Author's response to reviews

Title: Using focused ethnography in paediatric settings to explore professionals' and parents' attitudes towards expertise in managing chronic kidney disease stage 3-5

Authors:

  Ruth Nightingale Ms (ruth.nightingale@gosh.nhs.uk)
  Manish D Sinha Dr (manish.sinha@gstt.nhs.uk)
  Veronica Swallow Dr (Veronica.Swallow@manchester.ac.uk)

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Author's response to reviews: see over
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Christopher Morrey
Executive Editor
BMC Health Services Research

Dear Mr Morrey,

Amended title: Using focused ethnography in paediatric settings to explore professionals’ and parents' attitudes towards expertise in managing chronic kidney disease stage 3-5

Thank you for returning the reviewers’ comments.

We would like to thank both reviewers for their considered and very helpful reviews. We have responded to the comments below in bold text and in the manuscript. We believe the paper is now stronger and hope that the reviewers agree.

Reviewer: Gavin Daker-White

Major compulsory revisions:
1. You need to reference the following systematic review. You might also benefit from explaining your own findings in light of theirs: Pediatrics 2008;121;349 Allison Tong, Alison Lowe, Peter Sainsbury and Jonathan C. Craig Systematic Review of Qualitative Studies Experiences of Parents Who Have Children With Chronic Kidney Disease: A Systematic Review of Qualitative Studies

   Thank you for pointing out this omission. We are aware of this author’s 2008 SR, some of which is contemporaneous with work by Dr Swallow (the last/senior author on this current paper) and colleagues [e.g. Swallow, V., et al., Childhood chronic- kidney-disease: A longitudinal-qualitative study of families learning to share management early in the trajectory. Patient Education and Counseling, 2008. 73: p. 354 - 362.]

   The two bodies of work are complementary; indeed a 2012 SR of qualitative studies of children’s experiences of dialysis which Dr Tong co-authored found only 17 studies out of 120 that were potentially eligible. [Tjaden, L., Tong A et al., Children’s experiences of dialysis: a systematic review of qualitative studies. Archives of Disease in Childhood, 2012. 97(5): p. 395-402]. One of the 17 was our own (The 2008 PEC paper referred to above). Dr Tong’s SR found our study to be 1 of only 5 that described the participant selection strategy, 1 of only 6 that reported the presence of non-participants, 1 of only 5 that reported the use of recording equipment, 1 of only 11 that provided
respondent quotations, 1 of only 2 that recorded using software to code data and the only one that reported participant feedback on preliminary findings. The SR findings relate to parents also so are relevant to this current paper and are considered in our discussion section in this current paper.

2. I would take care of the use of the term “ethnography.” This does not appear as an ethnography, although ethnographic methods were used. I have seen others speak of “focused” or “applied ethnography” in this context, which might be more relevant. I would personally badge this as a qualitative and observational study. By page 22, it now appears as a “participant observation” study. Given that the observer was a nurse, I think that this label is much more appropriate. Thus, some clarity is needed over the terminology of your methods, and this should be standardised throughout the manuscript.

‘Focused ethnographic exploration’ is already referred to on p8 of the previously submitted paper, but the reference is now included and we describe the method briefly.

As stated in the Authors’ Information section (after conclusion/competing interests) the researcher collecting data was an occupational therapist not a nurse: “RN is an occupational therapist and qualitative researcher with experience in child health”; This was very relevant as renal teams do not include occupational therapists, therefore there was little likelihood of professional conflict of interest arising during the observations or analysis which may have happened if the researcher had for instance been a nurse, doctor or dietician. However, because of the sensitive nature of the observations, involving families living with complex health care issues, it was important that the researcher was comfortable in a child health setting and understood the type of environment that exists in a busy children’s ward, outpatient department and the homes of families living with long term conditions, which RN was. Therefore, to avoid such a misunderstanding arising for readers we have added a sentence into the methods/study setting section to clarify this.

Minor essential revisions:
1. Abstract, Methods: “Framework” should read “a framework” or “the framework method [of qualitative data analysis].” Although as I read the main paper, it seems as though you did not use the framework method as I understand it (see http://www.biomedcentral.com/1471-2288/13/117 ), but rather used a theoretical framework from the literature. But when we get to page 10 I am further confused. Thus, some clarity is needed on this aspect of your methods.

