Reviewer's report

Title: Extending life for people with a terminal illness: a moral right or an expensive death? Exploring societal perspectives

Version: 2 Date: 18 October 2014

Reviewer: Amanda Wolf

Reviewer's report:

Minor Essential Revisions
1. Provide an abstract

2. Include a statement about ethical approval/s.

3. In the Methods section, detail is provided on the statement set and the participants. There is a need to clarify that the statement set was selected with attention to ensuring a representative sample of the ‘population’ of opinions relevant to the study. Researchers should be convinced that the statement set is as fully ‘saturated’ as far as they can judge, and that there are no known relevant opinions that are not contained, more or less, in the set. However, Q methodology’s principles for selecting participants (from whom to collect Q-sort data) need to be more carefully described, without attributing the ideal of representativeness and saturation to the selection of sorters (although the methods actually used were entirely appropriate). Q methodology does not proceed by iterative data collection and analysis, ceasing only when no new views are discovered.

4. In the first paragraph of the Results, the inclusion of the two general public factors is explained. It is misleading to state that this ‘accounts’ for the views of the general population. Rather, the ‘meta’ Q sorts take their place vis-à-vis the views of the purposive sample, and serve mainly to position them.

5. Tables 2 and 3 make clear that ‘exemplars’ are defined by the flagging method, giving the 19, 15, and 16 exemplars noted in paragraph 2 of the results section. However, based on the text in that paragraph, there should be fewer exemplars, as some of the flagged sorts do not meet the condition of ‘highly positively associated with one factor and negatively, or hardly, associated with the other two accounts’ – that is, they are ‘mixed loaders’. The statistical measure for ‘highly associated’ is correctly reported (0.37); thus EX005 and 14 others amongst the three factors should not be counted as ‘exemplars’.

6. In the Results, paragraph 3, two statements are noted as ‘consensus’ statements; however in the last paragraph of the Factor 1 description, a third statement (#8) is also described as a consensus statement. Clarify the use of ‘consensus’ in these two places.

7. In the second paragraph of the Factor 2 description, a claim is made that
‘extending treatments is considered wrong’. But statement 29 does not (on its own) suggest anything more than a definitional matter (that not giving access to medicines is the same as killing).

8. The Ethical and Policy Implications are based on arguments about the way ‘public opinion’ can inform decisions. Since the study has used non-representatives (experts), some justification is needed for taking their views as indicative of the public (especially as Factor 3 did not have a parallel in the general public study).

Discretionary Revisions

1. The title phrase ‘a moral right or an expensive death’ can be omitted; it could lead a reader to expect something more comparative than the study that is reported.

2. There is some debate as to how to classify Q methodology, whether as ‘mixed methods’ or as a unique approach that uses both quantitative and qualitative data. Both claims are made (last paragraph on the first section in Background and first paragraph of methods). I suggest omitting mention of mixed methods.

3. The Background section presents an argument that NICE’s perception of public support for special life-prolonging treatments may not have been a fully accurate reflection of the views of its Citizens Council (and the public). This same section then notes an analysis of the support offered by some in the supplemental guidance consultation that seemed to rely on the lack of fully capturing the value of end-of-life extensions (not unlike aspects of the interpretation of Factor 3). Later, the authors suggest that NICE should ‘provide a transparent account of how public values are incorporated into processes’ (Ethical and Policy Implications, paragraph 2). While I find the need for transparency persuasive, the authors could clarify (a) that there is reason to question NICE’s (earlier) interpretation of societal values (and that this may simply be due to a lack of good evidence for them, hence the value of the study that is reported); (b) that over and above transparency, there may be a need for better understanding of what accounts for support/lack of support for NICE’s guidance (again a contribution of the study).

4. In Data Collection, it would be helpful to see the range of academic disciplines in the set of participants.

5. The ‘purposive sample’ may be better named ‘expert sample’ in part to describe the participants more accurately and in part to contrast with ‘general sample’

6. In a few places, factor interpretations are described as narratives (for example in the first sentence of the Factor 3 discussion). It might be helpful to clarify in the introduction to the factor presentations, in what sense they can be considered as narratives.

Minor issues not for publication.
1. For the minus sign, use a typographical minus sign (or an n-dash) and not a hyphen

2. In the Results, factors are referred to as one, two and three, but in the discussion as 1, 2, and 3. Please choose one format (numerals are preferred) and use consistently.

3. There is a typo in the authors’ list in Cam Donaldson’s email.

4. Use the journal style for in-text references (numbers in square brackets) and check the reference-list formatting

5. Line 46: the sentence refers to generic health technology assessment agencies, so should be lower case; the abbreviation is not needed (it is only used a few times, and is ambiguous (eg line 109 as between the agency and the job the agency does).

6. Line 97: lower case on ‘Social’; I suggest avoiding the abbreviation SVJ (not used enough).

7. Line 138: grammatical problem needs fixing.

8. Line 277: ‘each . . . is’

9. Line 443: ‘different . . . from’

10. Line 477: perhaps re-express ‘close other’

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** Yes, and I have assessed the statistics in my report.

**Declaration of competing interests:**

I declare that I have no competing interests