Reviewer's report

Title: The Liverpool Care Pathway: A Systematic Review Discarded in cancer patients but good enough for dying nursing home patients?

Version: 0 Date: 18 Jan 2017

Reviewer: Giles Birchley

Reviewer's report:

Dear Authors

Many thanks for resubmitting this paper for review. It has improved very much since the last iteration, however, it still needs more work to be of publishable standard. Nevertheless it is an interesting discussion of an important topic that, with some more work, will be very suitable for this journal.

I found the discussion interesting, but somewhat one-sided. That the LCP lacks RCT evidence is evident from the Cochrane reviews on the topic. But, while your discussion stops at this point, there is much more to explore. RCTs are famously difficult to apply to a range of important areas, and end of life care is one of them. What would constitute acceptable evidence in the absence of RCTs? or do the tenets of evidence based medicine simply dictate that these areas are somehow less important because they cannot be studied? Without adequate exploration of these points your argument feels somewhat like a straw-man.

On what basis should we avoid the LCP, rather than adapt it or ensure adequate training is available? You already reference Anthony Wrigley's paper on the topic, and it would be useful to address his arguments. I've suggested you might start with the principle of precaution, but do not dictate the arguments you should employ. But you need to engage with this question.

You give a rather thin description of the events that led to the withdrawal of the LCP in the UK; as the Wrigley paper suggests this was very unsatisfactory both in the hysterical nature of the (mainly tabloid) coverage and the eventual response of the government. By not engaging with this history, your argument seems to rest on the reasonableness of the withdrawal of the LCP in the UK, but any engagement with these events will show that many involved in palliative care considered it was anything but reasonable. Your paper will be very much strengthened if you engage with this history and consider other reasons to criticise the LCP. I suspect you must engage in more detail with what the LCP is and does to properly make these criticisms.
Finally you end without delivering a proper conclusion, what should replace the LCP, is it advance care planning? How would this be better?

Besides these major changes there are a number of minor revisions to attend to. My comments in detail are as follows (I refer to the page and line numbers in the publishers pdf):

Abstract.
In Background

"The Liverpool Care Pathway (LCP) is an interdisciplinary procedure" - procedure is not quite the right word - protocol would be better

In Methods

Somewhere, you need to make it clear that LCP has been widely used in nursing homes for dementia patients in Norway, which is the rationale for undertaking the review

In Results

"The search identified 12 studies, but none describing a methodological adaption" - Do you mean 'a methodology for adapting'?

In conclusion

"There is a need to develop good practice in palliative medicine" - palliative care for dementia patients, or palliative care in general?

Page 3
Major revisions:

"End-of-life care pathways (e.g., LCP and Integrated Care Pathway [ICP]) are designed" (line 15)

-As you subsequently conflate LCP and ICP (see comments for p6), can you clarify here the differences between LCP and ICP, if any?
Minor revisions:

- The double bracketing of [ICP] may cause confusion with references. If already within the brackets, I'd suggest giving acronyms as e.g. "hereafter, ICP" rather than opening additional brackets. I also note that you subsequently spell out the phrase 'integrated care pathway' in full, so you may not need this particular acronym.

"concerning the appointment of a legal guardian, making reservations against" (line 47)
-I suggest changing "making reservations against" to 'antecedent decisions against'

"resuscitation, and information about the LCP" (line 50)
-I suggest changing "and information" to 'and giving information'

Page 4

Major revisions:

"Concerns were addressed in the media and public debates and eventually led to the independent expert evaluation; "More Care, Less Pathway", the Neuberger report ." (line 7)

-I think this needs rewording. I'm not sure that "eventually led" captures the experience of professionals at the time, and some sort of timeline would be useful as the public inquiry appeared to follow rapidly from concerns in some sections of the media. To understand the role of the media in the demise of the LCP consider:

The assault on the Liverpool care pathway BMJ 2012; 345 doi:
http://dx.doi.org/10.1136/bmj.e7316

Doctors leaders, charities, and hospices back Liverpool Care Pathway BMJ 2012; 345 doi:
http://dx.doi.org/10.1136/bmj.e6654 ;

I realise the media storm that led to the wholesale abandonment of the LCP is not the main focus of the paper, but since your paper is predated upon the problems of the LCP some balancing comment would be welcome at this early stage.

- Rather than "independent expert evaluation", please indicate the Neuberger report was an 'independent review commissioned by the UK Government', as this is both transparent and accurate.

Minor revisions

"highlighted that especially told people" (line 0) - makes no sense, is this a typo?

Page 6

Minor revision:

"investigate the barriers of the implementation of the integrated care pathway (LCP)" (line 55)

-I am not clear if the integrated care pathway is a separate pathway or the same as the LCP from this - please clarify this when you first mention the LCP and ICP on page 3.

Page 7

Minor revision:

"However, in these publications the implementation and use of the LCP in participating NHs and people with dementia specifically are not reported. Neither were patient outcomes." (line 49)

-"Neither were patient outcomes" is a fragment and needs to be merged with the preceding sentence

Page 9

Minor revision:

"The implementation period lasted for 18 months and was executed by an experienced palliative care nurse" (line 43)
-Please substitute 'executed' for 'undertaken'. Execute has a second meaning in English - it also means 'kill'. Given the palliative care context it may be more sensitive to use a different term (executed sounds like the death penalty!).

