PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Caught between intending and doing: older people ideating on a self-chosen death
AUTHORS	van Wijngaarden, Els; Leget, Carlo; Goossensen, Anne

VERSION 1 - REVIEW

REVIEWER	Kim Van Orden, PhD University of Rochester School of Medicine, USA
REVIEW RETURNED	22-Sep-2015

GENERAL COMMENTS	This manuscript involves thematic analysis of 25 qualitative interviews conducted with older adults with a wish to die in the absence of a terminal illness. Strengths of the paper include examination of a topic of high public health importance—suicide/death wishes in later life—as well as use of qualitative methodology for a topic that is not yet well understood. My concerns are as follows: 1) The authors state that their aims are as follows: “The paper has two purposes: first, it provides in-depth insight in what it means to live in-between intending to live life and actually performing a self-chosen death, by giving insight in the tensions and polarities of living towards this ultimate decision, Secondly, it aims to deepen the scientific theoretical understanding of ‘rational suicide’ by evaluating to what extent the intentions and decisions of these older people appear to be (ir)rational.” My concerns about these aims are: 1) the sentences are very long and difficult to follow; 2) I don’t know what it means to provide “in-depth insight.” Do you mean to characterize a phenomenon? 3) I am skeptical that any analysis can appropriately evaluate whether or not the intentions are rational or not. Regarding the third point, the authors did not set up a priori what would qualify as ‘rational’ or ‘irrational’ but instead appear to use their subjective post-hoc interpretations of the qualitative data to drive their conclusion that the death wishes of their subjects are a combination of rational and irrational. I think their conclusions go beyond their data. 2) More information is needed on how n=25 subjects were selected out of 144 who reported interest in the study. This selection process raises issues of generalizability, or selection bias (e.g., could the interviewer’s stance on the issue of euthanasia in the absence of terminal illness have influenced who he/she invited to participate)? For example, 23 subjects were members of a Dutch right-to-die organization; how could this have influenced the results? 3) Depression severity was measured but not used in the analyses other to say that “there was no evidence of severe psychological disturbance among the subjects.” I believe this statement goes beyond their data in that some subjects (as reported by the authors)

	did report moderate to severe levels of depression. Further, many of the participants spoke about anxiety, but anxiety was not measured. 4) The theme of fearing becoming a burden came up in several of the narratives. I think this could be discussed a bit more (if only briefly), especially given that perceived burdensomeness is a key variable in a contemporary theory of suicide (Interpersonal Theory of Suicide). 5) The authors characterize their subjects as living "in-between" life and a self-chosen death. However, we do not know how many of the subjects will go on to die via "self-chosen death." Just as most with suicide ideation do not die by suicide, many who desire euthanasia do not choose this option. It is a mischaracterization to suggest that these individuals will engage in life-ending behavior. 6) As stated above, I think the authors' conclusions go beyond their data: "The self-chosen death in elderly people appears neither to be decisively irrational and pathological, nor rational." The authors do not specify what aspects of their data lead them to this conclusion. I do not see how the data support this conclusion. The authors also conclude: "To provide good care, it is of crucial importance to make a clear distinction between pathological suicide and a self-chosen death in older people." This statement assumes that there is a difference between suicide and self-chosen death, which is not substantiated by this paper; further, it implies that this paper helps make that "clear distinction," which, it does not. In sum, I believe the authors have a rich dataset that could inform the field's understanding of wishes to die among older adults. However, I think the manuscript in its current form does not fully capitalize on the strengths of the data, while the framing of the paper highlights the weaknesses of the data (e.g., setting the paper up for something the data cannot speak to). I wish the authors best of luck in their important work.

REVIEWER	Robert E. McCue, M.D. New York University School of Medicine Department of Psychiatry New York, New York USA
REVIEW RETURNED	23-Sep-2015

GENERAL COMMENTS	This study makes an important contribution to the discussion of rational suicide in the elderly. It highlights the ambivalence present after the putatively rational decision has been made.

