**Reviewer's report**

**Title:** Trends in Cause and Place of Death for Children in Portugal (a European Country with no Paediatric Palliative Care) during 1987-2011: a population-based study

**Version:** 0  **Date:** 28 Mar 2017

**Reviewer:** Anjali Shah

**Reviewer's report:**

This paper addresses the important question of trends in place of death and cause of death of children in Portugal. The study uses a population-based dataset and the methods are mostly appropriate. I was impressed by the depth some issues are covered in the Discussion, but other issues need additional explanation. I have some questions about the robustness and validity of the dataset, and subsequent conclusions. Could multiple imputation be used to handle the missing data? Also, I have included some minor points about better phrasing of some of the text.

Points to note:

**Title**
I would recommend adding 'Portugal', 'population-based' and the time period to the title, and a slight rephrasing of the text. An alternative suggestion for the title could be: Trends in cause and place of death for children in Portugal (a European country with no paediatric palliative care) during 1987-2011: a population-based study

**Abstract**

- Background, second sentence needs re-phrasing. Perhaps: 'One aim of palliative care is to enable a home death if it is desired and well supported.'
- Methods, end of first sentence: replace 'from 1987-2011' with 'during 1987-2011' or 'from 1987 to 2011'.
- Methods, in the second sentence add the capitalised words: 'We analysed death certificate data ON cause and place of death; THE main outcome …'
- Results, first sentence: 'the decrease in annual deaths from 3,268 to 572'. Was such a large decrease expected and can it be verified from other sources? Or could there be some problems with the recording of deaths in Portugal over this time period?
- Results, second sentence: was such a large increase in median age of death from 0.5 to 4.32 year expected? Again can this be verified or could this be due to a problem with recording deaths in Portugal over this time period?
- Results, second sentence: was such a large decrease in home deaths (from 35.6% to 11.5%) expected? Do you think healthcare system reform is the only reason for this change?
- Conclusions, needs rephrasing. Perhaps: 'This time-series analysis of paediatric deaths in Portugal (a European country with no paediatric palliative care) shows that palliative care needs are increasing. Children are surviving longer, and in contrast with countries where paediatric palliative care is thriving, there is a long-term trend of increasing deaths in
hospital instead of at home. Age, diagnosis, season and region are associated with home death, and should be considered when planning services to support families. Priorities should address the needs of the youngest children, those with cancer, neuromuscular and cardiovascular conditions.'

- Conclusions, final sub-clause 'inequities related to place of residence' - please delete this sub-clause or replace it with a more specific factor that is presented in one of the multivariable analysis tables.

Background
- Sentence 5 on line 62 - I would replace the word 'classification' with 'definition'.
- First sentence of paragraph 2, line 67 - I would replace the word 'wished' with 'desired'.
- Last sentence of paragraph 2, lines 70-72 - I would suggest a rephrasing to say 'Caring for and enabling a child to die at home increases parental adaptation to loss, while decreasing the burden on healthcare providers'.
- Line 76, amend as follows by using the capitalised words: 'available, and that THE HD proportion is high and INCREASING'.
- Line 81 amend as follows: 'Portugal represents the ideal setting…'.

Materials and methods
- First paragraph, line 88 needs rephrasing: The NIS provided a dataset free-of-charge with individual…'
- Please provide some information on the quality and completeness of the dataset.
- Third paragraph, line 105: the explanation of bed ratio is unclear. Please provide additional information.
- Third paragraph, line 106: Why was multiple imputation not used to handle the missing data? If possible, please re-do the analysis using this approach. If not, please rephrase the sentence to read 'Variables with at least 15% missing data were excluded.'
- Fourth paragraph, line 111 needs rephrasing: '…were entered INTO A multivariate analysis…'

