Author's response to reviews

Title: "It's alright to ask for help", developing competence, preparedness and confidence in family carers providing end of life care: findings from a qualitative study with carers and nursing staff.

Authors:

Emily J Harrop (harrope@cf.ac.uk)
Anthony Byrne (Byrnea2@wales.nhs.uk)
Annmarie Nelson (nelsona9@cardiff.ac.uk)

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Author's response to reviews: see over
Re: 1318584391005940 "It's alright to ask for help", developing competence, preparedness and confidence in family carers providing end of life care: findings from a qualitative study with carers and nursing staff.

Thank you for the opportunity to resubmit the above manuscript (title has been revised as per the suggestions below). We have made revisions to the manuscript as per the helpful suggestions made by the two reviewers, each of which is addressed in turn below (changes made to the revised manuscript have been highlighted for clarity). A list of abbreviations has also been included in the manuscript.

Reviewer One

1. Is the question posed original, important and well defined?

I found myself confused about the purpose of the paper. The aim as stated in the Methods section was “to explore the information and support needs of family carers”. However, this is not reflected in the title of the paper which is about developing competence etc. "It's alright to ask for help", developing competence, preparedness and confidence in family carers providing end of life care: findings from a qualitative study with carers and nursing staff.

While one solution may be to revise the aim of the paper I am not sure that this could be done without changing the results which at present are more in line with the aim than title. In the Discussion the authors appear as interested in discussing the need to develop an educational resource as in the implications of the reported results. The authors need to review the paper so that the aim, the title and the results are better aligned.

On reflection, we agree with Reviewer One that the title is confusing and so have amended the title accordingly: "It's alright to ask for help": findings from a qualitative study exploring the information and support needs of family carers at the end of life.
2. No response required

3. Is the interpretation (discussion and conclusion) well balanced and supported by the data?

The discussion is well balanced in respect of the previous literature. However, the data struggles to support any conclusions due to the very small numbers involved. While this is acknowledged the justification for the small numbers is not convincing. Furthermore, there is no discussion of the potential impact of such small focus groups on the results or the implications of only female carers. There is no mention of whether BME carers were involved or the need for further research if they were not.

We have extended the discussion on limitations to consider these additional limitations and make clear the need for further research using different groups.

Discretionary

A table that describes the characteristics of the participants would be helpful.

We have included tables detailing the characteristics of the participants.

Reviewer Two

Major Compulsory Revisions

Methods

1. Please indicate at the beginning of the Methods section what type of qualitative methodology was used and why it was chosen.

A critical realist approach based on in depth thematic analysis of the data set was used to explore the lived experiences, meanings and the reality of family carers, whilst at the same time paying consideration to how participants make meaning of their experience and in turn the influence of social context on such meanings. I have described this at the start of the Methods section as suggested.

2. Indicate where ethics review was conducted and approved, as well as the process for obtaining consent to participate.

This has now been explained in greater detail in the Methods section.

3. Since the carers were receiving or had received hospice care, the kind of care provided and for how long is important contextual information as services received might reduce their needs, and these may potentially not be reported as often. Please include a brief description of the services offered by the hospice and, if available, the actual amount of time carers had been receiving the service at the time of the focus group (would be the total time in hospice for the bereavement group). If this is not available, then please add the mean and median time in hospice care for the service as a whole.

Only the bereaved carers had been receiving hospice services for themselves ie the bereavement counselling. The current carers were known to the hospice because they attended the day centre with their relatives.
4. Explain the sampling strategy.

This is now explained in the Methods section - the day centre manager at the hospice sent out letters of invitation and participant information sheets to current carers who had been attending the day centre with their relatives and to the former carers who had attended bereavement counselling sessions at the hospice. Interested participants then contacted the team directly and suitable dates for the groups were identified. Nursing staff were approached and given participant information sheets by their managers.

5. Analysis and interpretation. It is stated that “established techniques were used for coding and comparison” but there is no reference for this. Please clarify the analysis section. For example, it is not clear at what point in the process the analytic framework was developed and how it was then used. Since there are only 4 transcripts, how many were actually double-coded? What there consistency from the start or was an adjustment required, and if so what was done?

Thank you for this suggestion; we have elaborated on this in the manuscript.

Discussion

Limitations section:

6. The reason given for the limitation in the number of carers and health care providers interviewed assumes that the study had to recruit from only one hospice. To me the fact that the study was carried out at only one hospice is a limitation that should be mentioned.