REVIEWER	Bianca Brijnath Monash University, Australia
REVIEW RETURNED	09-Nov-2015

GENERAL COMMENTS	An innovative paper providing much needed empirical evidence into what until now, has largely been a theoretical debate. The aims were clearly described, the method replicable, the findings presented in context, and the discussion appropriate for the most part. I offer the following comments with a view to strengthening the paper.

	Following implementation of some of these very minor changes, the manuscript should be accepted for publication. Terminology: The word 'elderly' has been critiqued by some as pandering into the ageist discourse wherein older people are seen as a burden. This is clearly not where the authors are coming from; hence it might be more useful to steer clear of such terminology, using the phrase 'older people' instead of 'elderly'. Methods: Further information is needed on the HADS. Why was it administered? If it was to screen out potential participants with high risk of depression and anxiety, then why was it administered at the end of the interview? How did participants' understandings and articulations of their distress correspond to their scores on the HADS? Were they made aware of their scores and if so, what were their responses to it? Much more needs to be done to complicate the scale and participant's responses to and on it. This is clearly not within the scope of the current article – unless the authors have the appetite for a major re-write! - instead perhaps they could think more critically around the scale with a view to crafting another paper on it and remove mention of it in this paper. Sample description: 23 of the 25 participants were active members of a Dutch right-to-die organisation. Therefore to suggest that the sample is generalizable to the entire Dutch population is erroneous. This point should be acknowledged in the limitations. Findings: pg. 13, line 7: what is a 'village in the city?' Discussion: The liminality or 'in-betweenness' of intending and performing self-directed death could be better linked to ideas of a 'good' and 'bad' death. Much has been written in anthropology about liminality, life-courses, and rites of passage. Some reference to this literature would perhaps strengthen the argument and sharpen the focus on the emotional dilemmas participants reported as well as put more context around their experiences. Social Science & Medicine published a special issues on this many years ago (Volume 58, Issue 5, Pages 883-996 (March 2004)). It would be useful to refer to that special issue to draw on some of these ideas – notably there are quite a few Dutch-based contributions in that issue, which the authors may find useful. In terms of the section on practical implications, it might be useful to revert to the data to check where older people would like to die. My interpretation was that they ideated dying at home, on their terms, and pain-free. Many has already accumulated the materials and technologies to achieve this result. As such the practical implications for health professionals might be minimal; rather it is more about a sustained ethical engagement with older patients about their wishes and desires, recognising that these wishes are fluid and subject to change. The authors make this point albeit indirectly and they could do so more explicitly. Finally, a judicious edit to reduce grammatical errors and improve readability and flow. As the authors are writing in a second language, I would expect the journal to assist with this process to facilitate publishing this innovative and important article.

VERSION 1 – AUTHOR RESPONSE

Responses to Reviewer 1:

1) We thank the reviewer for all helpful comments that have led to an improved version of the manuscript. Next, we value the reviewer's comments on the high public health importance of our study. We also appreciate her comments on the style of our manuscript and her challenge to reformulate our aim and make it more sharp and clear. We hope that we made considerable improvement.

For a restatement of our aim, please see page 6, line 18-20.

The terminology "in-depth insight" is fully in line with the qualitative phenomenological approach we used 1. This indeed means "to characterize this phenomenon" and provide "deep insight". However, for further clarification, we have revised the formulation. Please see page 6, line 19.

We highly value the encouragement to scrutinize the formulation of our aim ánd our conclusions, trying to put it more straightforward. Though I am afraid that we differ with the reviewer on that we used "our subjective post-hoc interpretations" to drive our conclusions. In our introduction, we have outlined how rational suicide is defined and what criteria should be met. In our discussion, we have attempted to describe to what extent the intentions (and decisions) appear to be rational or not.

We are of the opinion that our study does give clear indications about the intertwinedness of rationality and irrationality. And we believe that the results (and not our own interpretations) highlight the ambivalences, polarities and tensions after putatively rational considerations taken into account. Please, see page 6, line 18-20 (for the reformulation of our aim) and page 26, line 10-14 (for the reformulation of our conclusions).

2) We thank the reviewer for giving us the opportunity to provide more detailed information about our sample process and the generalizability. We have described our sample process (formerly published in another paper) in more detail and hope that we have adequately addressed the reviewer's concerns about a putative selection bias.

