

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

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| <b>TITLE (PROVISIONAL)</b> | Experiences of older people dying in nursing homes: a narrative systematic review of qualitative studies |
| <b>AUTHORS</b>             | Greenwood, Nan; Menzies-Gow, Emma; Nilsson, David; Aubrey, Dawn; Emery, Claire; Richardson, Angela       |

### VERSION 1 – REVIEW

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| <b>REVIEWER</b>        | Merryn Gott<br>University of Auckland, New Zealand |
| <b>REVIEW RETURNED</b> | 04-Feb-2018  |

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| <b>GENERAL COMMENTS</b> | <p>Thank you for the invitation to review this interesting paper. The topic of the review is certainly very important. The following issues occurred to me while reading the paper and hope will be helpful to revising the manuscript.</p> <p>Introduction<br/>Good context setting. The second sentence of the first paragraph which begins 'For example..' doesn't really provide an example of the previous point as it refers to the % of people living in care homes who are older, rather than the proportion of older people living in care homes increasing.</p> <p>Revise the sentence beginning 'In England and Wales...' to clarify figures for 2006 and 2016.</p> <p>Paragraph 2 provides interesting UK context, but BMJ Open is an international journal so it would be good if this paragraph could be internationalised, particularly given the origin of the studies identified by the review. The same point applies to the start of paragraph 3.</p> <p>I think more could be made of the last point in paragraph 3 – this helps provide the rationale for the study. Making this point earlier in the introduction would help build this case more strongly, as the previous paragraph makes the reader think the focus will be on palliative care interventions.</p> <p>Paragraph 4 – 2nd sentence – mention of 'good practice and policy' – where? UK? Other countries? Maybe add a reference also? Again I'd link this paragraph better with the aims of the study eg one argument could be that ACP will only work if we understand residents views of its utility/they see it as something worth engaging in rather than as something imposed.</p> <p>Paragraph 5 – 1st sentence : clarify whose future preferences eg older people/residents? 2nd sentence – clarify whether older people</p> |
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|  | <p>were living in care homes or not. Link final sentence back to the aim of the study as again it's not made very clear.</p> <p>Paragraph 6 – reference to a review. Clarify which patients and families (presumably care home residents and their families?). Sentence beginning: 'Consequently'...there are a lot of quant studies on these topics – maybe state that quantitative methods alone may not 'fully capture'. I'd move the last sentence to after you have stated the aim of the paper as it's not clear here why 'experience' needs defining.</p> <p>Another concept used in the review which needs defining is 'dying'.</p> <p>Also – clarify whether assisted living settings, retirement homes, intermediate care were included or excluded (presume excluded?).</p> <p>I note reviews were excluded, but presumably you checked whether previous systematic reviews on this topic had been conducted? If you picked these up in the search they would be mentioned elsewhere eg introduction?</p> <p>Page 7, top sentence – this rationale re. dates is only relevant to England, but the review is international?</p> <p>I note no search terms were included related to 'palliative care' (eg palliative, terminal etc). Do you think this has any implications given the focus of the study?</p> <p>Bottom of page 5 – 'references in the most recent review' – how were reviews identified given they were excluded from the search? How many reviews were identified? What was the scope of the reviews for which this was the most recent?</p> <p>Quality assessment – maybe add a reference to support adding researcher reflexivity? How was 'bias' detected? Isn't this terminology slightly problematic given a focus on qualitative studies? Bias in what?</p> <p>More information on analysis would be helpful. 'Narrative' in and of itself doesn't provide much information about how this was conducted. The data is from different sources (older people, staff, families) and gathered using very different methods. How, for example, was participant observation data treated? Can it be said to have equal ability to capture older people's experience as research which directly reports their experience in their own view? Clarify whether there was potential for other aspects of experience raised by older people to be identified (a totally 'top down' approach is at odds with the aim of capturing older people's own experiences).</p> <p>P. 9 sentence beginning 'three studies..' – later on the language is more definite ie that these studies did include the same participants. Was this clarified with the authors of those studies?</p> <p>Third paragraph, line 20 – sentence beginning 'Study participants...' I'd make this a bit clearer as initially it's confusing as the focus is in older people's experiences, so just remind the reader that it is staff and families reporting on older people's experiences. I'd also make more of the studies which reported older people's experiences directly ie 'Only x studies...'. And in Table 2 I'd make it clear which studies actually included older people's own experiences in their</p> |
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|  | <p>own words (because at the moment it only says which groups were included). So it might be worth another column focusing just on this – the danger is that the small amount of data that comes directly from older people gets swamped by that from families and staff. Later in that paragraph clarify what is meant by ‘close to death’ (I think this goes back also to the point I made earlier about how dying is being defined in this review).</p> <p>I wouldn’t consider open ended responses captured in a questionnaire to comprise qualitative data. If you want to make this claim then please provide a reference to support it. And again, discuss whether there are problems in treating these data as equal to that collected using traditional qualitative methods (as the former is much more directed by the researcher). P7 – when commenting on the quality of studies it is worth acknowledging at some point that what authors report re. their methods is often largely dictated by journal requirements and word limit constraints. For example, you’ve added reflexivity, which is an important issue for qualitative research, but this not being reported doesn’t mean it didn’t happen. Last point on page 7 is really interesting and important – it would be good to make more of this and be a bit clearer as authors not making clear their epistemological positioning is problematic in qualitative research.</p> <p>Table 2: is life expectancy the right term? I think this goes back to the definition of dying? Life expectancy at the point the study was undertaken? From whose perspective? How accurate was this estimate?</p> <p>In Table 3 I’m unclear what ‘themes’ means. Obviously there is always a tension in reporting findings of papers included in reviews – there is what the author ‘found’ and concluded and then there is the data extracted with relevance for the question posed by the review. It is the latter which should be adequately captured in this table and I’m not convinced it is at the moment. It is unclear to the reader what aspect of ‘experience’ each paper reported – might be clearer to relate back to the elements of experience noted in the original definition? Could you link more to Table 4? And in table 4, is it possible to highlight which aspects have data reported directly from older people? As noted above, I think it’s important to highlight the paucity of this type of research and not treat it as the same as experiences as reported by another person, as we know this is problematic.</p> <p>Discussion<br/>I’m a bit concerned about the framing of the discussion in terms of concluded from what are a small number of very diverse studies (with few from older people’s own experiences) that care is ‘poor’ and that older people in care homes are suffering. I don’t think the evidence as presented in this paper supports this claim. This also wasn’t really the point of the review as stated – the aim was to capture what we know about older people’s experiences of dying in care homes - not then make a link to the nature of care received. Also, later on a point is made that more open discussion of dying could reduce suffering. Again, this is a huge claim and, whilst I know it speaks to dominant narratives in palliative care, it goes well beyond the evidence of this particular review. Conclusions need to be tied much more tightly to the findings presented. There needs to be much more caution in these conclusions.</p> |
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|  | <p>What could be made more of is the weak state of evidence and methodological problems. A review is an opportunity to critique the state of evidence of a field and there's a lot to critique here! As noted later in the discussion the aim was to capture experience 'holistically' – from the findings presented it doesn't feel this had been done in previous research? Can an overall conclusion be made in relation to this aim? We should not be marching ahead developing interventions etc surely without understanding the experiences of older people? And making more of the need for research which is inclusive of people with dementia? Lots of innovative methods out there that palliative care researchers can learn from. Also, on the basis of these findings what are the recommendations for future researchers around approaches, conceptual clarity etc.?</p> <p>Not clear why 'dignity' is mentioned – obviously an important (if contested) concept (ie staff and 'patients' have different understandings of what it means), but not sure how it relates to the review findings.</p> <p>The fact that no findings were identified post 2010 will lead readers to query the search strategy so this should be defended in this paragraph also. (eg are you satisfied that search would have captured terminology used by colleagues in other disciplines to describe dying (notably gerontology). Also, discussing this only within the UK policy context is problematic as noted above.</p> <p>The sentence 'We identified several studies' relating to older people's future care preferences – this is a bit problematic as that wasn't the aim of the review and so may mislead readers as to the state of the literature on that topic.</p> <p>In the conclusion the claim is made that it is 'taboo' that has silenced talk of dying in care homes. It might be helpful to read Tony Walter's work on 'taboo'. Again claims that care is 'disturbing' are very big – be very clear what evidence claims such as these draw on. And it is important to consider whether the findings of the review relate to researchers focusing only on capturing negative experiences, rather than experiences only being negative.</p> <p>Thank you again for the opportunity to read this paper. I think it presents an important review to draw attention to the paucity of research in this area, particularly that directly reported by older people in their own voices.</p> |
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| <b>REVIEWER</b>        | Andy Hau Yan Ho<br>Nanyang Technological University Singapore |
| <b>REVIEW RETURNED</b> | 20-Feb-2018   |