7. Other limitations that should be discussed:
• all bereaved carers were from a bereavement counselling group
• all bereaved carers were women, 6/7 were wives
• all participants were from one hospice

This section has been extended to cover these limitations

8. Last paragraph of Discussion, sentence that ends with ‘settings’. This is the first time settings is mentioned and it does not make sense here.

We have amended this paragraph so that this makes more sense to the reader.

Conclusion

9. The conclusion should address conclusions drawn from the study results, not on speculation about development of an educational intervention in the discussion.

We have re-written the conclusion accordingly.

Minor Essential Revisions

Method

10. Participants: What was the gender distribution of the health care providers?

All the health care providers were female and this has now been detailed in the section on participants
11. Focus groups paragraph 2: please specify the type of clinician and type of relationship to the hospice service (as a clinician? researcher? other?) of the clinician researcher conducting the focus groups.

This researcher had worked for many years as a health care assistant at the hospice before entering an academic career in palliative care research.

Results

12. Some of the quotes are difficult to understand. Please either delete extra words (and insert “…” ) or else clarify in the preceding text or in brackets. Especially the following: “OK if they don’t want to that another thing”; “sensitive and sensible sorry,”; “And I just wish I hadn’t said anything and just let him have his injection and not call that GP out (on the weekend) because then perhaps on the Monday he could have either come here or going straight to, once he got into that sort of thing of going into that hospital they needed to go through a whole process of things before they would let him…”

We have amended the quotes to make them easier to understand.

13. Please clarify the title of the “Credibility and confidence” theme, i.e. credibility and confidence of what? in what? The section makes it clear what it’s about, but to me the title is not meaningful as is.

This has been amended to ‘identification and confidence in “carer” roles’ to better describe the meanings of this theme.

14. Indicate whether there were any intra- or inter-group areas of disagreement.

There was very little intra-group disagreement. Participants in the carer groups tended to tell personal stories as opposed to engage in debate over how they could be supported and in the nurse groups participants tended to build on one another’s suggestions as the group consensus began to form on what shape a support package might take within these group. The notable difference within the current carer group was between the perspectives and experiences of the daughter compared with the wives, although this was not disagreement as such, more a difference in experience and set of expectations towards health and social services. In terms of inter group differences there were differences in the type of support discussed between the more practical focus of the HCA group and discussions around more specialist knowledge eg diet, drug administration in the CNS group. Inter group differences were also apparent in the increased reflexivity and awareness of the former carers compared with the current carers. I have tried to bring these out more in the results section of the manuscript.

15. At the end of the Results, tie the three themes together.

A summary paragraph has been added.

Discussion

16. In the 3rd paragraph, the literature certainly indicates that there are high levels of caregiver need, therefore it is not clear what is meant by “low levels of need” in the sentence “Secondly, issues around more general carer confidence and low levels of need or role awareness…”

This has been amended to; issues around more general carer confidence and low levels of self-perceived need or role awareness.
17. That same paragraph ends with: “...building more general carer confidence in their caregiving roles and their perceived credibility in asking for support and advice.” My comment here is similar to that for the title of this theme; I don’t think this is the best way to describe what is meant. It begs the question of who is perceiving their credibility. Also, I would clarify that it is confidence in their [ability? competence? that they are actually in?] in their caregiving role.

We have amended to the following;

Such approaches could therefore serve a dual role of both enabling carer knowledge and competence in specific care domains, but also facilitating carer identification with, and more general confidence in their roles as ‘carers’, and in turn their own self perceived credibility to ask for support and advice.

**Discretionary revisions**

There is another review article that is very relevant and which you might want to reference and consider in the Discussion.


In addition to that review article, there are other papers that demonstrate and call for the need for individual education that needs to be provided on an ongoing, as-needed basis, e.g.


Thank you for these suggestions, both very interesting and relevant; we have cited them accordingly.

**Minor revisions not for publication**

I suggest using “family caregiver” as a keyword since it is more commonly used than carer outside of the UK. This can replace “family”.

This has been amended.

**Background, paragraph 2, last sentence:** Delete the word “prepare” after carers. For readers not in the UK, please explain what health care assistants are (training; roles).

This has been amended and an explanation has also been included.

We hope our revised manuscript addresses all suggested revisions and look forward to your decision in due course.

Yours sincerely,

Dr Emily Harrop