Reviewer's report

Title: The provision of generalist and specialist palliative care for patients with non-malignant respiratory disease in the North and Republic of Ireland: a qualitative study

Version: 0 Date: 14 Jan 2017

Reviewer: Morag Farquhar

Reviewer's report:

Peer review for BMC Palliative Care for PCAR-D-16-00170

Development of an integrated model of palliative care for people with non-malignant respiratory disease: a qualitative study.

Clare Mc Veigh, PhD, MSc, RN; Joanne Reid, PhD, RN, RNT; Philip Larkin, PhD, RN, RNT; Sam Porter, BSSC, PhD, RN; Peter Hudson, PhD, RN, RNT

Publication of research on palliative care in non-malignant disease is welcomed and this is an interesting piece of work, however I have several queries/concerns that need addressing or responding to.

Major concerns:

1) After reading the full paper it became clear that this piece of work seeks to identify the views of bereaved carers and health care professionals (HCPs) on palliative care in non-malignant respiratory disease (NMRD) in order to develop an integrated model of care for its delivery. Although the title refers to developing an integrated model of care there is no mention of this in the aim or methods. The aim and methods only refer to exploring service provision (they don't mention developing the model), and the aim refers to exploring service provision rather than exploring views of service provision. An exploration of service provision might have included a more quantitative mapping exercise, rather than just qualitative data collection on views. More clarity in the aim would be helpful.
2) Questions in the bereavement carer the topic guide refer to care in the "last year of life", most of the paper talks about "palliative care", and in other parts "end of life care". Which of these is the focus?

3) What was the rationale for only interviewing bereaved carers and not accessing the views of current carers, or patients? There may be a good reason, but it needs stating.

4) Fig 1 and Fig 2 would be better referred to in a sentence about the recruitment process e.g. "Figures 1 and 2 illustrate the recruitment process…"

5) Convenience sampling - but how were sites actually selected? Proximity to the researcher? Already known to the researcher? …?

6) Please state the spread of sites in the two areas: one rural and one urban in each?

7) I have concerns about the carer identification process and would like more detail:
   a. Where were the carers recruited from? Says by Respiratory Nurse Specialists (RNSs), but in primary care or secondary care, or both? Please comment in the limitations if only from secondary care as these will not necessarily reflect the population (not all NMRD patients have access to secondary care).
   b. Also, is there a potential limitation that sample is further biased as recruitment was via RNSs which means their patients all had an RNS (which is a higher level of care)?
   c. Presume RNSs first identified patient deaths (were there any other patient criteria other than diagnosis and death?), then identified those where they knew there was a carer and they had their contact details? This strategy requires RNSs to know who the carer was (our research has shown this knowledge is not common).

8) Line 109 - this is the first mention of MDTs - should they be referred to in the background?

9) Line 111 - which department? Respiratory?

10) Line 111 - secondary care HCPs only? If so, need to comment on this in the limitations

11) Line 112 - using the term "gatekeepers" here feels inappropriate as it has negative connotations and is usually used in the context of describing a barrier to recruitment. If there were gatekeeping issues then these should be discussed in the discussion section. Similarly using the term within Fig 1 and 2 is unusual.

12) Table 1 (carers) - any comment on these carers mainly being women? The mean age seems relatively young for NMRD. All carers were family - no friends (worth a comment?)
13) Table 1 (HCPs) - from primary or secondary care (this seems key given the attention to setting in the literature review)

14) Line 131 - where were the sites? Primary or secondary care?

15) Table 2 topic guide - refers to "towards the end of life" and "last year of life" - so should this be in the aims / title. Also, palliative care is not just in the last year of life. Also, the questions seem quite scripted, rather than "topics".

16) Table 3 - lot of questions for a focus group topic guide (and "Can you tell me…" is not an open question). Also, first mention of Healthcare Support Worker - should this role be referred to in the background?

17) Surprised to see % in a qualitative report of this kind, but does raise questions about the sample as the % who had accessed specialist palliative care (SPC) is actually very high (given that not all will need it) - far far higher than in our work with an English population-based sample of over 200 advanced COPD patients (where only one patient reported access to specialist palliative care). Also, not sure of the value of reporting that none of the bronchiectasis patients had SPC given that there was only one bronchiectasis patient.

