PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (see an example) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

TITLE (PROVISIONAL)	The beliefs and expectations of patients and caregivers about home haemodialysis: An interview study
AUTHORS	Tong, Allison ; Palmer, Suetonia; Manns, Braden; Craig, Jonathan; Ruospo, Marinella; Gargano, Letizia; Johnson, David; Hegbrant, Jorgen; Olsson, Mans; Fishbane, Steven; Strippoli, Giovanni

VERSION 1 - REVIEW

REVIEWER	Michael A Kraus MD FACP Clinical Chief of Nephrology Medical Director of home dialysis Indiana University Potential Conflicts: CMO of adult dialysis services at Indiana University Health Member Scientific Advisory Board for NxStage Medical Paid speaker for DaVita, NxStage Medical Unrestricted educational grants received from Fresenius Medical and NxStage Medical Minor stock holder of NxStage Medical
REVIEW RETURNED	02-Nov-2012

GENERAL COMMENTS	Excellent papaer regarding important need to understand concerns of patients and caregivers regarding home dialysis. Important discriptive interview research helps healthcare professionals understand the perceptions of home dialysis in patients on in-center hemodialysis without significant exposure or education regarding home dialysis. It is imperative to understand these perceptions to evaluate some barrriers to patient and care partner acceptance of home dialysis. Minor revisions are needed: Page 6 - Introduction: "...and of the 21,000 patients on haemodialysis in the United kingdom perform hemodialysis at home" - need to include the number who perform this at home. page 18 -the author cites reference 6 as to the results of the nocturnal arm. The nocturnal study was under recruited and under powered and this should be mentioned in this context. The authors support snd conclude that patients should be educated in the pre dialysis phase. They suggest that movement is unlikely once the patient is on a in center therapy. However, in the United States the majority of home hemodialysis patients are prevalent and not incident patients - suggesting that with proper education, patients and caregivers concerns can be overcome. This study is based on a limited short term exposure to written educational tools. This study does not evalaute whether a more prolonged repetitive educational program might impact prevalent patients. Certanly the suggested "individualized education and information for patients and their families...before patients start dialysis" is intended to be

	comprehensive and adjusted to the learning needs of the individuals. I think it is premature to assume similar education strategies in prevalent patients cannot impact the patient and caregiver perception and choice of therapies.

REVIEWER	Khaled Abdel-Kader Assistant Professor of Medicine Renal-Electrolyte Division Department of Medicine University of Pittsburgh Pittsburgh, USA No conflicts
REVIEW RETURNED	06-Nov-2012

THE STUDY	1) As the authors adequately acknowledge, the sample selected may have been biased and may not be representative of samples from other countries or cultures, though their results are similar to previously published findings. 2) Of note, only 1 patient below the age of 40 was included and only 3 patients on dialysis for <1year were included. Although thematic saturation was achieved, a sample with a larger number of young and/or incident (e.g., <6mo) patients may have raised additional/alternative perspectives and barriers/positive aspects. 3) There is a gap between the sample from which the data is gathered and that to which the authors recommend it be applied. This should be discussed. While the qualitative data provided by the investigators is interesting, the findings described in this work are limited to dialysis patients. The authors then argue persuasively for a need to target pre-dialysis patients. However, the barriers that are being targeted are those elicited from a largely prevalent dialysis sample. Whether similar findings would be noted in a pre-dialysis sample is less clear and there is relatively scarce literature on pre-dialysis patients in this regard. e.g., One might hypothesize that the loss of social support from HD patients and HD clinic staff interactions might not be an important barrier in pre-dialysis patients who have not experienced this "fellowship". Hence, whether the strategies outlined are likely to effectively target the barriers that prevent pre-dialysis CKD patients from choosing home HD is less clear. 4) On a related point, while pre-dialysis education has been shown to increase home dialysis selection in several published studies, I believe the authors should be more conservative when recommending that this plus additional strategies are needed in pre-dialysis patients. While I generally agree with their perspective, further exploration of barriers in pre-dialysis/incident dialysis patients would be informative. In addition, any potential interventions should be evaluated for effectiveness (statements in the abstract and key messages should be more carefully worded) 5) Can the authors provide additional information regarding how similar these 4 Italian cities (or their ESRD patients) are to the general Italian population.
RESULTS & CONCLUSIONS	6) Why was isolation from peer support categorized under health

	care by professionals vs. amateurs? Is this more of a social support concern? 7) As discussed above, the authors should be more conservative (in the discussion when introducing table 3) when discussing strategies to increase home dialysis by interventions other than education (e.g., caregiver respite, readily available technical/medical advice, peer support, etc). 8) Given the abundant data to suggest suboptimal CKD care by physicians (including nephrologists), I wonder if the authors would like to elaborate on any ideas regarding how proposed educational/support interventions could be structured to ensure wide availability to the appropriate CKD population).

