PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	"Beats the alternative but it messes up your life": Aboriginal people's experience of haemodialysis in rural Australia
AUTHORS	Rix, Elizabeth; Barclay, Lesley; Stirling, Janelle; Tong, Allison; Wilson, Shawn

VERSION 1 - REVIEW

REVIEWER	Julia Marley The University of western Australia, Australia
REVIEW RETURNED	14-Jul-2014

GENERAL COMMENTS	The authors describe the views and experience of rural Aboriginal Australians on haemodialysis. The study, which has been soundly conducted, privileges Aboriginal perspectives and is well presented in this manuscript. This study builds on the work by Alan Cass and co-workers, particularly the study by Anderson et al. (reference 32), who identified many of the same themes after interviewing Aboriginal and Torres Strait Islander people on HD across Australia. This work should be include in the introduction as well as the discussion. While there is still a lot of work to be done in Australia to improve health services for Aboriginal renal patients, some satellite services are run by ACCHSs (eg Kimberley satellite dialysis services). In the Goldfields Kidney Disease Nursing Management Program AHWs were seen to be crucial in developing culturally secure services and practices and providing support to dialysis patients (Tracey K, Cossich T, Bennett PN, Wright S, Ockerby C. A nurse-managed kidney disease program in regional and remote Australia. Ren Soc Australas J 2013; 9:28-34). Cass et al also recommend the use of AHWs within alternative workforce structures as part of the model of care for Central Australia (Cass A, Brown A, Togni S, Snelling P, Devitt J, Thomas M, Howard K, McGilvray A. Australian Department of Health and Ageing. Central Australia Renal Study. Part 3: Technical report. Canberra: Australian Department of Health and Ageing 2011). I think it would strengthen the manuscript if you include a discussion on the role of AHWs. Discussion: • There are no limitations. Please discuss the limitations of this study. • P22, line 39, can you please clarify what you mean by "Aboriginal patients managing their own treatment" and whether this leads to improved health outcomes or improved knowledge and understanding about health outcomes? Our study demonstrated similar mortality with non-Indigenous HD patients and due to

	limitations of the study we couldn't actually say that there was an improvement in health outcomes (reference 55). I'm not familiar with the other two references to comment on them. • P3. Why use end stage renal failure and not end stage kidney disease as a keyword? • P7, lines 28-32, please add in author initials. • P7, line 43, AMSs that are controlled by the Aboriginal community are normally referred to as Aboriginal Community Controlled Health Services (ACCHSs). • P9, line 12, please add in more detail about the type of health service (eg AMS/ACCHS or government) and the names of the Aboriginal Research Council and HREC (this information will not identify the communities involved). • P10, line 14, I found this sentence confusing, please consider rephrasing it. • P19, line 52, typo: "a other qualitative studies". • P21, line 54, typo" "30s 40s and 50s"; this should be "30s, 40s and 50s". • P22, line 41, you have used the abbreviation ESKD not ESRD in the rest of the manuscript.

REVIEWER	KONSTADINA GRIVA NATIONAL UNIVERSITY OF SINGAPORE
REVIEW RETURNED	18-Jul-2014

GENERAL COMMENTS	This is an interesting paper on the experience of Aboriginal patients on dialysis. The MS is confidently written and easy to read. There are however some issues that need to be addressed. (a) The authors need to make a stronger statement on unique contribution of their work. As presented, the study is not novel as others have been conducted with aboriginal people with ERSD and noted similar findings. The study righty draws on relevant empirical work with these patients but needs to explicate more what the study adds to what is known already. (b) Study sample comprised mainly patients long established on dialysis (most respondents had dialysis vintage greater than 5 years). These are essentially the dialysis survivors. The long vintage of patients needs to be noted as it presents limitation to generalizability of findings. In addition, issues related to recall bias related to diagnosis need to be commented. (c) It would be good to add when and where the interviews were conducted. (d) Analytical approach needs some elaboration. The authors state that they have conducted a grounded theory analysis but findings appear to be descriptive and presented too linearly. This seems more in line with inductive thematic analysis rather than grounded theory. The interpretative account given in the discussion does take this further but is not sufficiently connected to the data analysis. For example, the discussion on home HD and/or conflict between family wellbeing with health care requirements does not seem to be well linked to the study findings or quotes cited in the results section. One would expect some deduction but more relevant quotes that illustrate or resonate these issues should be added.

VERSION 1 – AUTHOR RESPONSE

Reviewer Name Julia Marley
Institution and Country The University of western Australia, Australia
Please state any competing interests or state 'None declared': None declared

The authors describe the views and experience of rural Aboriginal Australians on haemodialysis. The study, which has been soundly conducted, privileges Aboriginal perspectives and is well presented in this manuscript. This study builds on the work by Alan Cass and co-workers, particularly the study by Anderson et al. (reference 32), who identified many of the same themes after interviewing Aboriginal and Torres Strait Islander people on HD across Australia. This work should be include in the introduction as well as the discussion.

