Author’s response to reviews

Title: “I go into crisis when…”: Ethics of care and moral dilemmas in Palliative care

Authors:

Ludovica De Panfilis (ludovica.depanfilis@ausl.re.it)
Silvia Di Leo (silvia.dileo@ausl.re.it)
Carlo Peruselli (carlo.peruselli@gmail.com)
Luca Ghirotto (luca.ghirotto@ausl.re.it)
Silvia Tanzi (silvia.tanzi@ausl.re.it)

Version: 1 Date: 08 Apr 2019

Author’s response to reviews:

Dear Editor,

Please find enclosed the article : “I Go Into Crisis When…”: Ethics Of Care And Moral Dilemmas In Palliative Care that we are resubmitting for publication in “BMC Palliative care”, after the invitation for a resubmission by the Editor.

Thank you very much for reviewing our manuscript. We also greatly appreciate the reviewers for their complimentary comments and suggestions.

Together with the other co-authors, we have discussed the comments you reported in your e-mail, and revised the article accordingly. In addition, we also revised the English language.

You can find attached a point-by-point response to reviewer’s concerns. The revised parts of the article have been highlighted in red.

We hope that you find our responses satisfactory and that the manuscript is now acceptable for publication.

Rev. 1.1: I would like to thank the authors for providing a good read. The paper raises a meaningful topic for palliative care. The elaboration is, however, moderate. I hope this review can help to further the quality of this paper.
Many thanks for the comment.
We hope we improved the quality of the paper after revisions requested.

Rev. 1.2 : 1. This paper aims to introduce an additional ethical framework for studying, criticizing, and educating palliative care, namely the Ethic(s) of Care framework. It is presented as a totally new perspective, and, as a consequence, no other literature concerning the ethics of care in palliative care is used in this paper. Palliative care ethics is portrayed as being focused solely on principlism and/or on virtue ethics. I think this is an oversimplification. First, plenty of literature on Ethics of Care and palliative care exists. I would like to refer, for example, to the extensive work of professors Carlo Leget and Inge van Nistelrooy, who have published considerably about palliative care from an Ethics of Care perspective. Other palliative care ethics literature also refers, sometimes a little more implicitly, to Ethics of Care (themes). The Ethics of Palliative Care bij Ten Have cs comes to mind, as is Randall and Downie's The philosophy of palliative care. I would suggest to consult these and other relevant references to deepen the introduction.

Many thanks for the comment, we agreed with reviewer. According to his suggestions, we improved the Background section. Please see p. 3 (line 9-13; 20-21); p. 4 (line 8-11; 20-35); and p. 5 (line 1-23).

Rev. 1.3: The authors seem to pay for a slight lack of prescience on Ethics of Care. The interview guide looks like a tissue of different questions, not necessarily contributing to finding answers for the research questions. I understand that this interview guide cannot be changed, but with the above mentioned suggestions concerning the improvement of the Introduction there also needs to be a small reflection on the interview guide.

We opted for a “light” interview guide, according to Kvale’s indications (2007) which we did not explain properly. This remark allowed us to clarify how we defined the interview guide.
We wanted to guarantee the flexibility of a qualitative semi-structured interview in order to meet the participants’ agenda. Please, see p.7, line 11-14.

Rev. 1.4: I’m puzzled by the different aims mentioned in this article. I think consistency is preferred.
- in order to describe the relevance of Ethics of Care in Palliative Care, it is firstly important to explore how HPs make sense and face ethical issues emerging in the care relationship. (introduction, pg 4, line 59)
- this study aims at investigating how professionals make sense (of?) and handle ethical issues. (methods, pg 5, line 14)
- this article explores how HPs make sense and face ethical issues emerging in the care relationship. (discussion, pg 11, line 17)
(note that palliative care slowly seems to disappear in the latter aims).

Thank you for your advice. We re-wrote the aim of the study, accordingly. Also, this allowed us to positively answer to suggestions of Reviewer 2.
Please, see p. 6, line 2-3.

Rev. 1.5: In the discussion, the results are discussed in the light of Ethics of Care only, but I recognize a lot of elements that could be attributed to principlism and/or virtue ethics as well. Examples are described below. The distinction between the different ethical approaches feels rather artificial and actually distracts from the relevant findings from the interview study.
We agreed and re-wrote the discussion section following the reviewers’ suggestion. Please, look at p. 13-14.