Participants were purposefully sampled in two rounds: the first selection was based on respondents' initial description of their personal situation. Sample criteria were: richness of experiences; differences in (physical) health; different ideological and demographic backgrounds; and nationwide coverage. Next, potential participants were called by the interviewer to ensure the first selection. Some potential participants were then excluded, as they turned out to be so-called "if-then respondents": if their situation declined further, then they would prefer to have legal options for assisted dying, rather than having an actual wish to die at that moment. Others were highly politically driven. Their response was focused on advocating legalization of self-directed death, instead of giving a personal, experiential account. In a few cases, the respondents withdrew. We have included this information in the manuscript. Please, see page 7, line 13-22.

As mentioned in our manuscript, between April and September 2013, research advertisements including a short description of the research project were placed in several magazines. These magazines were deliberately selected, all targeting distinct audiences of older people and all having national coverage. We have included a minor addition. Please, see page 7, line 7-8.

While we deliberately chose various magazines in order to target a broad spectrum of audiences, it turned out that most respondents (i.e. also respondents who were recruited from the Christian elderly organisations) were member of the Dutch-right to die organization. Besides, it is important to take into account the specific cultural situation in the Dutch society, which is characterized by a very intense

and profiled end-of-life debate. Both facts are likely to have influenced the outcomes. Yet it is important to note that a growing awareness on death and dying, and the debate on how to determine time and manner of death has become more common, not only in the Netherlands, but in the Western world as such. These aspects are considered as important indicators of a 'good death' in the whole western world 2-6. Reflection upon these issues has encouraged us to sharpen our statement about the generalizability, i.e. by stating that the transferability of these findings to other similar groups of right-to-die sympathizers seems justified given the broad variation within our sample. Please, see page 29, line 15-19.

3) It is true that the self-assessment scale (the HADS, Hospital Anxiety and Depression Scale) was not analyzed in relation to the interview data. In the context of this research project, our sole aim was to gain a preliminary indication as to whether the wish to die was driven by a severe depression or not, as depression is the most frequently studied factor in relation to death wishes in elderly people.

In our revised manuscript, we included a table with participants' characteristics, mentioning the outcomes of screening for depression and anxiety. We hope this provides more transparency and clarity. This table was already used in an earlier article. We have gained permission to re-use this table for this article. Please, see page 8-9.

We think it is at least noteworthy that in the population under study, a close association between death wishes and depression is cautiously questioned, because only in one case there was an indication of a severe depression. This seems consistent with other research that also indicates that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety. However, we fully agree with the reviewer that much more research on this topic is needed to further explore this. So in order not to overstate our conclusions, we added some nuances and included a statement that further research is recommended. Please, see page 27, line 19 - page 28, line 3.

4) We thank the reviewer for this valuable suggestion. We indeed included a comment (with reference) on this theory in our discussion. Please, see page 27, line 10-18.

5) We agree with the reviewer that it is definitely true that people who desire euthanasia or suicide in the end might not choose this option. That is exactly why we chose for the characterization: (in-)between intending and doing. We have tried to accurately describe just this liminality (or 'in-betweenness'). It was not at all our intention to suggest that these individuals would indeed engage in life-ending behaviour, as this is indeed obviously unpredictable. We thus scrutinized our manuscript to remove this unintentional suggestion, as did our native proofreader.

However, to qualify the strong expression 'mischaracterization', it is important to note that our population turned out to be highly determined. In the year after the interviews, the interviewer received eight notices of elderly people who indeed engaged in life-ending behaviour and died via a self-chosen death. The researchers did not ask for such a death notice, however, these were sent at their own initiative. We included a short statement on this. Please, see page 10, line 3-5 & page 27, line 1-9.

6) We agree with the reviewer that we probably formulate our conclusions too firm here. So after reflection, we decided to delete our conclusions about pathological suicide. We rephrased our conclusion solely on our finding on the complexity of making a 'rational' decision, as we presume that our study does give considerable evidence of the intertwinedness of rationality and non-rationality and highlight the ambivalences, polarities and tensions after putatively rational considerations taken into account. Please, see page 25, line 13-15 & page 26, line 10-14.