Thank you for raising this issue, as already cited on p10, we did use the Framework approach as widely described by Ritchie et al and in methodological papers discussing the use of Framework in health care contexts including those authored by Dr Swallow. By coincidence Reviewer 2 suggested: “3) Page 10, It may be useful to refer readers more explicitly to the linked 2013 paper (or indeed others by some of the authors) which has more detail regarding the use of the Framework approach to analysis.” We have therefore made more explicit links to papers on Framework including some
relevant examples by one of the authors of this current paper (Swallow), on page 13.

2. Abstract, Methods: What is the distinction between the concepts “expertise” and “the expert patient”? They sound like different aspects of the same concept.

Thank you for highlighting this issue, we have amended the abstract in light of your comments.

3. Keywords: Should “chronic” be “chronic illness”? This is a good point, we have changed to chronic illness

“kidney” appears superfluous. CKD could be spelt out in full, and then you won’t need the word “chronic” which will become redundant. The term CKD is often used instead of, or interchangeably with terms such as kidney disease, or chronic kidney disease or renal disease so to optimise the use of search terms we have included all

Although “long term conditions” might be better in any case? The terms chronic illness/disease and long-term conditions are also often used interchangeably; in the US for example ‘chronic disease’ is still more common although in the UK long-term is becoming more common, so as this is an international journal both are required to optimise search results

Should “child” be “children,” or “paediatric”? This is another good point but in American literature the term Pediatric is widely used instead of the English paediatric; whilst child is both a word in wide use as well as a truncated version of the word children

4. Page 27: “The approach provided a rich source of visual data.” Is “visual data” the correct term? Doesn’t that rather refer to use of photographs or other artefacts as prompts in qualitative interviews?

Thank you for pointing this out, we have changed the term.

Discretionary revisions:
1. Page 3, “as parents learn to master the clinical skills to manage their child’s CKD at home.” Is “clinical” the correct word in this context?

Yes it is the correct word in this context to make very clear the distinction between typical parenting skills (e.g. dressing, feeding, nurturing the child) and clinical skills such as administering medications, dialysis and/or specialist diets (e.g. kidney or renal diets) that parents of children with long term conditions, including CKD 3-5 can be expected to prepare/administer at home as part of the child’s treatment regimen, and are essential to maintain their child’s optimum health in the circumstances.

2. Page 3, “This gap in the evidence may exist because of the perceived difficulty and ethical concerns around obtaining consent and safeguarding privacy when conducting research that involves observing interactions in clinical settings [5, 6].” Is this a general point, or is it supposed to reflect the specific difficulties of research involving children?
This point refers to both adult and child health care

3. Abstract, Conclusions; “We conclude that observational methods have the potential to elicit insights that are not readily available through other methods.” In my opinion, this point has already been made in numerous other reports. I would prefer to see a concluding comment that refers to the principle aims and objectives of the study.

**We have altered the abstract in this respect**

4. I was sometimes confused about whether this paper is a methodological report on the usefulness of observational methods in paediatric care, or a summary of findings concerning the management of CKD in children. Would it be better to focus on one or other aspect? The point that observational methods are useful in this field is well made, but sometimes repetitively. Having said that, the discussion of the processes and pitfalls in trying to undertake this kind of work are interesting and well explicated. Should the conclusions refer to CKD management or to the use of observational methods (as they do at present). If your main purpose is to argue for the utility of observational research in paediatric settings, perhaps the title should better reflect that?

**This is a helpful observation, we have changed the title to one which better reflects the aims of our paper**

5. Page 3, “Ethnographic research is one methodological approach that can address these challenges but it is argued that it has been overlooked as a methodology for the in-depth study of healthcare issues in the context in which they occur, due to these reported concerns [7].” I think you are mixing up several issues here. There are plenty of ethnographic and/or observational reports of studies in Health Services Research. I am not sure the “privacy” argument applies to observational/ethnographic study alone. I would be tempted to re-write this section so that it rather points to the potential utility of observational approaches, and refers to the wide extant literature on doctor-patient interactions and how useful these can be to understanding processes of self-management or peer support.

**We have discussed the utility of observational approaches in the background and methods sections.**

6. Did the research nurses who were observing sessions wear a uniform? It seems as though there was some possibility for researcher role problems and confusing them with clinical staff? This might need a bit further discussion [although there is quite a bit from bottom of page 14]. It seems like this did cause problems. Would it have been better if the observer/s was/were not clinically trained? This also relates to my concern about calling this study an “ethnography,” when the observer was not an impartial or naive observer, but a trained clinician in the field of interest.