Results
- 'Cause of death', line 127 needs rephrasing to perhaps: 'this INCREASE was more pronounced'
- Paragraph following Figure 1 and Table 1, line 142 needs rephrasing. Perhaps to: 'Over the study period age at death increased: median…' Was this change gradual or was there a specific year when a step change occurred?
- Paragraph following Figure 1 and Table 1, line 143 needs rephrasing. Perhaps to: '2011, specifically a decline…'
- Second paragraph following Figure 1 and Table 1, line 147: change 'deaths along time' to 'deaths over the time period'.
- Third paragraph following Figure 1 and Table 1, line 151: change 'half of CCCs' deaths;' to 'half the CCCs' deaths,'
- 'Place of death', first paragraph, lines 156-8: 'This trend was not explained by demographic changes, as it maintained with standardised percentages.' Please explain this statement, as it is unclear at present.
- 'Home death in Complex Chronic Conditions', first sentence, line 170: replace 'Along 25 years...,' with 'Over 25 years,...'.
- 'Home death in Complex Chronic Conditions', third sentence, line 172: replace 'and not equal...' with 'and it was not equal...'.
- 'Home death in Complex Chronic Conditions', line 175: replace 'In bivariate analysis...' with 'In the bivariate analysis...'.
- Paragraph following Table 2, line 195: 'The odds of HD decreased by 11% annually.' In which years did this change mostly occur? Were there any changes in death registration practices over this time?

Discussion
- First sentence: 'In this first, to our knowledge, time-series analysis of national paediatric mortality data relating to cause and place of death in a European country' - I would recommend deleting the words 'first, to our knowledge' as other European countries do evaluate trends in place and cause of death of children.
- First sentence, line 217: replace 'rising importance' with 'increasing importance'.
- Third sentence, line 219: 'MVA showed that the odds of HD were highest in the beginning of the time series,...' Please provide additional information on possible reasons for this trend.
- First paragraph, final sentence needs rephrasing, lines 223-4: 'This whole-population study allows reliable conclusions WHICH MAY HAVE implications for similar countries without PPC provision'. Perhaps replace the word 'allows' with a better word, such as 'supports'.
- Paragraph 3, lines 233-4: 'we observed the median age of death due to CCCs increased substantially, likely explained by medical advances'. Please provide additional information to support this statement. Is it possible to there may be issues with the quality and completeness of the dataset?
- Paragraph 3, Line 240: 'Neonatology should therefore be a greater priority for PPC provision.' The conclusion is not supported by the preceding paragraph. Across the world, infants are more likely to die in hospital than home, because infants may be better cared for in hospital than at home eg specialist training needed for staff/parents, additional equipment required and the need for other facilities and clinical/supportive care. Parents may not feel they can cope with an infant dying at home, and society may not accept that an infant should die at home either. I would recommend deleting this sentence, and add further information explaining this pattern. Likewise, deaths from some complex conditions may be better supported in hospital than at home.
- Paragraph 6, lines 260-1: as mentioned in comments on the Abstract - do you think the increasing trend of dying in hospital is only due to healthcare system reform? Have any other changes occurred during the study period?
- Paragraph 7, lines 275-6: 'To the best of our knowledge this is the first time that MVA was applied to examine factors associated with HD separately for infants and older children, acknowledging the dissimilarities.' It is common practice to do MVA by age at death with infants as a separate category, and to evaluate interactions for infants separately. A totally separate MVA analysis is not always required. I would recommend deleting this sentence.
Paragraph 6, methodological limitations. I would agree with the first point and I would add further that the analysis could not include the important factor time from diagnosis to death. The literature states that when this time period is less than 6 months, more children die in hospital because either they have acute conditions or little time was available to prepare for a death at home.

The second limitation ‘there may be measurement biases due to modifications in diagnostic, reporting and coding processes along time’. Please add much more information to this statement explaining the changes to the Portuguese death registration system that are known and the likely impact on the findings of this study. Also, please replace the word 'along' with 'over'.

A limitation needs to be added about dropping the variables that had more than 15% missing data, unless multiple imputation is used to amend the analyses and results tables.

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.

Yes

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.

I am able to assess the statistics

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