We would like to thank the reviewer all most sincerely for her helpful comments that led to an improved version of the manuscript. We presume that our revised manuscript now better highlight the strengths of our data.

Responses to Reviewer 2:
We thank the reviewer for endorsing the relevance of our study.

Responses to Reviewer 3:
We are very pleased to read that the reviewer is of the opinion that our manuscript provides an important empirical contribution to a largely theoretical debate. Next, we thank her for all helpful comments that have led to an improved version of the manuscript.

1) We thank the reviewer for this suggestion, as we were not aware of the critique on the phrase "elderly". We have changed this terminology throughout our article.

2) We thank the reviewer for these comments. We have considered the option of removing the reference to the HADS, but we decided not to do it. Because we think that - while we are careful in not overstating our conclusions - it provides an interesting preliminary indication about the association between depression and the wish to die in this population.

We will now further explain how and why we administered the HADS:

In the context of this research project, our sole aim was to gain a preliminary indication whether the wish to die in our sample was driven by a severe depression or not. This was done because in the literature, depression is one of the most frequently studied cause of death wishes in elderly people. However, in the Dutch debate it is frequently discussed whether the wish to die in older people (without terminally illness) should be seen as an existential rather than as pathological wish to die. The HADS was administered immediately after the interview to avoid influencing the characteristic openness of a phenomenological interview. We did not discuss the outcomes with the participants. To provide more clarity, we now included the exact outcomes of screening as participant characteristics in Table 1 (see page 8-9).

It is true that the outcomes are not analyzed in relation to the interview data as this was not our aim. However, we think it is at least somewhat surprising that in the population under study, a close association between death wishes and depression is cautiously questioned, because only in one case there was an indication of a severe depression. This seems in consonance with other research that also indicates that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety. However, we fully agree with the reviewers (both 1 and 3) that much more research on this topic is needed to further explore this. So in order not to overstate our conclusions, we added some nuances and included a statement that further research is recommended. Please, see page 9, line 15 – page 10, line 2 & page 27, line 19 – page 28, line 3.

3) We fully agree with the reviewer that our sample is not generalizable to the entire Dutch population. Initially, we tried to make this clear with the expression ‘similar populations’. We now tried to sharpen our formulation about generalizability a bit more: Please, see page 29, line 15 – 22.

4) A village-in-the-city [in Dutch: stadsdorp] is a quite recent initiative by and for (older) residents in an urban city neighbourhood to ensure modern neighbourliness. Especially older people aim to organize themselves to ensure that they can continue living an independent, active, healthy and safe live as long as possible. We thank the reviewer for the indication that further clarification is needed, so we

included a footnote to explain this term. Please, see page 14.

5) We fully agree with the reviewer, so we added some extra thoughts on this in the discussion 2-6. Please, see page 26, line 17-18 & page 29, line 19.

6) We thank the reviewer for this suggestion and do indeed agree that we could point at the need for ethical engagement more explicitly, so we did. Please, see page 28, line 14-16.

7) In order to improve readability and flow, we have sent our manuscript for proofreading to a professional native-speaker translator.

References

1. Finlay L. Phenomenology for therapists: Researching the lived world. West Sussex: Wiley-Blackwell, 2011.
2. Chabot BE, Goedhart A. A survey of self-directed dying attended by proxies in the Dutch population. Social Science & Medicine 2009;68(10):1745-51.
3. Seale C. Changing patterns of death and dying. Social science & medicine 2000;51(6):917-30.
4. Kellehear A. A social history of dying. Cambridge; New York: Cambridge University Press, 2007.
5. Pool R. “You’re not going to dehydrate mom, are you?”: Euthanasia, versterving, and good death in the Netherlands. Social Science & Medicine 2004;58(5):955-66.
6. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ: British Medical Journal 2002;324(7342):905.

VERSION 2 – REVIEW

REVIEWER	Kim Van Orden, PhD University of Rochester School of Medicine, USA
REVIEW RETURNED	09-Dec-2015

GENERAL COMMENTS	The authors have addressed my concerns and I believe this manuscript will make a valuable contribution to the literature.