This reference has been added to the Introduction

While there is still a lot of work to be done in Australia to improve health services for Aboriginal renal patients, some satellite services are run by ACCHSs (eg Kimberley satellite dialysis services). In the Goldfields Kidney Disease Nursing Management Program AHWs were seen to be crucial in developing culturally secure services and practices and providing support to dialysis patients (Tracey K, Cossich T, Bennett PN, Wright S, Ockerby C. A nurse-managed kidney disease program in regional and remote Australia. Ren Soc Australas J 2013; 9:28-34). Cass et al also recommend the use of AHWs within alternative workforce structures as part of the model of care for Central Australia (Cass A, Brown A, Togni S, Snelling P, Devitt J, Thomas M, Howard K, McGilvray A. Australian Department of Health and Ageing. Central Australia Renal Study. Part 3: Technical report. Canberra: Australian Department of Health and Ageing 2011). I think it would strengthen the manuscript if you include a discussion on the role of AHWs.

We have not discussed AHWs in this paper because it is specifically focussed on the concerns and issues raised by the patients themselves, therefore these findings and the discussion are based on the specific desires of participants. We would like to contribute to the literature addressing the urgent need for increased AHW within mainstream services as part of reducing Aboriginal people's fear of mainstream health services in a review or opinion piece as our next paper
Discussion:
- There are no limitations. Please discuss the limitations of this study.

Limitations have been at the end of the discussion, however there are several limitations and strengths contained in the article summary as per the journal guidelines. Therefore these may not be necessary in the main body of the text.

- P22, line 39, can you please clarify what you mean by "Aboriginal patients managing their own treatment" and whether this leads to improved health outcomes or improved knowledge and understanding about health outcomes? Our study demonstrated similar mortality with non-Indigenous HD patients and due to limitations of the study we couldn't actually say that there was an improvement in health outcomes (reference 55). I'm not familiar with the other two references to comment on them.

The text and referencing have been altered to address this comment and thank you pointing out our lack of clarity in the language used.

- P3. Why use end stage renal failure and not end stage kidney disease as a keyword?

This is the only key word option available on the Scholar submission platform

- P7, lines 28-32, please add in author initials.

This has been done

- P7, line 43, AMSs that are controlled by the Aboriginal community are normally referred to as

Aboriginal Community Controlled Health Services (ACCHSs).

Thank you for picking this up, AMSs changes to ACCHs.

- P9, line 12, please add in more detail about the type of health service (eg AMS/ACCHS or government) and the names of the Aboriginal Research Council and HREC (this information will not identify the communities involved).

This has been done

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- P19, line 52, typo: “a other qualitative studies”.

Fixed

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Fixed

- P22, line 41, you have used the abbreviation ESKD not ESRD in the rest of the manuscript.

Fixed

Reviewer Name KONSTADINA GRIVA
Institution and Country NATIONAL UNIVERSITY OF SINGAPORE
Please state any competing interests or state ‘None declared’: NONE DECLARED

This is an interesting paper on the experience of Aboriginal patients on dialysis. The MS is confidently written and easy to read. There are however some issues that need to be addressed.

(a) The authors need to make a stronger statement on unique contribution of their work. As presented, the study is not novel as others have been conducted with aboriginal people with ERSD and noted similar findings. The study righty draws on relevant empirical work with these patients but needs to explicate more what the study adds to what is known already.

We have made stronger statements about the unique contribution this work makes. It is the first qualitative study to explore rural dwelling Aboriginal people’s experience and perspective on being an HD recipient.

(b) Study sample comprised mainly patients long established on dialysis (most respondents had dialysis vintage greater than 5 years). These are essentially the dialysis survivors. The long vintage of patients needs to be noted as it presents limitation to generalizability of findings. In addition, issues related to recall bias related to diagnosis need to be commented.

We have added:

The majority of participants were established on HD longer than five years which may also impact on generalizability of the findings as part of the limitations of the study at the end of the discussion

(c) It would be good to add when and where the interviews were conducted.

We have done this on page 8 under data collection ie:

Interviews were conducted by ER at a location preferred by participants, (in most cases their homes) between March and November 2011. A ‘yarning’ technique was throughout the interviews.

(d) Analytical approach needs some elaboration. The authors state that they have conducted a grounded theory analysis but findings appear to be descriptive and presented too linearly. This seems more in line with inductive thematic analysis rather than grounded theory. The interpretative account given in the discussion does take this further but is not sufficiently connected to the data analysis. For example, the discussion on home HD and/or conflict between family wellbeing with health care requirements does not seem to be well linked to the study findings or quotes cited in the results section. One would expect some deduction but more relevant quotes that illustrate or resonate these issues should be added.

We stated that grounded theory was used as a coding technique only. However from there we did use an inductive standard thematic analysis technique. Further validation was provided by both the research team of 5 (4 experienced scholars from a variety of disciplines and the PhD student/first author) as well as the Aboriginal Community Reference group. This group gave feedback and input to the analysis at both the descriptive and interpretive phases of the analysis We have clarified this in the text with:

The CRG and co-authors then contributed to the interpretive analysis of the descriptive themes. The first author then searched for relationships between these interpretations and further substantiation within the data. Final themes and interpretations were validated by the CRG