**As previously explained the researcher was not a nurse and the significance of this is explained.**
Reviewer: David Clarke

Major Compulsory Revisions:
1. Whilst I appreciate the general point (page 3) regarding concerns which may have led to limited use of ethnography in healthcare research, I suggest the authors need a more balanced commentary and perhaps to acknowledge that, whilst ethnography remains challenging in children’s healthcare settings and in the wider healthcare sector, there is evidence of use of this approach in a wide range of settings and with a range of participants- see for example Anthropology & Medicine Volume 15, Issue 2, 2008, Fudge et al 2008 BMJ 2008;336:313, Kuper et al 2010 DOI: 10.1111/j.1365-2923.2010.03622, Clarke, et al Implementation Science. 8:96. doi:10.1186/1748-5908-8-96.

This seems important given that on page 5 and 6 the authors also review a number of studies in child health settings which have used observational methods.

Thank you for these useful suggestions, we have altered accordingly.

2. Page 8, it would be helpful to make clear that Phase 2 represents the ethnographic component of the study We have clarified this, please see p9-10.

and also to state in this section the criteria used to identify the two units selected for focussed ethnographic exploration. This is now explained on p10.

On page 9 the purposive sampling approach used is clear and helpful but does not indicate what the balance of case studies was between the two units, e.g. 1 and 5 or 3 and 3 etc, please clarify this. This is clarified on p11.

3. I was surprised that little in the way of description of the clinical and organisation contexts in which the study took place was provided. Given the concern of ethnographers with context and its impact on social actors and their behaviours and interactions this was surprising omission. I think there should be brief comment on this issue or a brief statement as to why it is not discussed in this paper.

Thank you for highlighting this issue, we have created a new sub-section (Study setting) in the Methods section and have briefly added additional information to that already present that describes the context.

4. I appreciate that the 2013 publication by the authors (reference 9) contains more detail on data collection methods but I think this paper, if it is to stand alone must also provide more detail on the nature of the ethnographic methods employed in this study, particularly as the paper aims to explore how the ethnographic methods were used as an ‘effective means of exploring professionals and parents attitudes towards expertise’. Please add some detail on where and when exactly observations took place, for what periods of time for specific observations and over what period of time and why in the whole of phase 2. Similarly what part does interview data and data derived from documentary analysis play in ethnographic research such as that described? These may be taken for granted notions within the research team but they need more explicit commentary here given the focus of the paper.
Detail has been added in as suggested, please see p12-13.

It is also rather confusing for the reader when referring back to the 2013 publication to find the ethnographic work referred to as phase 3 whereas in this paper it is referred to as phase 2.

Thank you for highlighting this error, we have corrected this and clarified that this paper reports on phase 3 of a three phased study.

5. On page 22 it is suggested that RN acted as a participant observer. The prior discussion suggests that participation may be restricted to engagement in social and non-specific communication related to aspects of a child’s care (so very much at the non-participative end of the continuum of observational approaches). Whilst this seems appropriate in the context of the study described, it does not necessarily accord with the more commonly accepted concept of participant observation where the researcher may be more active in the research setting. Further clarification of the participant role should be provided. 

RN’s role as a non-participative observer has been clarified.

Minor essential revisions:
1. There are some references which at present are incomplete e.g. 12, 15, 24, 26. 

Now complete

Discretionary revisions:
1. The paper acknowledges the uncertainties which staff and parents expressed regarding the nature of expertise. I felt that the discussion on page 5 tended to represent expertise as being largely related to forms of knowledge held or gained whereas later in the paper there is reference to clinical expertise (which seems to be about specific skills and associated decision making) and blended expertise which I don’t think is really defined or explained within the paper. We address this on p22.

2. It was refreshing to read about how some of the practical challenges in gaining consent on page 12-13 (people joining OPD appointments) and useful to read how this was managed. A similar brief explanation of how HCPs questioning of what was recorded in field notes was managed would be helpful for readers. 

Thank you for this positive feedback, we provide a brief explanation on p15.

3. Page 10, It may be useful to refer readers more explicitly to the linked 2013 paper (or indeed others by some of the authors) which has more detail regarding the use of the Framework approach to analysis.

Thank you, this is also addressed in response to reviewer 1.

Yours sincerely,

Ruth Nightingale

Veronica Swallow