Peer Review Report

Review Report on The support needs of patients requesting medical aid in dying and their relatives: a qualitative study using semi-structured interviews and written narratives

Original Article, Int J Public Health

Reviewer: Iris Hartog

EVALUATION

Q 1 — Please summarize the main findings of the study.

This study reports eight categories of support needs of patients requesting MAID and/or their relatives, based on the analysis of 9 in-depth interviews with patients, 5 written narratives from patients, 20 interviews with relatives and one interview with a patient-relative dyad. Eight categories of support needs were identified, from making sense of the patient's desire for MAID (only relatives) to support for facilitating social interaction. As most of the categories are social/existential, the authors conclude that patients and relatives experience the MAID trajectory as social/existential rather than medical. Thus, resembling the needs of patients/relatives in other end-of-life trajectories, patients requesting MAID and their relatives may benefit from a palliative care approach. An integrated approach of MAID and PC is thus warranted, instead as viewing them as conflicting.

Q 2 — Please highlight the limitations and strengths.

STRENGTHS: Next to the relevance of this article for practice, another strength of this manuscript is that the authors explicitly mention their epistemological stance and explain why they chose a qualitative approach. The steps in the methods are also relatively well described, although there are still a few possible improvements (see below).
What I found original and creative, is that respondents who refused to be interviewed, were asked to write down their narrative. However, as the researcher did not include extra patients to interview, this also turned out to be a limitation, as written narratives to not allow for asking extra questions and probing and therefore these results would be somewhat limited.

LIMITATIONS:
One limitation is that only one dyad was included. All the other relatives that were included, were already bereaved after a loved one had received euthanasia. This makes their account of the experience retrospective, while the experiences of relatives were storied during the MAID trajectory. It would have been interesting to have more dyads/triads included, to study their (different) needs in the same situation and how their perspectives and needs are intertwined. Or at least to include relatives who were still in the middle of the process.
I also consider it a limitation that the experiences of the patients and relatives were not analyzed separately. Lumping their experiences together does not seem to result in an in-depth understanding of the needs of both groups, as they are in such a different position.
This adds to the fact that the analysis that was carried out, is not really a thematic analysis, although it was described as such. What was developed, were categories, which are not 'themes'. In 'thematic analysis-language', they are 'buckets': categories tying together certain types of something, instead of patterns in the data underpinned by a central concept / core meaning that organizes the analytic observations.
In TA (six phases), creating categories of codes (needs, in this case) is usually the step BEFORE the final analysis in which, during a creative process, the themes are developed. As such, it seems that the analysis was aborted before the themes could be constructed. This results in a more descriptive account of the data instead of a more interpretative analysis.
Following what can be read in the methods section, I would rather call this qualitative content analysis (QCA).

And I think that when really developing themes to identify the core meanings of the participants' needs, the data from both groups could better be separated.

This was especially pointed out by Braun & Clarke, who were quoted by the authors when describing the method used. Please, see their more recent articles in which they clarify this, such as https://www.tandfonline.com/doi/epdf/10.1080/17437199.2022.2161594? and https://onlinelibrary.wiley.com/doi/10.1002/capr.12360 .

Also, I would advise the authors to read https://www.thematicanalysis.net/editor-checklist/ to make sure all relevant elements of the method are reported, such as why thematic analysis (TA) was the most appropriate approach and which type of TA was used.

Q 3　Please provide your detailed review report to the authors. The editors prefer to receive your review structured in major and minor comments. Please consider in your review the methods (statistical methods valid and correctly applied (e.g. sample size, choice of test), is the study replicable based on the method description?), results, data interpretation and references. If there are any objective errors, or if the conclusions are not supported, you should detail your concerns.

ABSTRACT
– p.1, l.21: what do the authors mean by "enhance effectiveness in practice"?

INTRODUCTION
– p. 2, l.33: which "undesired outcomes" do the authors refer to?

METHODS
– As in qualitative research the researchers actively engage in the generation of knowledge, using their own understandings of the context, it is preferred that the authors also state who performed the interviews, and what the background, relevant experience and stances/convictions regarding the topic are, of the interviewers and scholars involved in the analysis.
– As one of the 'relatives' was a 'close friend' and partners are not always married and thus 'relatives', it may be good to explicate the definition used of 'relative'.
– p. 3, l.68-76: it would help the reader if the authors would explicitly explain that (and why) besides one, no relatives of participating patients were included.
– p. 3, l.69: the inclusion criterion 'having expressed a desire for MAID to relatives' raises the question whether the experiences of these patients, whose desire may be quite hypothetical and may never be expressed to a physician, could be different from that of patients who are in an actual euthanasia trajectory with their doctor. It also raises the question if all the patients with a psychiatric disorder are in this first group, and what that means for their experiences and for interpreting the data. Also, the needs of relatives of the first category of patients may be quite specific, but none or just one of these relatives were included. Maybe the authors can reflect on this in their results or discussion section.
– p. 3, l.85-86: please clarify whether the participants were given the choice between an interview and written narrative, or were only provided with the latter option after refusing to be interviewed. (In the Discussion section, the word 'reluctant' was used).
– p.3, l.90: "malpractices" sounds quite strong and specific, was it phrased this way in the interviews? Did it also entail struggles, worries, existential questions etc, which are not necessary needs but also not malpractices?
– p.3, l. 91-93: please clarify if needs were only coded as '(support) needs if respondents explicitly mentioned some type of support, or also if they expressed a need in general (such as 'peace of mind', 'making sense of...' without wanting informal or professional support for this).
Also, please explain who provides, or would/should provide this support, according to the respondents or the authors. In the Discussion section (p. 8, l. 253-255) professionals are mentioned as the ones who should attend to these needs, is that because the respondents said so? And would it sometimes not be putting too much responsibility on healthcare providers, while sometimes, patients and relatives for example could also talk to each other sooner and more often, to enhance the sensemaking process et cetera?
p. 4, l.104-106 and l.117-119: data saturation is not an undebated quality criterion in qualitative research, as generalizability can never be a goal and one can never be sure that new meanings would not occur if new

respondents were interviewed, new researchers would interpret/analyze the data or the authors would have a new look at, or round of analysis of the data (for example to develop themes).
See for example Braun & Clarke: https://www.tandfonline.com/doi/full/10.1080/2159676X.2019.1704846 .

