understanding of the decisional needs of older adults receiving home care and their caregivers is important for designing SDM interventions to support those who feel uncertainty about options (decisional conflict), and/or who lack knowledge, or have expectation deficits, unclear values or insufficient supports and resources.[21] The ODSF has been used in previous studies including older adults,[26] and will enhance our understanding in the understudied area of decisional needs among older adults in home care."

Participants and recruitment

4. P. 11 line 28: Participants aged 18 and over will be included. This does not seem to be correct with regard to the aim of including older patients in the investigation.

The following sentence (noted in red) was added after the first sentence, to clarify rationale for taking an inclusive approach to include participants who identify as older adults:

"Phase 1 participants (aged 18 and over) will include: older adults who are receiving or have received home care services, and caregivers of older adults who are receiving or have received home care services. As aging is not a uniform process across populations, participants in the older adult group will consist of individuals who self-identify as older adults with home care experience. This approach aims to include individuals who share a worldview as an older adult. Participants under 18 years of age, such as caregivers caring for their grandparents, are excluded from this study as they may have additional concerns that can be further explored in future studies. "

5. P. 11 line 35: Patients and professionals of the SE Health were recruited. An information should be added, whether the SE Health organization has rules or guidelines to support decision-making by patients and caregivers. Perhaps this could influence the results of the study.

   Thanks for this suggestion. We have added on page 11:

   "To the best of our knowledge, SE Health does not currently have specific rules or decision-support guidelines for patients and caregivers that might influence results. We cannot speak to other home care companies that may have provided care to participants in this study."

Older adults and their caregivers

6. P.12 line 1: The duration of professional home care of the participants could be another interesting aspect.

   Thank you for this suggestion. Given small sample size in phase 1 of this study, we will explore this interesting dimension in a future phase of the study.

Interdisciplinary health and social care providers

7. P.12 line 14: An information should be added about the position of the included health and social care professionals, whether they are in constant contact with patients or working at the organizational level of services.

   The following sentence was revised (noted in red) to clarify that these care providers are all in direct contact with patients.

"Phase 2 participants (aged 18 and over) will include interdisciplinary front-line health and social care providers who provide in-person home care services to older adults. These include personal support workers (PSW), health care aides (HCA), or préposés aux bénéficiaires (PAB); registered nurse assistants (RNA); registered practical nurses (RPN) or licensed practical nurses (LPN); registered nurses (RN); advance practice nurses (e.g., nurse practitioners (NP), clinical nurse specialists); occupational therapists (OT); physiotherapists (PT); and other providers. Their client loads, hours per visit and number of visits per client can vary."

Data collection

8. P.14 line 0-15: The supplementary files is categorized in the Sections A-C. These categories should be used here.

   The following revisions (noted in red) were made to the sentence noted above. We removed the content description of the section.

   "The survey (Supplementary file 2) will include: 1) Section A – about you; 2) Section B – your views on decisions facing older adults (and their caregivers) in the home care setting; and, 3) Section C – your views on the decision-making needs of older adults (and their caregivers) in the home care setting."

Ethics

9. P.17 line 3: A sentence should be added, whether an information sheet was used to inform study participants.

   The following sentence (noted in red) has been added to the Ethics section.

   "Ethics approval was obtained from the Research Ethics Board at Southlake Regional Health Centre in Ontario, as well as from the Université Laval in Québec. Participants will be provided with an information sheet on the study and they will have time to ask questions about the study before enrolment. Informed consent will be sought from all study participants prior to their participation."

10. P.17 line 19: The Tier 1 SMD and KT team should be described.

    The following changes (noted in red) have been made to the section noted above:

    "Our dissemination plan includes: summary briefs to study participants; summary briefs for posting on our social media platforms; tailored reports for home are decision makers and policy makers to improve the resources provided to support older adults with their decision making at

home; to our research team (Tier 1 Canada Research Chair on Shared Decision Making and Knowledge Translation) to guide the development of robust decision support interventions for transforming how health and social care providers work with older adults and their caregivers to make decisions together."

Figure 1

11. P.26 line 18: Some details should be added to the last step of the study: "Integrate qualitative and quantitative findings

    The last step in the figure was revised as follows:

| Integrate qualitative and quantitative findings |
| --- |
| List the findings from each component of study and determine "meta-themes" that cut across findings from the different methods, as well as where a theme arises from one data set and not another. |

**VERSION 2 – REVIEW**

| | |
| --- | --- |
| **REVIEWER** | Anja Bieber<br>Institute of Health and Nursing Science<br>Medical Faculty<br>Martin Luther University Halle-Wittenberg<br>Germany |
| **REVIEW RETURNED** | 31-Aug-2020 |

| | |
| --- | --- |
| **GENERAL COMMENTS** | Dear authors, thank you for the revised manuscript, which has been significantly improved. There is still the question of the age of the participants for the qualitative interviews. You will include participants aged 18 and over. The focus of your study will be on older adults, i.e. usually people aged 65 years and older. The perspective of people aged 65 and over in connection with the SDM may be different from that of younger people. This should be taken into account when including the participants and/or interpreting the data. Kindly regards, Anja Bieber |

**VERSION 2 – AUTHOR RESPONSE**

Response to reviewer 2:

Dear Dr. Bieber,

Thank you for your thoughtful comment. To improve the clarity of the paper, we have removed the reference to “aged 18 and over” in the “Participants and recruitment” section (as noted in red below):

> “*Phase 1 participants ~~(aged 18 and over)~~ will include: 1) older adults who are receiving or have received home care services, and 2) caregivers of older adults who are receiving or have received home care services.”*
>
> “*Phase 2 participants ~~(aged 18 and over)~~ will include front-line interdisciplinary health and social care providers who provide in-person home care services to older adults.”*

We agree with your comment and have made the following revisions in the “Participants and recruitment” section (as noted in red below):

> “*We will purposefully select participants with different backgrounds (in terms of age, gender, native/non-native English speaking, racial and/or ethnic backgrounds, disability status and medical conditions) for maximal variability.[42] This selection strategy aims to identify decisional needs that might be common among participants with different backgrounds, as well as unique or diverse variations that might relate to certain conditions or context (e.g., decisional needs unique to older adults under 65 years of age who may not be eligible for public drug coverage due to their age). Thus, we aim to identify both the decisions older adults find most difficult, and the kinds of decisional support they might need depending on their decision-making contexts, cultures, and preferences.”*