Minor comments:
Rev. 1.6: p3, line 30: "good communication does not stem from innate quality"; I consider good communication to be partly talent, partly practice and practical wisdom. This is mainly a virtue ethics-perspective. You seem to argue that innate talent is not relevant?

We amended the sentence in order to better explain our point of view. Please, see p.3, Line 11-13.

Rev. 1.7: p4, line 6-11: how does this discussion of critique on the four principles relate to your particular aims and questions. Why is this relevant for palliative care, and for developing a communication training? This question is also relevant to the next paragraph, in which virtue ethics is explained, but without any explanation how this relates to palliative care.

Please, see our response to the comment 1.2.

Rev. 1.8: p5. It is not exactly clear from the paper (although I can guess), why the Ethics of Care approach in the paper is necessary for developing an ethics communication training in palliative care. p5, line 34: a "randomly selected sample" is quite unusual, and probably undesirable, in a qualitative interview study. Please explain why a random sample is relevant here. We hope we better explained why we choose ethics of care by the improvement through all the manuscript. Please, see the background section, discussion and conclusion.

Thank you for the comment which is in line with comment 2.4 from Reviewer 2. Regarding the term, we used it as we wrote in one of our article to explain how we proceeded. We know we used the term “randomly” with another meaning. We have amended it.

Rev. 1.9: p6, Table 1. The guiding questions belonging to "recognizing and dealing with ethical dilemmas within the care relationship do not deal with the "caring relationships". The questions are more general. Please explain why.

Thank you for the comment. We explained how we defined the interview guide, and given the Ethics of Care framework we followed, we specified that “relationship” should be considered an underlining premise. Please, see p.7 line 5-19.

Rev 1.10: p7, lines 1-25: You mention "ethics of care principles", "ethics of care pivotal features", and "ethics of care theoretical underpinnings". However, I cannot find an explanation of each of these phrases in the text. You would expect that the ethics of care principles are also guiding the design of an interview guide and are therefore worth mentioning.

We totally agreed and took the chance to better explain how we defined the interview guide.

Rev. 1.11: p7, line 38: i'm surprised that the interviews only took 20-30 minutes. My experience with talking about moral issues is that it takes a lot more time. Please explain. Did you get enough in-depth knowledge in these short interviews.
We made a mistake leaving this indication which refers to the study’s protocol rather than the actual duration of interviews. Apologies for this oversight. We amended it, updated and moved to the method section as requested by Reviewer 2.

Rev 1.12: 
p7, line 49: "global care": I would suggest "general care". Global care sounds more like global warming.
Many thanks, we accepted the suggestion.

Rev 1.13: 
p8-9: the results show ample examples of virtuous attitudes (e.g., affection through words, gestures, physical contact; a professional attitude) and a focus on principles, such as autonomy. These results suggest that your discussion/conclusion could be much more nuanced taking the different ethical approach into account. Morality in palliative care is about autonomy as well as about relational autonomy, is about vulnerability and having the right character/virtues to deal with this vulnerability. Especially for the development of a communication training I would recommend to intertwine all approaches

We agreed. We maintained our focus on ethics of care, but we tried to intertwine the approaches as suggested. Please, see the Discussion.

Rev 1.14: p9, line 46: "relational autonomy, correctness, sincerity and humanity" are big categories and need further elaboration to be credible in this context. It would be valuable to add an overview of the themes and subthemes derived from the data. Now it seems that themes from the data and theoretical concepts are interchangeable, making the quality of your analysis doubtful.

We added a table summarising themes and related sub-themes within the Results’ section. Please, see p.9.

Rev. 1.15: p10, line 40: "the narrated dilemma... etc." The following quotations, however, show that in personal dilemmas lie hidden principles, specific ethical frameworks (e.g. Christian ethics), virtues, and elements of care ethics. Please do not make it an Ethics of Care exclusive happening.
Please, see the revised version of the discussion.

Rev. 1.16: p12, line 41: "a deep theoretical research on ethics of care": this is not recognizable in the introduction and methods section

We hope in this revised version of the manuscript we better illustrated the theoretical research underlying the qualitative study.

Rev. 1.17: p12, line 58: it must be possible to at least provide some characteristics of the interviewees? I would say that is required to be able to adequately value the data.

Thank you for the indication: we added a table to show the participants’ characteristics we collected. Please, see p.6.
Rev.2: Thanks for authors for addressing this important issue in palliative care.
Many thanks for the comment.

