Author’s response to reviews

Title: Discussing end of life wishes - the impact of community interventions?

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Author’s response to reviews:

We wish to thank the reviewers for their comments, and to re-submit the above manuscript for consideration of publication in BMC Palliative Care. We have addressed the issues raised by the reviewers as detailed below:

Tim Luckett:

The main limitation of the study is that people who chose to attend were likely to be more willing to discuss end of life than most members of the public, as is reflected by their high rate of wills and level of comfort at baseline. Differences on these outcomes between study participants and those of previous population surveys are noted in the Discussion but the link is not made with a likely sampling bias due to a volunteer effect.

Interventions such as these will always be limited to those who are willing to attend, so this is not a limitation as such, just a reality. The proportions of people stating at baseline that they felt comfortable talking about death were quite similar to those of respondents to the Dying Matters survey.

We have added a few sentences in the discussion about potential bias. (Discussion, Summary of Findings, Characteristics of Participants, page 19, paragraph 3, lines 3 to 8).
We have also added a paragraph explaining that the lack of discussion about end of life and bereavement in the population may not result from people feeling uncomfortable. (Discussion, Effectiveness of the Interventions, page 21, second paragraph)

This is doubly important because a ceiling effect arising from this sampling bias is likely responsible for the limited intervention effect. Are there ways the authors could try to reach the mainstream public with their intervention in the future - e.g. via workplaces?

The ceiling effect may have limited the effect of the intervention on making people more comfortable talking about death, but it appeared to have large effect on prompting people to have those discussions, which was the primary aim of the intervention.

The CLWDW programme continues to develop new projects, including some based in workplaces. We have added some information about this. (Discussion, Effectiveness of the Interventions, page 22, second paragraph)

The Introduction is quite detailed and goes beyond the rationale for the reported study. Some of the minor points could perhaps be moved to the Discussion or else removed altogether.

We have cut down and re-organised the Background section (Background pages 3 to 5). We have moved some of the information previously included in the Background (relating to public attitudes to talking about death and dying) to the Discussion section, in various locations.

Introduction

P3 line 8 - I suggest replacing 'postulate' with 'have been developed on the assumption that'
We have amended the text as suggested (Background section, page 3, first paragraph, line 5).

P3 line 40 - please clarify what is meant by 'In a study of independence in people over the age of 75, 42 of 72 participants (58%) talked about death, although they were not specifically asked about death'.

We have deleted reference to this study, in order reduce the length of the Background section.

P3 line 53 onwards - is 'expected death' more widely used and understood than 'aware dying'?

We have amended the text as requested. (Background section, page 3, paragraph 2, line 7).

Methods

More information is needed about how people were recruited to take part in the intervention and research. This is important because of the obvious risk of sampling bias and implications for generalisability highlighted above.

We have now added this information. (Methods, The intervention, page 6, end of first paragraph, and end of 3rd paragraph, also ‘Methods - The Research’ page 7, paragraph 3)

More information is needed about the questions in the survey and whether these were validated.

We have now included additional information. (Methods, The research, page 7, end of paragraph 1).
A rationale is needed for why age was considered to be such an important lens for reporting of results - for example, did the authors have hypotheses about how views might differ between age groups?

Other surveys, in particular the Dying Matters surveys, have shown that having a will or having talked about funeral wishes was positively associated with increasing age. We have added a reference to this (Background, page 3, paragraph 3, lines 3-5).

We also found many differences by age group within our own data.

And why were over/under 65 years and 10 year age groups from 35 years onwards chosen as the focus for analyses? The Discussion mentions that the results on age 'made sense' to the authors but do not cite any relevant literature.

