PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	The older patient considering treatment for advanced renal disease: Protocol for a scoping review of the information available for shared decision making.
AUTHORS	Raj, Rajesh; Ahuja, Kiran; Frandsen, Mai; Jose, Matthew

VERSION 1 - REVIEW

REVIEWER	Edwina Brown Imperial College Healthcare NHS Trust UK
REVIEW RETURNED	29-Aug-2016

GENERAL COMMENTS	The proposed protocol for a scoping review on shared decision making in advanced kidney disease is well designed and appropriate

REVIEWER	Martin Wilkie Sheffield Kidney Institute UK Involved in the development of a dialysis decision aid other wise none declared
REVIEW RETURNED	31-Aug-2016

GENERAL COMMENTS	The objective of this scoping review is to explore the information that may support decision making for people of aged 65 or older in relation to advanced chronic kidney disease management. The premise is that the principles of "shared decision making" should under pin discussions regarding whether to dialyse for this group of people. These concepts are clearly important and a systematic evaluation of information pertaining to these topics would be of value to patients and health care teams. My main concern is that the scope of the review is so broad that the work will lose focus. The authors should consider formulating a more focussed question. I have a number of observations. • Care needs to be taken with the term “elderly” since it can be seen as pejorative depending on context – better to use the term “older people”.

	• How was the age cut-off arrived at since age itself is not the over-riding prognostic factor? The paper concludes that a counselling should be specific to patient factors – I am not sure that selecting an age cut-off is a mechanism to avoid that. • The scope of this review is enormous – since it essentially includes virtually all aspects of care in people who have CKD in this age group. Although a scoping review is intended to be broad, it seems to me that authors would potentially have an unmanageable task and that they should attempt to focus the review and to be more specific in their goals. For example will biochemical factors be included, or health economic considerations, volume control, co-morbidity or medicines management? • I am concerned that dialysis or not is the basis for the dichotomy since prognosis, end of life care, symptom control etc are necessary components whether dialysis is chosen or not and the approach that has been adopted suggests either dialysis choice or holistic care. • I found some domains to be insufficiently well described – eg dialysis care - would assisted peritoneal dialysis be included, what about self-care in centre, assisted home haemodialysis, dialysis frequency per week and impact on quality of life. Will there be an exploration of decision science eg experience of decision making, confidence in decision, impact of changing decisions? • Will the review include studies that report the presentation of information to patients; will it include methods of presenting patient material and patient acceptability. • How will health literacy, the impact of socio-economic deprivation, mental capacity or language barriers be considered in the work?

REVIEWER	Dr Nicola Thomas London South Bank University, UK
REVIEW RETURNED	06-Sep-2016

GENERAL COMMENTS	Thank you for asking me to review this paper. I have some comments which I hope are helpful. 1. Typos and grammatical errors - there are a few errors, especially concerning upper and lower case letters 2. Abstract - the abstract needs to include some more specific recommendations about how the findings will be used, for example clinical practice guidelines?. 3. There are some issues with terminology that need sorting out. It is suggested that 'elderly people' are over the age of 65 years, but I am not sure that everyone would agree! Suggest to use the term 'older people' not 'elderly' throughout. 4. Page 4, line 38. I think this should be re-worded "...renal

	physicians lead the discussions", as this not fit with the theory of shared-decision-making. 5. Page 5, line 35. I also wonder if the language in this sentence, sits well with the topic of shared decision-making. The language suggests that physicians take control, so please consider amending..."The clinician, therefore, has to contend with a wide range of information, which extends across quantitative and qualitative domains, before making a recommendation." 6. I think it would be helpful to add the theory of shared decision-making (eg. Stacey, Legare et al (2010) Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. Patient Educ Couns 80:162–172) prior to the objectives. For me there needs to be a discussion about where information-giving sits within SDM. 7. The review questions, and inclusion/exclusion criteria seem appropriate 8. Concept: you need some justification of why certain study types are included for certain questions. For example, why not qualitative studies to answer Question 1b? 9. Key words - will you not include chronic kidney disease? 10. I would like to see further critique of the method - why use an amended version of the Joanna Briggs methodology? Plus the steps need to be more clearly defined, perhaps with a Table that describes the process, and include on Page 6, line 9 Overall it is an interesting protocol worthy of publication once these recommendations above have been considered.