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| <b>GENERAL COMMENTS</b> | <p>This is a potentially important paper that systemically reviewed and synthesized qualitative literature published on the experience of dying among older nursing home residents. While the paper is generally well-written, there are a number of issues that the authors need to address before the manuscript is deemed fit for publication.</p> <p>1) While the authors provided a detailed description of the search and screening processes of their review, to my knowledge, there is a series of studies that qualitatively examined end of life experiences of terminally-ill nursing home residents in Hong Kong; these studies do appear to fit under the sampling frame but were not included in the review (e.g. Ho, Luk, Chan, et al. (2015). Dignified Palliative</p> |
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|  | <p>Long Term Care... American Journal of Hospice and Palliative Medicine, 33(5), 439-447.). Thus, a more comprehensive search is warranted, or, the authors need to provide justifications for why this body of works was excluded.</p> <p>2) The authors presented the results of their review mostly in the forms of tables, with very little elaborations. Findings of systematic synthesis was provided only through Table 4, but again with minimal elaboration on 6 themes identified. Instead of using the bulk of the discussion section to describe the challenges in identifying relevant articles, the authors should spend equal time explaining critically the 6 themes identified as well as their implications for practices and polices, as this is the major objective of their research. Without such critical elaboration, the current manuscript is not adding much new knowledge to to the field.</p> <p>3) The authors stated that only qualitative data were used in the review, however, it appears that quantitative data from questionnaires were reported for Brayne et al. (2008). More clarification of data used is required here.</p> <p>4) There is inconsistency in the formatting of tables, for example Table 1 uses hyphen citations, while all other Tables use bracket citations.</p> <p>With the above, a major revision that addresses the concerns raised in recommended.</p> |
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### VERSION 1 – AUTHOR RESPONSE

#### Revisions

Editorial Request: Please include the PROSPERO registry number in the text of your manuscript.