We collected age data in ten-year age bands because we felt it would be more acceptable to participants than asking their exact age or date of birth. The age-bands used mirror those used in the Dying matters surveys. We have now added this information (Methods, the research, end of first paragraph, page 7)

The analysis by age group was based on observed trends in the data. We have added the following sentence with the Methods section “For age groups, the original ten-year age-bands were collapsed into larger bands according to visual trends observed in the distribution of the data.” (Methods, The research, page 8, last paragraph, lines 4-6)

We are unaware of any relevant literature that might explain observed differences by age group. Therefore any potential explanations are speculative /intuitive. We have slightly amended our wording to better reflect that (Discussion, effectiveness of the interventions, page 22, second paragraph)
(Assuming I have understood correctly) why did the regression analyses only look at independent relationships of socio-demographic variables to survey responses rather than in a multivariate way?

We did not undertake multivariate analysis for the majority of analyses, because reported experiences and attitudes did not vary by any socio-demographic variable except age group. In the case of having a will, this also varied by level of neighbourhood deprivation – hence the inclusion of a multi-variate analysis for this variable only. We have added a sentence to the discussion to highlight this lack of variation (Discussion, Characteristics of participants, top of page 20).

The Results contain a brief summary of responses given to open survey questions. Information is needed on how these data were analysed.

We have added a line of explanation at the end of the ‘Methods’ section. (Methods, The research, last line, page 8)

Results

Are data available to compare the 74% of attendees who responded with those who didn't on socio-demographic variables?

This information is not available because it was impractical to collect it. We have added a sentence to explain this (Methods, The Research page 8, top paragraph, last sentence).

Table 4 refers to non-responders, but doesn't it really mean people who provided baseline/post data but not 3 month follow-up?
You are right. We have amended the table title and headings to clarify this. We have also amended the text at (Results, follow-up, response rate and potential bias, page 15, paragraph 2, lines 1&2).

Are the results reported under the heading of 'Preparations for end of life' all baseline?

Yes. We have now clarified this. (Results, baseline and post-event, preparations for end of life, page 9, start of paragraph 1).

Tables 1 and 2 requires headings for columns (age groups) and rows (survey items?). Table 2 also needs to explain the direction of significant results for under/over 65 years; and what about people who were exactly 65?

We have amended Tables 1 and 2 as suggested. People aged exactly 65 are included in the 'over 65' category. We have made some minor amendments to the text to explain this.

Nancy Preston (Reviewer 2):

1. Background line - line 20 - what were these interventions - did they inform your intervention?

We have added some information about other published interventions within the discussion section (Discussion, Effectiveness of Interventions, 2nd paragraph, page 20)
Our intervention was informed by the more general literature on health promotion and end of life, especially the ideas of Alan Kellehear.

2. Why was socioeconomic data collected - just to clarify representative of area?

We wanted to see what socio-economic groups the intervention was reaching, and to identify whether there were any significant differences between socio-economic groups, in terms of needs and response to the intervention. We have added a sentence to explain this (Methods, The research, page 7, first paragraph, lines 11-14)

3. Advance care planning was covered in the presentation but did this result in any changes? I can see people said they were going to discuss end of life wishes but did you measure if they were going to document this?

The aim of the intervention was to encourage people to discuss their wishes with the people close to them, as well as to help open up conversations about death, dying and bereavement more generally. The survey therefore concentrated on these outcomes, and did not include questions about documentation of wishes.

4. Overall in the results consider whether so much detail is required in the narrative if already in the table. The results are described well in the discussion which perhaps could be transferred to the discussion.

We felt that most of the detail should probably remain within the text, for ease of reading and understanding. However, we have deleted three sentences. These include:

Baseline and Post-event, Demographics, page 9, first paragraph, lines 3&4

Baseline and Post-event, Preparations for end of life, last sentence, page 11
5. The discussion is quite general focussing heavily on the results and needs the most attention. This needs to be supported by the wider literature, which should be referenced. Perhaps tie into the systematic review about other community interventions.

We have added a paragraph which ties into other community interventions, including some of those described in the referenced literature review and another described in a paper published since the review was undertaken. (Discussion, Effectiveness of the interventions, page 20, paragraph 2).

Thank you for your consideration

With all good wishes

Katharine Abba (on behalf of all authors)