VERSION 1 – AUTHOR RESPONSE

Comments from Reviewer 1

1. Typos and grammatical errors - there are a few errors, especially concerning upper and lower case letters

We have revised the manuscript and paid renewed attention to spelling and grammatical errors. We hope the revised version is satisfactory.

2. Abstract - the abstract needs to include some more specific recommendations about how the findings will be used, for example clinical practice guidelines?.
Thank you for this suggestion. We have included this suggestion under the heading “Ethics and Dissemination” in the abstract.

3. There are some issues with terminology that need sorting out. It is suggested that 'elderly people' are over the age of 65 years, but I am not sure that everyone would agree! Suggest to use the term 'older people' not 'elderly' throughout.

Thank you for this suggestion. We concur, and have replaced the term elderly with the words ‘older adult’ throughout the text; we have also re-worded the title of the manuscript to reflect this.

4. Page 4, line 38. I think this should be re-worded "...renal physicians lead the discussions", as this not fit with the theory of shared-decision-making.

Thank you for pointing this out. This line was quoted verbatim from the Australia New Zealand Society of Nephrology clinical guidelines for supportive care of CKD. We appreciate that this line conveys a

different message when viewed out of the context of that paper. We have removed this phrase, and extensively rewritten this part of the manuscript to more accurately reflect the recommendations in that important paper.

5. Page 5, line 35. I also wonder if the language in this sentence, sits well with the topic of shared decision-making. The language suggests that physicians take control, so please consider amending..."The clinician, therefore, has to contend with a wide range of information, which extends across quantitative and qualitative domains, before making a recommendation."

Thank you. In order to reflect the primacy of the shared decision making process, and the need for 'equipoise' by the clinical team, we have extensively rewritten the "Background" section of the manuscript. The paragraph referred to in this suggestion has been removed and replaced. We hope this new iteration will more accurately reflect the optimal role of the clinical team in the process.

6. I think it would be helpful to add the theory of shared decision-making (eg. Stacey, Legare et al (2010) Shared decision making models to inform an interprofessional perspective on decision making: a theory analysis. Patient Educ Couns 80:162–172) prior to the objectives. For me there needs to be a discussion about where information-giving sits within SDM.

We have found this a valuable suggestion, and have taken it on board. The text now contains a paragraph on shared decision making (fifth paragraph under 'background'). The role of the clinical team in terms of this model for shared decision making has been described. We clarify in the new manuscript that the information that is the subject of the proposed scoping review is the information that is used as part of the 'information exchange' step of the shared decision making process.

7. The review questions, and inclusion/exclusion criteria seem appropriate
Please note the modifications in the review questions and in the inclusion / exclusion criteria.

8. Concept: you need some justification of why certain study types are included for certain questions. For example, why not qualitative studies to answer Question 1b?
This was an error. Information to answer the questions may be available from all forms of research; this has been corrected in the manuscript. After revising the 'review questions' in accordance with reviewers' comments, we have used new question numbers under the 'Concept' section, and we have now rewritten the text, and tried to present this in such a way as to convey that all types of studies may be used to answer any of the review's questions.

9. Key words - will you not include chronic kidney disease?
Chronic kidney disease has now been included as a key word.

10. I would like to see further critique of the method - why use an amended version of the Joanna Briggs methodology? Plus the steps need to be more clearly defined, perhaps with a Table that describes the process, and include on Page 6, line 9

The term 'amended' was used to reflect the fact that the headings in this protocol paper do not exactly correspond to the suggestions in the Joanna Briggs methodology paper. This term 'amended' has now been removed, since it may well imply a modified protocol, as you have suggested. The study protocol description continues to follow the Joanna Brigg's methodology.
As per the suggestion, a flow chart has been included to explain the study methodology (Figure 1).

Comments from Reviewer 2

My main concern is that the scope of the review is so broad that the work will lose focus. The authors should consider formulating a more focussed question.

Thank you. The perceived gap in literature that the scoping review seeks to address, in specific terms, is the gap within the kinds of information that clinical teams provide to older adults deciding whether to undertake dialysis or not (in addition to all the other aspects of care for advanced chronic kidney disease). We observe that while the decision may be easier in the younger adult groups, where dialysis is often seen as a bridge to transplantation, there are more layered considerations in the older adult. Information in this area is still evolving, and we believe the time is ripe for a scoping review. While the spectrum of all care given to patients with chronic kidney disease is indeed broad, this review seeks articles where the population studied has been specifically described as older adults or the elderly. We anticipate that this stipulation will help us focus the review more tightly.
Since decisions that are made about dialysis in the older adult have to consider several factors across many domains, we want to avoid inadvertently neglecting important considerations. However, we appreciate the concern that the scope of the review is very broad. In response, we have narrowed the scope of the review, as detailed in the last paragraph below. The narrower scope of the review has now been added as a 'limitation' under the "Strengths and Limitations' sub-heading.