This has been added (p 4).

#### Formatting amendments

1.No Data Sharing Statement - Please embed your DATA SHARING STATEMENT in your main document file.

This has been added (p18) 'Data are not shared but may be found in the nine studies critically reviewed as part of this review. No additional unpublished data are available for this study.'

#### Reviewer 1

Good context setting. The second sentence of the first paragraph which begins 'For example..' doesn't really provide an example of the previous point as it refers to the % of people living in care homes who are older, rather than the proportion of older people living in care homes increasing.

Thank you for highlighting this. We have revised this to read: 'Worldwide, life expectancy is continuing to rise and increasing numbers of older people require support towards the end of their lives with significant proportions of older people living in care or nursing homes.' p2

Revise the sentence beginning 'In England and Wales...' to clarify figures for 2006 and 2016.

Thank you for this suggestion. We have clarified this and it now reads: 'In England and Wales, for example, in 2006, 19.2% of older people aged 65 and over died in care homes[3], compared with 24.7% a decade later[4].'

Paragraph 2 provides interesting UK context, but BMJ Open is an international journal so it would be good if this paragraph could be internationalised, particularly given the origin of the studies identified by the review.

Thank you for this comment. We were using the UK as an in-depth example and added the example of reference [7] to provide an international context. To make this clearer, we have now added: 'These programmes have been recognised and adopted in many other countries. Programmes such as the Liverpool Care Pathway, for example, have been disseminated to over 20 countries in a range of settings including care homes[7]'. p2

The same point applies to the start of paragraph 3. We have removed the first sentence of this paragraph entirely – we no longer think it adds anything and it did perhaps make it appear UK focussed.

We have reworked the early part of the 4<sup>th</sup> (now 3rd) paragraph. It now reads: 'Evidence relating to the implementation of end of life care policy in care homes is sparse and limited. For example, an evidence synthesis[9] of the implementation of the end of life care policy in care homes in the UK only identified three relevant studies. (p 2)

I think more could be made of the last point in paragraph 3 – this helps provide the rationale for the study. Making this point earlier in the introduction would help build this case more strongly, as the previous paragraph makes the reader think the focus will be on palliative care interventions.

Thank you for this constructive comment We have moved this sentence to an earlier paragraph. We have changed the next paragraph and its emphasis (p 2/3). It now reads: 'Evidence relating to the implementation of end of life care policy in care homes is sparse and limited. For example, a review of the literature relating to the efficacy of palliative care interventions for older people living in care homes[9/10] also only found three relevant studies. All were undertaken in the United States of America (USA) and all were described as 'poor' quality. The authors suggested that care home structure and culture may be an important barrier or facilitator of the success of any approach to palliative care influencing the generalisability of the interventions. They also highlighted that the outcome measures used within the studies were predominantly process related, which may not automatically translate to positive patient experiences and that future studies should incorporate residents' views of their care[9/10]. A UK based evidence synthesis[9/10] of the implementation of the end of life care policy in care homes in the UK also only identified three relevant studies. Some improvement in resident outcomes and in the ability of staff to recognise and deliver care to meet resident needs were highlighted. However, the dearth of studies and the possibility of other factors influencing care means it is not possible to be confident that these improvements could be attributed to these interventions. Here too the evidence failed to highlight the experiences of those receiving the care.'

Paragraph 4 – 2nd sentence – mention of 'good practice and policy' – where? UK? Other countries? Maybe add a reference also?

On reflection, we have decided to delete the sentence beginning 'Although recommended as good practice and supported by policy..' to avoid locating it in any country.

Again I'd link this paragraph better with the aims of the study eg one argument could be that ACP will only work if we understand residents views of its utility/they see it as something worth engaging in rather than as something imposed.

Thank you. We have added the following to link the paragraph better and to help build up to the review aims: 'Taken together, these publications highlight the need to bring together the evidence for how end of life is experienced by those at the centre of it – the older people themselves. Without this essential perspective, it might be argued that their care is unlikely to improve.' p3.

Paragraph 5 – 1st sentence : clarify whose future preferences eg older people/residents? 2nd sentence – clarify whether older people were living in care homes or not. Link final sentence back to the aim of the study as again it's not made very clear.