Page 10

Minor revisions:

"It is however, challenging to discern a meaningful summary of the LCP-related statements given by relatives." (line 14)

-this wording is obtuse - can you expand and/or reword to give a better sense of what the paper contains e.g. 'There is no summary of statements about the LCP from relatives ...'? 

"Ekestrom et al.,(2014) and included 44 family members of diseased patients" (line 36)
-"Diseased patients": What types of disease? does disease mean anything specific in this context? If not it is verbiage.

"However, small numbers of participants in the LCP sub-groups and a not-randomized study design make interpretability of results challenging" (line 46)

-Please indicate how selection to each group took place if it was not randomized

-By "Interpretability" do you mean 'transferability'? Or is there something about interpretability I'm missing? Overall I'm not clear why non-randomization should affect interpretation. Please clarify or reword.

"The second study, by Verhofstede et al., (2015) was a methodological approach," (line 51)
-do you mean 'took a methodological approach'?

"Phase 0 (preclinical phase) consisted of a nonsystematic review" (line 53)

-does the study define the non-systematic review any better than this? lots of different review approaches are non-systematic (narrative review, purposive sample, qualitative synthesis etc. etc.).

Page 11:
Major revisions:

"In summary, regarding the research question 1, we found no studies that described LCP's measurement characteristics pertaining to validity, reliability, and responsiveness" (Line 19)

-You mention validation and testing in the review question, so I can see where validity comes from, although I think you should revert to validation (validity may be taken to mean something different) but where do reliability and responsiveness come from?

It is also now apparent that you are not clear about what is mean by validation. I would suggest that some of the studies you mention have validation elements, i.e. examined whether LCP improves symptom control, relatives perception of death etc. etc. Why are these not valid measures? Here or somewhere you please offer some discussion of what you think is acceptable validation and why.

"Yet, this was a retrospective investigation." (Line 48)

-Again, this seems unfair to frame as a criticism, especially in this section, which is reporting your findings not your opinions. A well designed retrospective study is quite adequate in this situation, indeed, there are multiple ethical hurdles, primarily the need for any study itself to avoid negatively impacting on a patient's death (by e.g. invasion of privacy) in prospective designs in this area. I suggest removing this comment from this section, and placing it within the discussion with appropriate acknowledgement of the reasons prospective designs are used in this area. I note you pick this up in your commentary about the Cochrane reports on page 13 which also invites broader discussion.

Page 12

Major revisions:

"This suggests that LCP is not adapted and measures of validity, reliability or responsiveness are lacking in this setting" (line 23)

-as noted above, somewhere you must indicate what you consider to constitute such measures in this context

"The study was not blinded, which can contribute to measurement errors and Hawthorne effect (30)." (line 42)

-It is unclear how you would blind such a study. How do you blind carers who are following the LCP to the fact they are following trhe LCP? Unless you can explain this, this dissolves into a straw man argument - you must acknowledge this difficulty.
Minor revisions:

"Other studies had low response rates with a potential response bias towards only positive responses" (line 47)

- Why would the bias just be to positive responses and not negative ones? Explain or remove this comment.

Page 13

Minor revision:

"LCP originally was set to resolve." (line 29)

- For accuracy I suggest rewording "set to resolve" as 'intended to reduce'.

Major revision:

"In general, due to the insufficient validated outcome measures and use of control conditions in clinical studies, these reviews did not draw any conclusions based on existing literature and even recommended that LCP use should be avoided for use in NH settings and among people with dementia, until such studies exist." (Line 48)

Given the barriers to the sorts of studies you suggest, I would like some discussion of whether what you discuss is a failing of LCP use or of evidence based medicine; See e.g. Kerridge et al. Ethics and evidence based medicine BMJ 1998; 316 doi: http://dx.doi.org/10.1136/bmj.316.7138.1151 Some acknowledgement of the problems of conducting RCTs in many areas, and the problems that failing to acknowledge the validity of other designs causes.

Minor revision:

Separately, and optionally, the questionable nature of the withdrawal of the LCP in the UK (rather than it's reform - see Wrigley -your reference 48 - for critical coment) means our argument is quite easy to undermine. Your argument here might be strengthened if you advance a more solid basis for avoiding LCP in this instance, for example, by employing the precautionary principle. A good philosophical introduction to this principle (although not one that uses it in relation to LCP) is: Meyerson, D. Innovative Surgery and the Precautionary Principle J Med Philos (2013) 38 (6): 605-624. DOI: https://doi.org/10.1093/jmp/jht047
Minor revision
Change "At a NH" (line 14) to 'In a NH'

Page 15

Major revision:
Page 15 overall-

The paragraph is an interesting discussion, but you lack a conclusion. Are you therefore saying that having LCP and no training is worse than no LCP and no training? This is a valid position, and seems to flow from your conclusions, although the abstract suggests you will argue for other interventions such as Advance care planning at this stage. As it stands the paper finishes without a clear end: You must clearly state your conclusion about what should happen now.

Minor revisions

Line 29
"dying population deceases" - change 'deceases' to 'dies'
"financial gain by" - change 'by' to 'from'
Line 34
"the whole staff" - change to 'all staff'
"LCP, alone" - remove the comma
Line 36
"After criticism in social media" - please give a reference for this
"and smaller parts" - what does this mean? Reword more clearly.

I know how disheartening it is to have a paper returned with yet more work to do. However, the paper has improved immeasurably since last time, and you are now in reach of making a very valid and important contribution to the discussion of the LCP; I look forward to reading the next iteration.
Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

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

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