¥ Care needs to be taken with the term "elderly" since it can be seen as pejorative depending on context – better to use the term "older people".

We concur, and have replaced the term elderly with the words 'older adult' throughout the text; we have also re-worded the title of the manuscript to reflect this.

¥ How was the age cut-off arrived at since age itself is not the over-riding prognostic factor? The paper concludes that a counselling should be specific to patient factors – I am not sure that selecting an age cut-off is a mechanism to avoid that.

As discussed above, the focus of this review is on information pertaining to the older adult population, where the choices around therapy have less discriminatory 'pros and cons'.
We concur with the observation that selecting an age cut-off is not ideal. We have therefore removed the age cut-off stipulation throughout the paper and replaced it with the requirement that study authors refer to their population as elderly, older or geriatric. We will incorporate descriptions of the age groups studied in the discussions of relevant articles.

¥ The scope of this review is enormous – since it essentially includes virtually all aspects of care in people who have CKD in this age group. Although a scoping review is intended to be broad, it seems to me that authors would potentially have an unmanageable task and that they should attempt to focus the review and to be more specific in their goals. For example will biochemical factors be included, or health economic considerations, volume control, co- morbidity or medicines management?

Thank you. We have restricted the scope of the review as detailed in the last paragraph below.
As discussed in the preceding responses, we anticipate that restricting the inclusions to studies reporting on older adults will reduce the number of studies selected for inclusion. Additionally, the scoping review seeks information that will be relevant to the shared decision making process around whether to have dialysis or not – as the data is being collated and summarised, the authors hope to focus attention on this aspect, and summarise information that speaks to this concept primarily. This is yet another additional mechanism to help with managing the review. In the final report, we will include a section that describes the information that was not included in the narrative review, if

indicated.

¥ I am concerned that dialysis or not is the basis for the dichotomy since prognosis, end of life care, symptom control etc are necessary components whether dialysis is chosen or not and the approach that has been adopted suggests either dialysis choice or holistic care.

We thank the reviewer for this particularly insightful comment. As stated previously, the ambit of this review is the information that contributes to the choice between having dialysis or not having dialysis; we appreciate of course that all other aspects of management (as in the examples provided by the reviewer) are similarly indicated and appropriate across both treatment options. In response, we have extensively re-written the manuscript, highlighting the fact that although the 'dichotomy' considered is between having dialysis or not, that distinction occurs within the setting of several other similar 'supportive care' measures in both pathways. We would like to draw attention to the corrections under the abstract (introduction section), background (paragraphs 3,4 and 5 have been rewritten) and in the wording of the review questions (table 1).

¥ I found some domains to be insufficiently well described – eg dialysis care - would assisted peritoneal dialysis be included, what about self-care in centre, assisted home haemodialysis, dialysis frequency per week and impact on quality of life.
Under operational definitions (page 8 of original manuscript), the definitions for dialysis have been expanded to explicitly include all forms of dialysis treatment)

¥ Will there be an exploration of decision science eg experience of decision making, confidence in decision, impact of changing decisions? Will the review include studies that report the presentation of information to patients; will it include methods of presenting patient material and patient acceptability. How will health literacy, the impact of socio-economic deprivation, mental capacity or language barriers be considered in the work?

Thank you for raising these questions which collectively speak to the enormous amounts of data potentially available to this scoping review. In order to maintain focus, we have re-framed our questions, such that decision-making science, presentation of information and the impact of other factors on decision making (health literacy, SE status, cognitive impairment or language barriers) are no longer included as part of the review.
We anticipate that some of these factors (e.g., cognitive impairment) may also impact on prognosis, and such information may be anticipated to be included in that context. Please see amended table 1, as also the subheading 'concept' under "Inclusion Criteria". We have also referred to this change as a new 'limitation' of this study (see "Strengths and Limitation of this Study" in the abstract)

VERSION 2 – REVIEW

REVIEWER	Nicola Thomas London South Bank University, UK
REVIEW RETURNED	04-Nov-2016

GENERAL COMMENTS	Thank you for reading my comments and making the changes as suggested. The paper is much improved now and I can recommend for publication