REVIEWER	Dr Rosemary Masterson Department of Nephrology, Royal Melbourne Hospital, Melbourne, Vic 3050, Australia
REVIEW RETURNED	15-Nov-2012

RESULTS & CONCLUSIONS	It is hard to draw conclusions from such a small study cohort varying widely in age and duration of time on dialysis.
REPORTING & ETHICS	I cannot see any reference to an ethics committee approval in the paper.
GENERAL COMMENTS	I do not think this paper provides any novel data beyond what has already been published.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1 – Dr Michael A Kraus:

1. “Introduction: "...and of the 21,000 patients on haemodialysis in the United kingdom perform hemodialysis at home" - need to include the number who perform this at home.”

We thank the reviewer for this comment and clarify that the 1% refers to both the US and UK populations. For clarity, we rephrased the statement to, “…only 1% of the nearly 400,000 patients on haemodialysis in the United States and the 21,000 patients on haemodialysis in the United Kingdom, perform their haemodialysis at home. “ (Page 6, paragraph 1 - marked copy)

2. “page 18 -the author cites reference 6 as to the results of the nocturnal arm. The nocturnal study was under recruited and underpowered and this should be mentioned in this context."

We agree and note that reference 6 does not report analysis of home versus in-centre dialysis and therefore removed this citation. (Page 19, paragraph 2 - marked copy)

3. “The authors support and conclude that patients should be educated in the pre dialysis phase. They suggest that movement is unlikely once the patient is on a in center therapy. However, in the United States the majority of home hemodialysis patients are prevalent and not incident patients - suggesting that with proper education, patients and caregivers concerns can be overcome. This study

is based on a limited short term exposure to written educational tools. This study does not evaluate whether a more prolonged repetitive educational program might impact prevalent patients. Certainly the suggested "individualized education and information for patients and their families...before patients start dialysis" is intended to be comprehensive and adjusted to the learning needs of the individuals. I think it is premature to assume similar education strategies in prevalent patients cannot impact the patient and caregiver perception and choice of therapies."

We take the reviewers point. As advised, we have softened our suggestions regarding pre-dialysis education throughout the manuscript. (Page 3, paragraph 1; page 4 key messages; page 17, paragraph 1; page 17; paragraph 2 - marked copy)

Reviewer 2 – Dr Khaled Abdel-Kader:

4. "As the authors adequately acknowledge, the sample selected may have been biased and may not be representative of samples from other countries or cultures, though their results are similar to previously published findings."

As the reviewer noted, we acknowledged this by stating, "The transferability of our findings to other settings is uncertain as all interviews were conducted in Italy and patients were recruited from four centres within Diaverum, a for-profit dialysis service provider. Despite this, similar findings have been identified in other studies on patient-perceived barriers to home haemodialysis." (Page 18, paragraph 2 – marked copy)

5. "Of note, only 1 patient below the age of 40 was included and only 3 patients on dialysis for <1year were included. Although thematic saturation was achieved, a sample with a larger number of young and/or incident (e.g., <6mo) patients may have raised additional/alternative perspectives and barriers/positive aspects."

We appreciate the reviewers point. We also clarify that patients aged under than 40 years comprise a very minor proportion of the patient population in the recruiting dialysis units and the number of incident patients on dialysis (e.g. <6 months) ranges from only 0 to 2 patients across the study units. In considering feasibility and transferability of the findings, we purposively selected participants such that the study population would be better reflective of the type of patient population in the dialysis centres i.e. patients aged over 40 years and/or have been on dialysis >1 year.

6. "There is a gap between the sample from which the data is gathered and that to which the authors recommend it be applied. This should be discussed. While the qualitative data provided by the investigators is interesting, the findings described in this work are limited to dialysis patients. The authors then argue persuasively for a need to target pre-dialysis patients. However, the barriers that are being targeted are those elicited from a largely prevalent dialysis sample. Whether similar findings would be noted in a pre-dialysis sample is less clear and there is relatively scarce literature on pre-dialysis patients in this regard. e.g., One might hypothesize that the loss of social support from HD patients and HD clinic staff interactions might not be an important barrier in pre-dialysis patients who have not experienced this "fellowship". Hence, whether the strategies outlined are likely to effectively target the barriers that prevent pre-dialysis CKD patients from choosing home HD is less clear."