Apologies that this was unclear. It now reads: 'Future preferences concerning end of life care in care homes have also been investigated. For example, in an interview study many older people in care homes said they were ready to die but were concerned about the process of dying and wanted a peaceful, pain free death, without life-saving treatment or hospital intervention[14/15]. Similarly, some acceptance that end of life was approaching was reported also, but there were differences of opinion regarding the readiness to engage in end of life care discussions[15]. Many had not discussed this with nursing home staff. In a similar vein, missed opportunities to have conversations about end of life with residents and assumptions about end of life preferences were also reported elsewhere amongst nursing home residents in the USA[16].' P3

Paragraph 6 – reference to a review. Clarify which patients and families (presumably care home residents and their families?).

We have re-read this paragraph and have not changed it as we believe it is clear that it is referring to people in care homes as it reads: 'A recent systematic review[17] summarised the literature on what families and patients believe could be done to improve end of life care in nursing homes.'

Sentence beginning: 'Consequently'...there are a lot of quant studies on these topics – maybe state that quantitative methods alone may not 'fully capture'.

Thank you. We have amended the sentence to read: 'Consequently, quantitative methods alone may fail to capture less tangible psychosocial aspects fully ...' p4

I'd move the last sentence to after you have stated the aim of the paper as it's not clear here why 'experience' needs defining.

We have done this as suggested and also added a subsection entitled 'Definitions'. p4

Another concept used in the review which needs defining is 'dying'.

Thank you for this. As you know, defining dying is very challenging and the term is used in a variety of ways in the literature and in practice. To some extent we were led by the authors definition (if they provided one). Following this comment, we realised that we had only broached this in the Discussion section. We have therefore added the following in the Definitions section: 'Defining dying is very challenging with the term in the literature being used in a range of ways. The focus of this review was on older people at the end or very near the end of life. For this review, this was taken as 'dying'. Each identified paper was scrutinised with this in mind. We were led by how the authors described or defined dying but only included papers where the review team agreed that the majority of participants were close to death.' p4

Also – clarify whether assisted living settings, retirement homes, intermediate care were included or excluded (presume excluded?).

These settings were included so we have clarified this with the following (p4/5): '.... experiences of dying in residential care (e.g. nursing or care homes, retirement homes and assisted living facilities).

I note reviews were excluded, but presumably you checked whether previous systematic reviews on this topic had been conducted? Ie if you picked these up in the search they would be mentioned elsewhere eg introduction?

Apologies that this was unclear. We only identified one review that related to the overall topic – Fosse et al (2014). This summarised what patients and families believe can be done to improve end of life in care homes. However, although relevant, it did not answer our research questions as it was not specifically looking at experiences of dying. As we mentioned in our paper, we also searched the

references from this paper to ensure we were not missing any relevant papers. To clarify this on p5 we have added:

‘As no review that synthesised the qualitative research evidence relating to the experiences of older people of dying in care homes was found, this review therefore aimed to identify and synthesise ..’

Page 7, top sentence – this rationale re. dates is only relevant to England, but the review is international?

In order, to make the review relevant to the situation today, we felt we needed to have a cut off in the included studies. Although this was a review of international literature, it was felt that one important policy document should be used as a starting point and we selected the UK National Services Framework has had wide ranging impact and is frequently cited.

We tried to address this by emphasising its significance and impact.

I note no search terms were included related to ‘palliative care’ (eg palliative, terminal etc). Do you think this has any implications given the focus of the study?

As with any review, there was a trade off with being too inclusive or too restrictive with the included literature. We wanted the focus of this review to be on the experiences of older people in care homes who did not receive supplemental care from external providers. In our initial searches, we found the term ‘palliative care’ most frequently referred to the implementation of specific interventions often delivered by professionals who were not based in the nursing home, rather than simply palliative measures routinely provided in nursing homes.

Bottom of page 5 – ‘references in the most recent review’ – how were reviews identified given they were excluded from the search? How many reviews were identified? What was the scope of the reviews for which this was the most recent?

We think this may have been misread - Fosse et al was the only relevant review.

Quality assessment – maybe add a reference to support adding researcher reflexivity? How was ‘bias’ detected? Isn’t this terminology slightly problematic given a focus on qualitative studies? Bias in what?

Thank you for this helpful comment. Mays and Pope [24] refer to the importance of reflexivity but it was not originally included in the quality rating scale by Greenwood et al 2009 [23]. To improve the scale, a question about reflexivity was added. We have mentioned this reference again to make it clearer. We agree that the terminology was inappropriate for qualitative research and have changed this to read: ‘... the assessments were used to interrogate the methodological quality of the studies in a systematic fashion...’ p6’

More information on analysis would be helpful. ‘Narrative’ in and of itself doesn’t provide much information about how this was conducted. The data is from different sources (older people, staff, families) and gathered using very different methods. How, for example, was participant observation data treated? Can it be said to have equal ability to capture older people’s experience as research which directly reports their experience in their own view? Clarify whether there was potential for other aspects of experience raised by older people to be identified (a totally ‘top down’ approach is at odds with the aim of capturing older people’s own experiences).

With hindsight we agree with this comment and have added more detail which we hope is sufficient: ‘Data sources were wide and included interview and observational data. This diversity makes synthesis more difficult. In order to capture what the authors regarded as most important, data used came from both the Findings and Discussion sections. The synthesis was undertaken by three or more members of the review team and was intended to summarise and explain the study findings as presented in the text by the study authors.’