18) Line 206 - we would expect variation in access to SPC as not all patients need it (it is a specialist service). Also think you need to be more specific here.

19) Line 212 - says carers perceived that receipt of services from a RNS would have benefitted the patient - but earlier text implies that carers were recruited by RNSs, so their patients must all have been getting RNSs? Confused.

20) The report on the carer interview findings feels thin, particularly given the range of topics on the topic guide. And it is all focused on the patients but there were questions about carer support and carer bereavement support too.

21) Line 244 - what were the differences (in prognostic uncertainty) by HCP type? This may be more illuminating and useful than differences by geographical location.

22) Line 293 - how did the HCP views vary? Again - by professional group?

23) Line 327 - mixed perspectives of role of SPC - again, did the perspectives vary by professional group? Also, I am not sure I saw this in the data presented (nor did I see mixed perspectives about when SPC should be introduced)
24) Line 334-335 - says presence of a model ensured receipt of optimal palliative care, but the carers had said they didn't get this. So it is that the presence of a model meant that HCPs believed it enabled optimal palliative care?

25) Discussion:
   a. Lines 349-349 re inconsistent access to SPC, and line 350 re the majority not receiving SPC - but was this because not all patients needed SPC (generalist palliative care was sufficient)? In addition see point above about the high % who seemed to be getting SPC.
   b. Line 355 - not sure you can say patients wanted access to SPC as they were not asked.
      Also, did the carers want access to SPC or to palliative care (from generalists) - not all generalists provide it.
   c. Line 359-360 - do you really mean SPC or provision of palliative care (from generalists too), as not all patients need SPC. Much of the paper seems to focus on specialist access/provision.
   d. Lines 379-386 - I am not sure I saw this in the results as presented (that HCPs indicated that palliative care may also be viewed as only relevant to COPD, not ILD or bronchiectasis).
   e. Lines 383-386 - I am not sure I saw this in the results as presented (that inequalities related to recognition of the role of palliative care amongst different types of non-malignant disease)
   f. Lines 394-395 - I am not sure I saw this in the results as presented (that some HCPs felt SPC should be provided to all) - also, they may not all need it
   g. Lines 395-398 refers to "international" guidance but references British guidance
   h. Line 402-403 states that policies specific to bronchiectasis do not provide guidance on introduction of SPC services but higher up in same paragraph it suggests that reference 19 does?
   i. Line 403 - is this the correct reference? Ref 40?
   j. Line 405 - does this refer to your data ("many HCPs...") , if so then why is it referenced? If not, then may need amending as it reads as though it is about your data.
   k. Line 408 - something wrong with referencing as ref 43 is the MRC framework
   l. Line 415 - something wrong with referencing as ref 44 is about cancer
m. Line 429 - wonder if it would have been better to have just focused on the two "minority" NMRD disease groups of ILD and bronchiectasis?
n. Limitations - additionally may need to comment re my queries about carer recruitment and HCP recruitment (if all secondary care).
o. How did the telephone interviews compare to the face-to-face ones? Anything to discuss on this?

26) Conclusion:

a. Odd to introduce a figure in a conclusion section - better in the discussion (or even results). Also think you can combine Fig 3 and Table 4 - put the Table 4 text in a box joined to the bottom of Fig 3 as then all the information is in one place. If you don't combine them then rename Table 4 as Box 3 (as it isn't really a table)
b. Potential model - how was this developed? Who by? Did anyone endorse it? Did you take it back to stakeholders? Given that this is in the title of the paper there should be more detail on this - and it shouldn't be left until the conclusion
c. Table 4 - no mention of carer needs?
d. Introduction of the MRC framework here feels rather late. This whole paper could be presented as part of MRC framework Pre-Clinical phase, and the MRC follow on phases suggested could be more clearly labelled as Phase I/II/II/IV (which might demonstrate understanding of the framework). Or at least move this discussion point to the discussion section.
e. Line 462 - what do you mean by "further interventional research"?
f. Line 466 - how would it be modelled on Higginson et al and Teno et al? Do you mean in terms of methodology, intervention design, recruitment…?

