

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Young Adults' Perspectives on Living with Kidney Failure: a Systematic Review and Thematic Synthesis of Qualitative Studies
AUTHORS	Bailey, Phillippa; Hamilton, Alexander; Clissold, Rhian; Inward, Carol; Caskey, Fergus; Ben-Shlomo, Yoav; Owen-Smith, Amanda

VERSION 1 – REVIEW

REVIEWER	Rachael Walker Eastern Institute of Technology New Zealand
REVIEW RETURNED	11-Oct-2017

GENERAL COMMENTS	<p>A very well written manuscript and well conducted SR using appropriate frameworks. This SR adds to the body of knowledge in this area and has important significance to clinical practice and patient care.</p> <p>Some considerations for the authors: On page 6 (line 44-48) when discussing Systematic review and meta-analysis you may consider changing the working to make it easier for the reader to understand you are talking about 2 separate studies/results if you state something to the effect of "the results of which are reported elsewhere". The boxes with quotes may be better combined into one table? A diagram or thematic schema may also be useful to the reader to demonstrate how the themes are linked.</p>
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REVIEWER	Tania Burns St George Hospital, Sydney, Australia
REVIEW RETURNED	19-Oct-2017

GENERAL COMMENTS	<p>4. Are the methods described sufficiently to allow the study to be repeated? There is no search strategy included. To cite a separate systematic review and meta-analysis of quantitative data is not appropriate. If this is a review of qualitative data as the title states, then the search strategy will reflect this. I would like to see the search terms used for this review and also the date range. No start date is given. Although the title states this is a systematic review of qualitative studies, the paper also tries to incorporate a meta-analysis of the quantitative data already published by one of the authors. This makes for very confusing reading. The findings of the published quantitative review would be better included in the discussion section along with some of the 69 papers analysed.</p>
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In figure 1 the number of papers in the meta-analysis should be removed as they are not relevant to this paper.

6. Are the outcomes clearly defined?

It would be helpful to see the global themes and organising themes displayed in a figure to better understand how they relate to each other.

7. If statistics are used are they appropriate and described fully

As it stands at present there is no detail regarding the systematic review and meta-analysis of the quantitative data other than to cite the reference where it is published. The reader of this paper has no information about the quality of the findings that are cited. As mentioned before this meta-analysis is only relevant as a paper to illuminate the findings of the qualitative systematic review presented and not as a part of the structure of this paper.

8. Are the references up-to-date and appropriate?

On the whole the references are very good, but on page 19 mention is made of psychosocial outcomes recently being identified and then papers from 2016 and 2008 are cited. 2008 is not recent.

10. Are they presented clearly?

Data in the results section is not presented consistently. Some data is identified with a key, some is not eg, page 10. Some is presented in boxes eg, page 11, 13, 14 some is not page 9, 10, 12. The key is good but should be introduced clearly at the start of the results section, not after the first quote. The results lack depth and sometimes do not fit the theme eg, page 11 the data regarding developing an identity is included under the theme of activity and participation.

11. Are the discussion and conclusions justified by the results

As mentioned before the section in the discussion entitled "Convergence of qualitative and quantitative literature analyses' is not appropriate as the reader of this paper does not have any information about the process of the quantitative review. Instead the individual papers analysed in the quant review should be used to make individual points rather than this one paper representing the whole.

The discussion is not very detailed. It does not explore the global theme of difference desiring normality although it touches on liminality and thwarted dreams and ambitions.

This will be a very nice paper but it is currently confused by trying to rely on the author's previous published work rather than using the literature as a whole to support the findings. According to the title this is a systematic review of qualitative studies and so everything in this paper needs to relate to that without piggybacking off another review.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Rachael Walker

Institution and Country: Eastern Institute of Technology, New Zealand

Competing Interests: None declared

- A very well written manuscript and well conducted SR using appropriate frameworks. This SR adds to the body of knowledge in this area and has important significance to clinical practice and patient care.

Some considerations for the authors:

- On page 6 (line 44-48) when discussing Systematic review and meta-analysis you may consider changing the working to make it easier for the reader to understand you are talking about 2 separate studies/results if you state something to the effect of "the results of which are reported elsewhere".

Authors' response: Thank you for your comments. We have made your suggested changes to the text, which now reads:

'This thematic synthesis aimed to identify and synthesise qualitative research describing how kidney failure impacts on the lives of young adults, to identify areas which might require research and clinical attention, to ultimately improve patient outcomes. A systematic review and meta-analysis of the quantitative research on the psychosocial impact of RRT on young adults was undertaken alongside this qualitative synthesis, the results of which are reported elsewhere [9]. This paper presents the findings of the qualitative literature synthesis, which might help us to explain the quantitative findings, adding the patient voice and rich context to numerical results [10].'

- The boxes with quotes may be better combined into one table?