P. 9 sentence beginning ‘three studies..’ – later on the language is more definite ie that these studies did include the same participants. Was this clarified with the authors of those studies?

Thank you for pointing this out. We approached all authors of the included studies (not specifically about this issue but to ask if they could identify any other studies) and although some of them did respond, not all did. After, close scrutiny of the papers the entire review team was convinced that these studies involved the same participants because the demographic characteristics of the participants were the same but the studies were answering different research questions. However, we have amended the paper to clarify this: ‘Nine studies fitted the inclusion criteria (Table 1). Close scrutiny of three of these studies[26-28] suggested to the team that they incorporated the same participants. We considered reporting them together in the review but decided to keep them separate because they focused on different aspects of older people’s experiences.’ p7

Third paragraph, line 20 – sentence beginning ‘Study participants...’ I’d make this a bit clearer as initially it’s confusing as the focus is in older people’s experiences, so just remind the reader that it is staff and families reporting on older people’s experiences. I’d also make more of the studies which reported older people’s experiences directly ie ‘Only x studies...’.

To make this clearer, we have reworded this section to read: ‘Some studies investigated the perceptions of older people’s experiences with a mixture of participants including older people themselves and others. Five investigated the perspectives of older people themselves[26-28,31,33], five included the perceptions of informal or family carers[26,27,31,33,35] and four included nursing home staff perceptions [26,31,32,36].’ p7

And in Table 2 I’d make it clear which studies actually included older people’s own experiences in their own words (because at the moment it only says which groups were included). So it might be worth another column focusing just on this – the danger is that the small amount of data that comes directly from older people gets swamped by that from families and staff.

Thank you for this comment. Authors often put the data from diverse sources together making this difficult. We have looked at the table again and feel that by bolding the sections in Table 4 that included older people’s interviews, we have now covered this without over playing it.

Later in that paragraph clarify what is meant by ‘close to death’ (I think this goes back also to the point I made earlier about how dying is being defined in this review).

We have added the following to explain what we mean: ‘... the vast majority of residents were close to death – authors described them as, for example, within hours or days of death at the time of the study or described how many died during the study.’ (p8).

I wouldn’t consider open ended responses captured in a questionnaire to comprise qualitative data. If you want to make this claim then please provide a reference to support it. And again, discuss whether there are problems in treating these data as equal to that collected using traditional qualitative methods (as the former is much more directed by the researcher).

Thank you for this comment. It was not an unproblematic decision for the review team and was discussed at length. We had highlighted their different data sources in Table 3 to help identify them to the reader. It was decided to include it because the study authors described undertaking thematic analysis of open-ended questions which they reported as themes – which we saw as very much qualitative terms. In the interests of comprehensiveness, we therefore included this study. However, we have mentioned this in the potential limitations of the study on p 15: ‘It might be argued that the study which included analysis of open-ended questions in a questionnaire[36] should not have been included but the framing of the analysis was qualitative and it was included for comprehensiveness.’

P7 – when commenting on the quality of studies it is worth acknowledging at some point that what authors report re. their methods is often largely dictated by journal requirements and word limit constraints. For example, you’ve added reflexivity, which is an important issue for qualitative research, but this not being reported doesn’t mean it didn’t happen.

Thank you for this insightful comment – we totally agree about this issue and are ourselves sometimes ambivalent about undertaking quality appraisal especially for qualitative research where word counts can be particularly challenging. We have rewritten this paragraph (p 6): ‘Assessment of study quality in qualitative research is a contentious issue because of the differing paradigms and diversity in data collection [23] but it is also important to point out that the value of study quality ratings is limited by the fact that authors are often restricted in the details they can provide because of journal word counts. However, quality assessment was undertaken to interrogate the methodological quality of the studies in a systematic fashion, rather than to exclude any study.’

Last point on page 7 is really interesting and important – it would be good to make more of this and be a bit clearer as authors not making clear their epistemological positioning is problematic in qualitative research.

Thank you for this. We hope you will agree that the best place to follow this up is in the discussion and have therefore added the following (p 18): ‘Furthermore, unlike much of the research identified here, future qualitative research should be grounded in explicit, appropriate epistemological positions to enhance the transferability of the findings.’

Table 2: is life expectancy the right term? I think this goes back to the definition of dying? Life expectancy at the point the study was undertaken? From whose perspective? How accurate was this estimate?

We used this term reflecting how authors described their studies. We have added ‘length of time to death as described by the study authors’ to the title to Table 2. We have also followed this up in the Discussion when considering the challenges around identifying dying and therefore reviewing the literature.

In Table 3 I’m unclear what ‘themes’ means. Obviously there is always a tension in reporting findings of papers included in reviews – there is what the author ‘found’ and concluded and then there is the data extracted with relevance for the question posed by the review. It is the latter which should be adequately captured in this table and I’m not convinced it is at the moment.

We have broken this comment down and have tried to respond to it in parts to make our thoughts and responses clearer.