27) References - something has gone wrong with the referencing - refs 45 and 46 are missing (or rather some earlier refs are missing so that there are only 44 listed but 46 referred to in text)

28) Fig 3:

a. Could have four levels with a lower level of "Generalist palliative care" without Specialist Respiratory Care? - as not all patients get even Specialist Respiratory Care
b. Is the left hand "Assessment" bar meant to have an arrowhead at the top - are you meaning increasing levels of assessment/more frequent levels of assessment as you move up the levels?
c. Is the model about patients only? Or does it include carers?

Minor points:
1) Line 59 - write "approx." in full
2) In several places references relating to just ILD or bronchiectasis are used to support statements about NMRD in general e.g. sentence at lines 59-61.
3) Line 75 - replace "primary setting" with "primary care setting"
4) Line 88 - should be a : not a ;
5) Line 98 - "in the North..." rather than "throughout the North..." (a couple of sites can't really be "throughout")
6) Line 105 - "...was not straight" rather than "...is not straight"
7) Line 107-108 - they can't be "participants" if been excluded, so needs a different word (e.g. "carers" or "Potential participants")
8) Line 109 - this is the first mention of MDTs - should they be referred to in the background?
9) Table 1 - some spacing variability issues (n=1) / (n= 1)
10) Table 2 and Table 3 - could be labelled as a Box 1 and Box 2 rather than as tables (as not really tables)
11) Line 157 - is the word "approach" or something missing at the end of sentence?
12) Line 158 - delete "large", and refer to as dataset (not plural)?
13) Line 167 - delete "further" (as no mention of initial verification)
14) Line 201 - patients' (not "patient's")
15) Line 218 - insert "when" ("...for their palliative care when in hospital")
16) Line 230 - delete "additionally"
17) Line 239 & 287 - insert "of" "...theme of...
18) Line 275 - insert "in" ("...HCPs in the ROI...")
19) Lines 325-316 - replace (...) with [...] ?
20) Sometimes you use "health care professional", sometimes "HCP"
21) Lines 332-333 seem to repeat what is in the two lines following
22) Line 334 - something wrong with this sentence "the presence of" … "was used" - needs reviewing
23) Line 436 - change "would" to "might"
24) Line 442 - change "the patient and carer's needs" to "patient and carer need"
25) Line 443-44 - delete, as this is really a repeat of the sentence above
26) Line 445 - change "will" to "should"
27) Table 4 - rename as "Proposed levels…" (as untested/unendorsed?)
28) Line 457 - insert "to" ("With regard to…")
29) Fig 1 title should contain "bereaved carers"
30) Fig 2 title should contain "HCPs"
31) Fig 1 - refers to "section 3.5" but there is no section 3.5 - suspect this figure is taken from a report which had that section?
32) Fig 2 - refers to "section 3.6" but there is no section 3.6 - suspect this figure is taken from a report which had that section?
33) Fig 3 title - could refer to "patients with…" rather than just the disease?

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.
No

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.
Yes

Are the conclusions drawn adequately supported by the data shown?
If not, please explain in your comments to the authors.
No

Are you able to assess any statistics in the manuscript or would you recommend an additional statistical review?
If an additional statistical review is recommended, please specify what aspects require further assessment in your comments to the editors.
Not relevant to this manuscript
Quality of written English
Please indicate the quality of language in the manuscript:
Acceptable

Declaration of competing interests
Please complete a declaration of competing interests, considering the following questions:

1. Have you in the past five years received reimbursements, fees, funding, or salary from an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?
2. Do you hold any stocks or shares in an organisation that may in any way gain or lose financially from the publication of this manuscript, either now or in the future?
3. Do you hold or are you currently applying for any patents relating to the content of the manuscript?
4. Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript?
5. Do you have any other financial competing interests?
6. Do you have any non-financial competing interests in relation to this paper?

If you can answer no to all of the above, write 'I declare that I have no competing interests' below. If your reply is yes to any, please give details below.

I declare that I have no competing interests

I agree to the open peer review policy of the journal. I understand that my name will be included on my report to the authors and, if the manuscript is accepted for publication, my named report including any attachments I upload will be posted on the website along with the authors' responses. I agree for my report to be made available under an Open Access Creative Commons CC-BY license (http://creativecommons.org/licenses/by/4.0/). I understand that any comments which I do not wish to be included in my named report can be included as confidential comments to the editors, which will not be published.

I agree to the open peer review policy of the journal