Author's response: Thank you for this suggestion. As suggested by reviewer 2 we have chosen a single consistent approach to presenting our quotes and have now removed the quotes from the boxes and embedded all the quotes in the main text.

- A diagram or thematic schema may also be useful to the reader to demonstrate how the themes are linked.

Authors' response: Thank you for this comment. We have added a thematic schema as suggested (see Figure 2).

Reviewer: 2

Reviewer Name: Tania Burns

Institution and Country: St George Hospital, Sydney, Australia

Competing Interests: None declared

4. Are the methods described sufficiently to allow the study to be repeated?

- There is no search strategy included. To cite a separate systematic review and meta-analysis of quantitative data is not appropriate. If this is a review of qualitative data as the title states, then the search strategy will reflect this. I would like to see the search terms used for this review and also the date range. No start date is given.

Authors' response: As requested by the editorial team we have now added our search strategy for the Medline, EMBASE and PsycINFO databases as supplementary material. As you will see from our strategy, it was extensive, and not limited to MeSH terms or to certain study designs so as to identify all possibly relevant research, including mixed-methods studies such as that by Harwood et al. As we detail in our methods, the references of all identified relevant papers were also screened for any potentially missed papers. The dates of our searches are now provided in the methods. The different databases searched have different start dates, and these are now specified in the supplementary material.

- Although the title states this is a systematic review of qualitative studies, the paper also tries to incorporate a meta-analysis of the quantitative data already published by one of the authors. This makes for very confusing reading. The findings of the published quantitative review would be better included in the discussion section along with some of the 69 papers analysed. In figure 1 the number of papers in the meta-analysis should be removed as they are not relevant to this paper.

Authors' response: Thank you - we have made the suggested change to Figure 1, and updated the flow chart since running the search strategy up to November 2017.

We have not incorporated the meta-analysis of the quantitative data into this study; the methods and results report only on the qualitative synthesis. The quantitative research review is referenced in the introduction and discussion to highlight that as a research group we had undertaken a review of the full breadth of qualitative and quantitative research. We believe that a greater understanding is gained by exploring the findings of both reviews together. The thematic synthesis of the qualitative literature provides further detail and explanatory background to the quantitative findings, and adds patients' voices to the meta-analyses. It adds rich context to the life impacts seen in the quantitative review, and provides reasons for and the experiences of the identified quantitative findings. In addition new themes were identified not reported in the quantitative literature: 1) Difference desiring normality; 2) Thwarted or moderated dreams and ambitions; 3) Uncertainty and liminality.

6. Are the outcomes clearly defined?

- It would be helpful to see the global themes and organising themes displayed in a figure to better understand how they relate to each other.

Authors' response: Thank you for this suggestion. We have added a thematic schema as suggested (see Figure 2).

8. Are the references up-to-date and appropriate?

- On the whole the references are very good, but on page 19 mention is made of psychosocial outcomes recently being identified and then papers from 2016 and 2008 are cited. 2008 is not recent.

Authors' response: Thank you for highlighting this – we agree that 2008 is not recent, and as such have removed the word 'recently' from the sentence you referenced.

10. Are they presented clearly?

- Data in the results section is not presented consistently. Some data is identified with a key, some is not eg, page 10. Some is presented in boxes eg, page 11, 13, 14 some is not page 9, 10, 12. The key is good but should be introduced clearly at the start of the results section, not after the first quote.

Authors' response: Thank you for your comments. As this is a synthesis of seven individual studies the reporting will naturally vary according to the reporting in the individual papers, and many of the papers didn't identify the characteristics of the person who was the source of a quote. As suggested we have added the following sentence to earlier in the results section:

'When reported in the primary research paper the characteristics of the person to whom the quote belongs are provided after the quote: Key: Age (in years), Sex (M=male; F=female), RRT (HD=haemodialysis; PD=peritoneal dialysis; Tx=transplant)'

As suggested we have removed the quotes which had been presented in boxes and embedded them within the text so that presentation of the data is consistent.

- The results lack depth and sometimes do not fit the theme eg, page 11 the data regarding developing an identity is included under the theme of activity and participation.

Authors' response: In our results we have reported three global themes, and five organising themes. Each theme is illustrated by at least three participant quotes, and illustrative quotes are from different primary papers. We have added a thematic schema to demonstrate how the themes are related. This was not the opinion of the first reviewer who felt that this was 'a very well written manuscript and well conducted systematic review.'