The study authors usually referred to ‘themes’ so we adopted their use of the word. We have therefore changed the Table heading slightly to Authors’ identified themes (pXX). In terms of the table layout, we felt it was much clearer to have two tables one of which focussed on the more general findings (Table 3) and the other which summarised those relevant to the review very succinctly (Table 4). Keeping theme like this allows the review readers to appreciate the scope of the included studies but also to focus on our review questions.

It is unclear to the reader what aspect of ‘experience’ each paper reported – might be clearer to relate back to the elements of experience noted in the original definition? Could you link more to Table 4? And in table 4, is it possible to highlight which aspects have data reported directly from older people? As noted above, I think it’s important to highlight the paucity of this type of research and not treat it as the same as experiences as reported by another person, as we know this is problematic.

This is difficult to do as many studies included a variety of perspectives including the observations of researchers. However, to highlight where the findings included the perspectives of older people directly, we have bolded these in Table 4 and have commented on this in the text. This now reads: In Table 4 the experiences of dying in the studies that included the older people themselves are bolded. This highlights that irrespective of the participant groups, there are many similarities in the perceptions of these experience – for example all studies reported the centrality of physical symptoms and care received.’ P 8.

Discussion -I'm a bit concerned about the framing of the discussion in terms of concluded from what are a small number of very diverse studies (with few from older people's own experiences) that care is 'poor' and that older people in care homes are suffering. I don't think the evidence as presented in this paper supports this claim. This also wasn't really the point of the review as stated – the aim was to capture what we know about older people's experiences of dying in care homes - not then make a link to the nature of care received. Also, later on a point is made that more open discussion of dying could reduce suffering. Again, this is a huge claim and, whilst I know it speaks to dominant narratives in palliative care, it goes well beyond the evidence of this particular review. Conclusions need to be tied much more tightly to the findings presented. There needs to be much more caution in these conclusions.

Thank you for this thoughtful comment. We have modified the way this is written (p15) to emphasise that care needs to be taken in interpreting the findings and specially stating how many studies described each experience. It now reads: 'Care must be taken in interpreting the findings given that few relevant studies were identified. However, seven of the nine included studies highlighted the physical discomfort of dying in a nursing home with older people often experiencing pain, pressure sores and thirst. Added to this, six studies described many people suffering psychologically – loneliness and depression were often described. Although our aim was not originally to look at the link between care and experiences, most authors here made a clear direct link between inadequate care and these negative experiences, stating that they were often preventable or at least amenable to change. This is significant as it demonstrates the impact of the physical environment and staff. Only one study[28] specifically investigated cultural aspects of these older people's experiences, a significant omission given the importance of religion and culture surrounding death.'

What could be made more of is the weak state of evidence and methodological problems. A review is an opportunity to critique the state of evidence of a field and there's a lot to critique here! As noted later in the discussion the aim was to capture experience 'holistically' – from the findings presented it doesn't feel this had been done in previous research? Can an overall conclusion be made in relation to this aim? We should not be marching ahead developing interventions etc surely without understanding the experiences of older people? And making more of the need for research which is inclusive of people with dementia? Lots of innovative methods out there that palliative care researchers can learn from. Also, on the basis of these findings what are the recommendations for future researchers around approaches, conceptual clarity etc.?

This is a really helpful comment - thank you. We have added the following: 'An aim of our review was to provide a more holistic picture of the experiences of older people dying in care homes. By bringing these study findings together we have arguably taken a small step in this direction but future research needs to have this as a priority. Without an in-depth understanding of these experiences, it is hard to see how interventions can be expected to improve older people's experiences. Similarly, although potentially challenging, research needs to start including more people with cognitive difficulties to learn about their experiences. This will require greater user involvement in setting research questions and in subsequent research design but as their involvement is gaining momentum in other research, studies here could also benefit from this.' p16

Not clear why 'dignity' is mentioned – obviously an important (if contested) concept (ie staff and 'patients' have different understandings of what it means), but not sure how it relates to the review findings.

We have changed this to read: 'Here it was only clearly highlighted in one study [26]. This is perhaps surprising given its importance in healthcare generally.' p15

The fact that no findings were identified post 2010 will lead readers to query the search strategy so this should be defended in this paragraph also. (eg are you satisfied that search would have captured terminology used by colleagues in other disciplines to describe dying (notably gerontology). Also, discussing this only within the UK policy context is problematic as noted above.

We were very surprised to be unable to identify any later research and went back to try and check if we had omitted anything. However, no additional studies were identified. Early on in the searches we

looked at other published studies from a range of disciplines (but primarily nursing and gerontology), their keywords etc. and concluded that our search strategy was the best we could do (i.e. not too wide or too narrow) given the research questions.

The sentence 'We identified several studies' relating to older people's future care preferences – this is a bit problematic as that wasn't the aim of the review and so may mislead readers as to the state of the literature on that topic.