Rev. 2.2: The Abstract is well structured and informative even if it can be improved.
The aims of the study lack in specificity to be clear for the reader. Investigating cannot be seen as an aim by itself.
Rather than a study design it is more a methods (qualitative methods), furthermore few words on data collection and analysis.
In the paragraph on setting/participants (p.3 line 44) I suggest to add some few information about number of participants by profession, to mention that they randomise the selection. Details needed to offer the opportunity for readers to gather more info about the study.
As conclusion the authors affirm that "ethics of care seems to emerge as a theoretical framework ....". Which is not mentioned in the main. I suggest to draw conclusions related to the aim. Thank you for these important remarks.

We hope the changes we made meet the expectations. In particular, we clarified the aim of this study, accordingly also to your next comments and we modified the methods section as suggested. Please, see p.6-9.

Rev. 2.3: The introduction is well written and consider the main approaches to ethics in palliative care.
Authors propose an alternative to the previous theoretical approaches regarding ethics and care.
However it is not clear enough for me how study objectives/aims are related to the background. The aim as reported by authors is: "investigating how professionals make sense and handle ethical issues" while in the background (p.4 line 59-61) it seems that the aim is "to describe the relevance of ethics of care...). I would suggest authors to be more clear with the aim and to outline how the background is connected to aim. In specific authors should explain the link between the relevance of ethics of care and the need "to explore how HPs make sense and face ....."

We clarified the aim of the study as suggested by the reviewer.

Rev. 2.4: Methods
Design: the theoretically-driven thematic analysis is a method to analyse qualitative data rather than a study design and can be reported under data analysis.
Study population: the authors report clearly a selection criteria for participants as well as they use a randomization procedure. The type of hospital wards may need some more details. What did they mean by "wards involved in the care ...." Geriatrics ward or other disease specific wards or ....

Thank you for the comment. We totally agreed with you and changed accordingly the text. Regarding the “randomly” selected participants: we used a term we wrote in one of our article to explain how we proceeded. We know we used the term “randomly” with another meaning. We have amended it. In addition, we added details about participants’ characteristics and related information (even wards) (p.7).

Rev. 2.5: Data Collection: the information about data collection are detailed. The concern is that the data analysis proceed by fitting results into a set of themes used for the development of the interview. There is a high bias risk since using a set of themes already available don't allow authors to check if new themes emerge. The process of coding interviews and then moving to the development of categories and themes is missing (see for example Marks and Yardley, 2004 on research methods for clinical and health psychology). Usually a kind of code book is developed in order starting from the
first interview in order to support researcher in coding the interviews.

Yes, we re-wrote the data analysis section to clarify how we proceeded.

Rev. 2.6: In the result section the authors report that 16 out of 20 agreed to participate. I suggest to move it into the methods section as well as the sentence about the duration of the interview. How authors set the number of participants? It is a convenience number, they refer to some literature data; usually in qualitative research the concept of saturation is used to define number of interviews. Can authors give some details about.

We agreed. We made the requested changes.
We also specified that the sample was a convenience one. Regarding saturation: we highlighted that as a limitation of our study.

Rev. 2.7: Results: the results are well reported and sentences represent well the underlying theme described. I have to outline again the importance of describing, in the methods section the details of data analysis. All results fit into a pre-constructed scheme of themes, so results seem as a way for the operationalization of a concept or a kind of how theories are represented in practice. A confirmative analysis? I suggest to consider the whole process from setting aims, to describing methods to presenting results.

We improved the methods section as suggested by the reviewer.

Rev. 2.8: Discussion: In my opinion discussion should start by considering the aim of the study. And what authors report is different from the aims described. I would suggest authors to clearly set the aim of the study and to link discussion to the aim.
The discussion is about morality and its role in care considering the ethics of care approach.
I would suggest authors to connect the discussion paragraph to the study results.

We hope in the revised version of the manuscript we clearly set our aim, and accordingly connected the discussion.

Rev. 2.9: Conclusions: The authors conclusion "highlights the importance of providing …." (P.13, line 16). It is not clear to me how this recommendation can be drawn from the results of the study. At least the results inform on what are the main aspects of ethics of care reported or described by health professionals which can be used to develop a course content.
While the last sentence of the paragraph is related to the aims of the study which seem to be a kind of confirmative study of the ethics of care approach.
Strength and limitation: The authors report a list of limitation of the study but no strength are reported.

We hope in the revised version of the discussion and conclusions we better explained the connection between results of the study and the promotion of ethical training program.
We also re-wrote the paragraphs to make strengths clearer.