Author’s response to reviews

Title: The last week of life of nursing home residents with advanced dementia: a retrospective study

Authors:
Franco Toscani (toscani47@gmail.com)
Silvia Finetti (istitutomaestroni@fastpiu.it)
Fabrizio Giunco (fgiunco@dongnocchi.it)
Ines Basso (guinness05@live.it)
Debora Rosa (drosa@dongnocchi.it)
Francesca Pettenati (francesca.pettenati@gmail.com)
Alessandro Bussotti (bussottia@gmail.com)
Daniele Villani (daniele.villani50@gmail.com)
Simona Gentile (simona.gentile@ancelle.it)
Lorenzo Boncinelli (lboncinelli@tin.it)
Massimo Monti (massimo.monti@pioalbergotrivilzio.it)
Sandro Spinsanti (gianorom@tin.it)
Massimo Piazza (file@leniterapia.it)
Lorena Charrier (lorena.charrier@unito.it)
Paola Di Giulio (paola.digiulio@unito.it)

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Author’s response to reviews:

Torino, December 2nd 2019

Dear Sirs,

We really thank the reviewers for the helpful suggestions that improved the text.
In general
All the proposed suggestions to improve the readability of the paper were accepted: the sentences were reworded, as suggested. All the changes related to language have been made.

We rechecked all roundings of the percentages, both in text and in tables.
We add in each table the sample size (n=...) analysed to make easier to follow each description of the results. The sample size differs from 482 residents for missing data about some specific topic (i.e. information on nutrition and hydration in table 2; data about administered drugs in table 4) and it was specified in the text.

The text had been reviewed by a professional translator (Trudy Perdrix-Thoma, professional standards editing). We rechecked everything but if necessary will ask for a further reading.

Specifically.

1. Rebecca Wilson

Overstatement of the aim. You are right, we rephrased the aim according to your suggestion: the aim of the study was to evaluate clinical interventions and care at end of life…
The size of the NH affects the care provided? As stated in pag 3 lines 16-29 each NH should guarantee a &gt;901 minutes/week of care per resident. Of course larger NHs are more likely to have physiotherapists or other services. To our opinion this should not affect the end of life care, that is mostly provided by doctors, nurses and nurses aides.
Pag 4 line 19. Palliative sedation 7 days before death but not 60 days. We did not collect the information whether any palliative sedation was attempted 60 days before death because we assumed that palliative sedation is started shortly before death and if attempted and then suspended, should be considered an exception.
Pag 5, line 27. Why cause of death was missing for some patients. The cause of death is registered for every patient in a special form that is sent to separate archives. Unfortunately for some patients was not any longer in the clinical records due to different archiving policies. If you think that we need to justify it we will add a sentence to the discussion.
Pag 6 line 19. It is not clear how the N of 130 came about. You are right. Patients with palliative nutrition and hydration were those hydrated by mouth only and those that received less than 1000 ml of fluids by SFA. We had also specified that for 13 patients (469 + 13= 482) information on nutrition and hydration was missing. Table 3 reports the information on the 482 patients.
Table 4. We specified in the methods that the information refers to all the administered drugs. We added the ATC code for further clarity but if you think that it could be confusing we can remove it

2. Melany Handley

We modified the title as follows: The last week of life of nursing home residents with advanced dementia: a retrospective study
Abstract conclusions. Following your suggestion the abstract conclusions have been modified.
Pag 3 line 36. We left “loss of all intelligible vocabulary” as it was taken from the original description of the Fast scale
Table 1. We modified the row of the table that shows the median age (and its IQR) at NH admission of the study sample. In this way there should not be doubts anymore, and it should be clearer that this is the only continuous variable summarized in table 1. All the others and absolute and relative % frequencies, with their CI95% as stated in the first row of the table (n / % / CI95% (%)

Pag 7 line 16-19. The sentence was rephrased according to your suggestions “for people with advanced dementia, hospitalization can be aggressive and may be of limited clinical benefit”

Pag 8 line 38. You are right: the sentence was too strong, though in advanced dementia patients resuscitation attempts should not be started. We rephrased the sentence as follows: some questionable, considering the advanced dementia stage of patients, resuscitation attempts

Line 53 to page 9 line 7. The sentence was not clear at all. It was rephrased as follows: These findings also show the need to improve the knowledge of NH staff, included physicians, on these issues.14 This need is reflected in the urgency placed on national regulatory bodies and international scientific boards to produce up-to-date,…

Page 9 line 14.15: unclear how the author arrived at the statement: One of the most disappointing findings was the extremely low presence of ADs, whether they were self-written or communicated by relatives, the poor attitude toward implementing advance care plans, and the scarcity of guardians and/or surrogates. We removed “the poor attitude towards implementing advance care plans” as the other statements are supported by our data (only 12.4% of residents had a guardian)

Pag 9 line 38. We substituted investments with efforts

Pag 10 line 50-56. The sentence “In particular, insufficient acknowledgement of the inappropriateness of some drugs and interventions, and health professionals’ (in particular, physicians) fears and prejudices regarding critical end-of-life decisions” was rephrased as follows “In particular, insufficient acknowledgement of the inappropriateness of some drugs and interventions, and reluctance to implement end-of-life palliative care decisions”

Page 11 we rephrased the sentence as follows: as well as changes in NH staff and general population cultural approach to death and dying in order to outline clinically correct care strategies that can be agreed upon by NH residents and their families

Sincerely,

Lorena Charrier
Paola Di Giulio
Franco Toscani