We were trying to highlight that there is other research – which could perhaps be described as parallel to our focus but little that had the experiential focus we were aiming for. To make it clearer, we have reworded this: 'Our initial searches identified several studies describing participants' future preferences surrounding their death (e.g.[14]) but few describing their experiences of dying.' p15

To avoid being too UK centric we have slightly altered other wording as well: 'In the UK, policy changes relating to end of life care in 2008[6] increased attention on palliative care but despite this, we identified very few studies relevant to our research question either in the UK or elsewhere or after this date.' p14

In the conclusion the claim is made that it is 'taboo' that has silenced talk of dying in care homes. It might be helpful to read Tony Walter's work on 'taboo'. Again claims that care is 'disturbing' are very big – be very clear what evidence claims such as these draw on.

With hindsight we were probably over-reaching the implications of our findings and have removed the sentence about taboos surrounding death and changed this to read: 'The challenges, both practical and ethical, to investigating death and may well be a contributing factor to the limited research available on this important topic.' p17

We have also changed the claim about disturbing aspects of care to read: '... the review team were struck by the many aspects of care and experiences identified that seemed potentially avoidable.'

And it is important to consider whether the findings of the review relate to researchers focusing only on capturing negative experiences, rather than experiences only being negative.

Thank you for this – it is a really good point. We have added the following: 'Perhaps in future, a more comprehensive picture might be gained by adopting an appreciative enquiry approach [42] focussing on positive experiences and what works well, rather than on negative aspects of older people's experiences.' p18

Thank you again for the opportunity to read this paper. I think it presents an important review to draw attention to the paucity of research in this area, particularly that directly reported by older people in their own voices.

## Reviewer 2

This is a potentially important paper that systemically reviewed and synthesized qualitative literature published on the experience of dying among older nursing home residents. While the paper is generally well-written, there are a number of issues that the authors need to address before the manuscript is deemed fit for publication.

1) While the authors provided a detailed description of the search and screening processes of their review, to my knowledge, there is a series of studies that qualitatively examined end of life experiences of terminally-ill nursing home residents in Hong Kong; these studies do appear to fit

under the sampling frame but were not included in the review (e.g. Ho, Luk, Chan, et al. (2015). Dignified Palliative Long Term Care... American Journal of Hospice and Palliative Medicine, 33(5), 439-447.). Thus, a more comprehensive search is warranted, or, the authors need to provide justifications for why this body of works was excluded.

Thank you for bringing this body of research to our attention. Our focus was very specific. We identified this work in our searches but it did not fit our inclusion criteria (pages 4/5) . We have re-checked and looked at it again and unfortunately, although very interesting it does not capture what our review was hoping to learn. Our focus was on understanding the experiences of dying of these older people or the perceptions of those close to them of how the older people experienced dying. The work suggested here does not have this focus and seems to be more about the processes of care provided by the various stakeholder involved. Similarly, e.g. Ho AH, Chan CL, Leung PP, et al. (2013) does not relate to the experience of dying. We had hoped our aim was clear but hope the following addition clarifies this (p 4): 'As no review that synthesised the qualitative research evidence relating to the experiences of older people of dying in care homes was found, this review therefore aimed to identify and synthesise the findings of qualitative studies investigating older people's (aged 65 years or over) experiences of dying in nursing or care homes.'

2) The authors presented the results of their review mostly in the forms of tables, with very little elaborations. Findings of systematic synthesis was provided only through Table 4, but again with minimal elaboration on 6 themes identified. Instead of using the bulk of the discussion section to describe the challenges in identifying relevant articles, the authors should spend equal time explaining critically the 6 themes identified as well as their implications for practices and policies, as this is the major objective of their research. Without such critical elaboration, the current manuscript is not adding much new knowledge to the field.

Thank you for this constructive comment. We have looked back at this and have added some more detail on p 8. 'Table 3 and Table 4 show that all the included studies highlighted the physical discomfort of dying with many older people experiencing potentially avoidable symptoms such as pain, pressure sores, dypnea and thirst. In all studies except[33], physical discomfort was highlighted in association with the care given to the older person, which was often seen as inadequate both by the researchers observing and the staff themselves. Aspects of care such as inappropriate food and drink[28], assessment[26] and monitoring [35] were also mentioned. Negative psychological aspects such as loneliness and depression were described in six studies[26,31,33-36]. Spiritual aspects of people's experiences such as religion and existential issues were also described[28,31,32,34-36]. However, two studies highlighted that death[31] and existential issues[32] were seldom discussed unless raised by older people themselves. In contrast to the other studies, one [35] also highlighted good spiritual and psychological care received by the older people.'

Chan and Kayser-Jones study[28] stood out for focusing on the importance of cultural aspects of care emphasising the additional difficulties of Chinese people at the end of life in terms communication barriers and beliefs around illness and death. However, the uniqueness and individuality of these older people's experiences were also clear in other studies (e.g. [36, 33]).

The studies that included experience of dying from the perspective of the older people themselves are highlighted in table 4. Irrespective of the participant groups, many similarities are evident in the perceptions of this experience, particularly in relation to the centrality of physical symptoms and the care provided. Psychological and spiritual factors were also frequently reported themes.' p8/9

We have also revised the Discussion (p14): 'Although only nine studies were identified, these studies have implications for our understanding of the what it is like to die in a care home or nursing home. The aspects of their experiences that were identified suggest that more could be done to improve their experiences whether in terms of pain or other symptom relief or the overall physical environment. Insufficient staffing [27,35] and poor communication [26,28,31] were highlighted although there was

recognition of the challenges for staff. The role of families was not always highlighted but improved communication[26,35] and flexibility in their involvement was suggested[27].’