Regarding the quote identified on page 11, we would argue that a sense of identity is inextricably linked to social participation, and therefore the quote is appropriate and relevant. Etienne Wenger argued that 'Identity in practice is defined socially not merely because it is reified in a social discourse of the self and of social categories, but also because it is produced as a lived experience of participation in specific communities.' He went on to argue that 'An identity, then, is a layering of events of participation and reification by which our experience and its social interpretation inform each other. As we encounter our effects on the world and develop our relations with others, these layers build upon each other to produce our identity as a very complex interweaving of participative experience and reificative projections. Bring the two together through the negotiation of meaning, we construct who we are.' [Wenger, Etienne (1998). *Communities of Practice: Learning, Meaning, and Identity*. Cambridge: Cambridge University Press]

11. Are the discussion and conclusions justified by the results

- As mentioned before the section in the discussion entitled "Convergence of qualitative and quantitative literature analyses' is not appropriate as the reader of this paper does not have any information about the process of the quantitative review. Instead the individual papers analysed in the quant review should be used to make individual points rather than this one paper representing the whole.

Authors' response: We have removed the discussion subtitle 'Convergence of qualitative and quantitative literature analyses' and substantially edited the phrasing of this section of the discussion to demonstrate how the qualitative synthesis provides explanatory background to the quantitative systematic review (see below). We have enhanced our reference to the quantitative systematic review by adding references to six individual primary quantitative papers.

The section previously titled "Convergence of qualitative and quantitative literature analyses' now reads:

'A recent quantitative systematic review and meta-analyses found that compared with healthy peers, young adults with transplants had lower quality of life [9]. Our thematic synthesis suggested possible reasons for this: including the effects of transplant medications on appearance, and ongoing restrictions in diet, medication and activities. The poor quality of life is also likely to be explained by the persistent sense of liminality, and experience of transplantation as not the 'normal life' that was anticipated pre-transplantation.

This thematic synthesis found that young people had to moderate career expectations due to their disease, resulting in a mismatch between the jobs they wanted and those they were offered. Participants also reported difficulties disclosing their disease to employers, with a perceived impact on the likelihood of and security of employment. Many individual quantitative studies, have reported that young adults on RRT are more likely to be unemployed [9, 17, 28-31]: often despite education levels comparable to their healthy peers [9, 28, 31]: these qualitative findings highlight possible reasons for this.

Numerous quantitative studies have reported that young adults on RRT are less likely to be married or to have a long-term partner [9, 29, 32, 33]. The thematic synthesis found that young adults reported that their renal disease had an impact on their confidence in pursuing, and ability to establish and maintain intimate relationships. Young adults reported concerns finding a partner who would accept their need for RRT, and many reported rejection as a result of their renal failure. Concerns regarding fertility, heritable disease and parenthood were also reported as impacting on relationships.'

- The discussion is not very detailed. It does not explore the global theme of difference desiring normality although it touches on liminality and thwarted dreams and ambitions.

Authors' response: The discussion comprises almost a third of the whole paper, and includes a discussion of results in the context of the broader literature, both renal and non-renal. We include a discussion of the strengths and limitations of the study, and the implications for clinical practice. We have explored the theme of difference desiring normality as a theme that is inextricably linked to the other themes reported.

We emphasise how the sense of difference intertwines with uncertainty to lead to social isolation: 'They described a sense of difference, and uncertainty, both of which were intertwined with a sense of social isolation.'

We highlight how the persistent sense of difference after transplantation contributes to the continued sense of liminality:

'This has previously been described in the renal literature [26, 27], including the experience of transplantation not always delivering the desired/expected normality of wellness, and so in many ways continuing the liminal state [26].'

We also describe how the sense of difference contributes to the poorer quality of life identified in quantitative research:

'The poor quality of life is also likely to be explained by the persistent sense of liminality, and experience of transplantation as not the 'normal life' that was anticipated pre-transplantation.' Difference is also implicit in the discussion sections regarding employment and relationships, which emphasise the difference young adults on RRT experience compared to healthy peers, and the reasons for this. We have added the following sentence to make this explicit:

'The sense of difference identified in the synthesis is likely to both cause and result from the described differences in employment, intimate relationships and social isolation.'

We are limited by the journal's word limit for original articles (4000 words) which we have reached, and we therefore do not feel we can expand the discussion further.

- This will be a very nice paper but it is currently confused by trying to rely of the author's previous published work rather than using the literature as a whole to support the findings. According to the title this is a systematic review of qualitative studies and so everything in this paper needs to relate to that without piggybacking off another review.

Authors' response: The methods and results reported relate solely to the results of the qualitative synthesis, which are presented exclusively within this article. Whereas it is true that the allied quantitative review was conducted by other members of the research group, neither the first author (PB) nor the senior author (AOS) of this qualitative synthesis were involved in the conduct or publication of the quantitative review: to suggest this article 'piggybacks' off an allied but independent review is unfair.

VERSION 2 – REVIEW

REVIEWER	Rachael Walker Eastern Institute of Technology, Napier, New Zealand
REVIEW RETURNED	01-Dec-2017

GENERAL COMMENTS	Happy with revisions made by authors.
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