We appreciate this comment. As noted in our response to Point 3 above, we softened our arguments regarding pre-dialysis patients. Also, we included an additional paragraph to acknowledge that the relevance, appropriateness and effectiveness of these strategies may be different between pre-dialysis and prevalent dialysis patients. (Page 18, paragraph 1 – marked copy)

7. "On a related point, while pre-dialysis education has been shown to increase home dialysis

selection in several published studies, I believe the authors should be more conservative when recommending that this plus additional strategies are needed in pre-dialysis patients. While I generally agree with their perspective, further exploration of barriers in pre-dialysis/incident dialysis patients would be informative. In addition, any potential interventions should be evaluated for effectiveness (statements in the abstract and key messages should be more carefully worded)"

As advised, we have softened our recommendations regarding pre-dialysis education throughout the manuscript including the abstract (Page 3, paragraph 1 – marked copy); and key message (page 4) – marked copy. Also, we included an additional sentence on future research of barriers to home haemodialysis in the pre-dialysis/incident patient population, "…the effectiveness of education about home haemodialysis for patients currently treated with in-centre haemodialysis warrants further study. In addition, given the present study is conducted with patients and their families currently treated with dialysis, the effects of predialysis education on patient and caregiver treatment preferences in regions without established home haemodialysis also deserve further evaluation." (Page 17, paragraph - marked copy)

8. "Can the authors provide additional information regarding how similar these 4 Italian cities (or their ESRD patients) are to the general Italian population."

We can confirm that the study population treated in the centres involved in the study resembles the standard characteristics of the prevalent hemodialysis population in Italy, according to the data reported in the Italian registry of dialysis and transplant (www.ridt.org). The similarity is based on evaluation of: mean age, % with various comorbidities, mean values of Kt/V, albumin, treatment time, mean number of treatments per week, mean hemoglobin value, mean ferritin value, mean calcium, phosphorus, calcium x phosphorus product, interdialysis body weight gain, mean arterial pressure, proportion of diabetics. In our report, we have now added a sentence stating that "the key characteristics of the studied population, including mean age, proportion with various comorbidities, mean values of Kt/V, albumin, treatment time, number of treatments per week, hemoglobin, ferritin, calcium, phosphorus, calcium x phosphorus product, interdialysis body weight gain, mean arterial pressure and proportion of diabetics were similar to those reported in the Italian dialysis and transplantation registry annual report (available at www.ridt.org)." (Page 18, paragraph 2 - marked copy)

9. "Why was isolation from peer support categorized under health care by professionals vs. amateurs? Is this more of a social support concern?"

We take the reviewer's point and "isolation from peer support" is now re-categorised as a standalone theme.

10. "As discussed above, the authors should be more conservative (in the discussion when introducing table 3) when discussing strategies to increase home dialysis by interventions other than education (e.g., caregiver respite, readily available technical/medical advice, peer support, etc)."

As advised, we have reworded the discussion to take a more conservative approach in discussing strategies to increase home dialysis. (Page 14, paragraph 4 – marked copy)

11. "Given the abundant data to suggest suboptimal CKD care by physicians (including nephrologists), I wonder if the authors would like to elaborate on any ideas regarding how proposed educational/support interventions could be structured to ensure wide availability to the appropriate CKD population)."

As suggested, we included additional paragraph to suggest how education and support interventions

could be structured to ensure wide availability to the appropriate CKD population: “Educational and support interventions may be delivered by specific nurse specialists involved in predialysis care and education and included as a part of predialysis clinics. Moreover, we suggest establishing database management and communication between the team members to plan and implement educational strategies, offering group education with patients and families, providing video-based and online materials for patients and families, and allowing patients and families to meet other patients who are established on home therapies.” (Page 18, paragraph 1 – marked copy)

Reviewer 3 – Dr Rosemary Masterson:

12. “It is hard to draw conclusions from such a small study cohort varying widely in age and duration of time on dialysis.”

We purposively selected participants to capture a wide range of demographic and clinical characteristics (including age and duration of dialysis) to the point of saturation. Therefore we can draw valid conclusions. Also, the participant characteristics reflect that of the standard dialysis population and therefore the findings are likely to be transferable to other areas/practices.

13. “I cannot see any reference to an ethics committee approval in the paper.”

Details on ethics committee approval was provided under “Ethics approval” on page 23 – marked copy.

14. “I do not think this paper provides any novel data beyond what has already been published.”

The novelty of the paper is the information is obtained in a population in which haemodialysis is not an option - and so patients and clinicians have little experience with home HD. This is an important population as, if home HD is to be established more widely, these are the regions that need to be involved and applying data from regions in which home hemodialysis is available and better understood may be erroneous.