3) The authors stated that only qualitative data were used in the review, however, it appears that quantitative data from questionnaires were reported for Brayne et al. (2008). More clarification of data used is required here.

Thank you for this important comment. This point was also picked up by the other reviewer. We have responded to her about this as well but in summary, this was something the review team discussed in detail. After discussion, we concluded that these data should be included as although they were not what would always be considered qualitative data, the authors described the data using qualitative terminology. In the interests of comprehensiveness, we included this study. We had highlighted the different data sources in Table 3 but have now also mentioned this in the potential limitations of the study on p 15. ‘It might be argued that the study which included analysis of open-ended questions in a questionnaire[36] should not have been included but the framing of the analysis was qualitative and it was included for comprehensiveness.’

4) There is inconsistency in the formatting of tables, for example Table 1 uses hyphen citations, while all other Tables use bracket citations.

Thank you for highlighting this. We have gone through and corrected this to make them consistent.

#### VERSION 2 – REVIEW

|                        |  |
|------------------------|--|
| <b>REVIEWER</b>        | Merryn Gott<br>University of Auckland, New Zealand |
| <b>REVIEW RETURNED</b> | 29-Mar-2018  |

|                         |  |
|-------------------------|--|
| <b>GENERAL COMMENTS</b> | <p>Thank you for the opportunity to review this paper again. I think all recommendations have been appropriately addressed and the paper is much improved and makes an important contribution to the existing literature. I just identified a few minor corrections to consider:</p> <p>1. "This diversity makes synthesis more difficult. In order to capture what the authors regarded as most important, data used came from both the Discussion and Findings sections" (top of page 7). Material in the discussion would not normally be considered 'data' for the purposes of a review. Please clarify.</p> <p>Table 2 title: Older residents’ experiences observed reported on or when interviewed<br/>Consider rephrasing as slightly confusing</p> <p>Table 3: Brayne et al - I'm not sure reporting numbers of participants from whom themes were identified is appropriate for a sample size of 10.</p> <p>Table 4: Themes identified mapped with older people’s experiences<br/>I found this title slightly confusing - the text describes the purpose of the table well, but just consider making this title clearer</p> |
|-------------------------|--|

## VERSION 2 – AUTHOR RESPONSE

Reviewer's Comments to Author:

Thank you for the opportunity to review this paper again. I think all recommendations have been appropriately addressed and the paper is much improved and makes an important contribution to the existing literature. I just identified a few minor corrections to consider:

Thank you – we agree it is much improved by your input.

1. "This diversity makes synthesis more difficult. In order to capture what the authors regarded as most important, data used came from both the Discussion and Findings sections" (top of page 7).

Material in the discussion would not normally be considered 'data' for the purposes of a review. Please clarify.

Apologies that this was unclear. We hope we have clarified this and it now reads: 'In order to capture what the study authors regarded as their most important findings, data incorporated in the themes and study conclusions (Table 3) came from their findings and discussion sections respectively.'

2. Table 2 title: Older residents' experiences observed reported on or when interviewed

Consider rephrasing as slightly confusing.

Thank you for pointing this out. We have replaced the title with: 'Residents' experiences (as observed by others or identified by participants)'

3. Table 3: Brayne et al - I'm not sure reporting numbers of participants from whom themes were identified is appropriate for a sample size of 10.

Apologies this was unclear. The (I) and (Q) did not refer to participant numbers but refer to how the data were derived. We have therefore highlighted this in the Key below the table.

4. Table 4: Themes identified mapped with older people's experiences

I found this title slightly confusing - the text describes the purpose of the table well, but just consider making this title clearer.

To make it clearer we have replaced it with: 'Reported themes mapped onto the key aspects of older people's experiences as defined for the review'

## Correction: *Experiences of older people dying in nursing homes: a narrative systematic review of qualitative studies*

Greenwood N, Menzies-Gow E, Nilsson D, *et al.* Experiences of older people dying in nursing homes: a narrative systematic review of qualitative studies. *BMJ Open* 2018; 8(6):e021285. doi: 10.1136/bmjopen-2017-021285.

There is an error in the references. Reference number 17 is cited as:

Fleming J, Farquhar M, Brayne C, *et al.* Death and the oldest old: attitudes and preferences for end-of-life care—Qualitative research within a population-based cohort study. *PLoS One* 2016;11:e0150686. doi:10.1371/journal.pone.0150686

However, the correct reference is:

Fleming J, Calloway R, Perrels A, *et al.* Dying comfortably in very old age with or without dementia in different care settings – a representative “older old” population study. *BMC Geriatr* 2017;17:222. doi:10.1186/s12877-017-0605-2

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*BMJ Open* 2018;8:e021285corr1. doi:10.1136/bmjopen-2017-021285corr1