DATA ANALYSIS:
– Please, clarify that (and why) you analyze the patient and relative interview data together, although their position in the MAID process is very different and their accounts are also 'realtime' versus retrospective, and partly written versus only interviewed.

RESULTS
– Figure 1: it may help the reader if the authors could clarify which of the needs categories apply to only the patient, only relatives, of both (possibly to which extent).
– p. 6, l. 180: Was the existential question about failing as a relative (only) mentioned by relatives of psychiatric patients requesting MAID, or by relatives of patient with other non-terminal conditions?
– p. 7, l.188: could "individually" be a more appropriate word than "independently", here?
– p. 7, l.191: please check if all the results paragraphs are written in the right verb tenses, preferably the past tense ("were" instead of "is", in this line).
– p. 7, l. 194: It would help the reader if it was explained what type of "adverse events" is referred to.
– p. 7, l. 200: "Support for facilitating" may be a pleonasm; "support for social interaction' would suffice.

TABLE 3:
– It would help the reader if the quotes were integrated in the text.
– Please double check if all the quotes are as concise as possible. For example, the first one may be just as relevant if it would start with the fourth sentence: "I know that, in my case...".

DISCUSSION
– p. 8, 248-251: The authors do not seem to refer to literature in the specific needs of family caregivers of patients receiving palliative care, although a lot of research has been done on this topic.
See for example:
+ Fernandes CS and Angelo M. Family caregivers: what do they need? An integrative review. Rev Esc Enferm USP 2016; 50: 675-682. 2016/09/30. DOI: 10.1590/S0080-623420160000500019.
+ Tieman J, Hudson P, Thomas K, et al. Who cares for the carers? carerhelp: development and evaluation of an online resource to support the wellbeing of those caring for family members at the end of their life. BMC Palliat Care 2023; 22: 98. 20230720. DOI: 10.1186/s12904-023-01225-1.
+ Wang T, Molassiotis A, Chung BPM, et al. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. BMC Palliat Care 2018; 17: 96. 2018/07/25. DOI: 10.1186/s12904-018-0346-9.
+ Melin-Johansson C, Henoch I, Strang S, et al. Living in the presence of death: an integrative literature review of relatives' important existential concerns when caring for a severely ill family member. Open Nurs J 2012; 6: 1-12. 2012/03/01. DOI: 10.2174/1874434601206010001.
+ van Roij J, Raijmakers N, Ham L, et al. Quality of life and quality of care as experienced by patients with advanced cancer and their relatives: A multicentre observational cohort study (eQuiPe). Eur J Cancer 2022; 165: 125-135. 2022/03/03. DOI: 10.1016/j.ejca.2022.01.039.
+ Zhu Y, Pei X, Chen X, et al. Family Caregivers' Experiences of Caring for Advanced Cancer Patients: A Qualitative Systematic Review and Meta-synthesis. Cancer Nurs 2022; 46: 270-283. DOI: 10.1097/NCC.0000000000001104.
+ Berry LL, Dalwadi SM and Jacobson JO. Supporting the supporters: What family caregivers need to care for a loved one with cancer. Journal of oncology practice 2017; 13: 35-41.
+ Dang S, Looijmans A, Ferraris G, et al. Exploring the Needs of Spousal, Adult Child, and Adult Sibling Informal Caregivers: A Mixed-Method Systematic Review. Front Psychol 2022; 13: 832974. 2022/04/12. DOI: 10.3389/fpsyg.2022.832974.
+ Movisie and Vilans. SOFA-model: samenwerken met mantelzorgers, (2021). -> This model is an interesting addition to the role of relatives as care provider that is usually the main focus of attention for relatives of patients.

– p. 10, l. 300–301: In my opinion, including bereaved relatives of cancer patients who received euthanasia, cannot 'make up' for a lack of included patients with terminal conditions, as relatives cannot give in-depth insight in the needs of these patients.
– p. 10, l. 314–319: the "Diamond model" by Prof.dr. C. Leget may be interesting in this regard.

GENERAL REMARK

I was wondering if the authors are familiar with the Dutch book "Leven met euthanasie" by Theo Boer, Stef Groenewoud en Wouter de Jonge. In the accounts of relatives described in this book, being engaged in the process and having enough time to process and making sense of the patient's desire for MAID, is one of the main findings.
It makes me wonder if a thematic analysis of only the relatives data from your study would result in a theme revolving around engagement and time, as patients often only explicate their wish for MAID after they completed a journey in their mind, without engaging their relatives in this. Thus, for relatives this request often comes out of the blue and for them, the MAID trajectory can feel as "too fast" as they are 'behind' in the mental process. The second quote in Table 3 seems to illustrate this experience.

PLEASE COMMENT

Q 4   Is the title appropriate, concise, attractive?

The phrase "their relatives" suggests that the relatives of the interviewed patients were also interviewed, which does not seem to be the case. However, I can't think of a title tackling this problem while still being as concise as possible.

Q 5   Are the keywords appropriate?

Yes, if only 5 key words are allowed. However, as "patients and relative" is already part of the title, using other key words such as "family caregivers" and "euthanasia" of "physician-assisted suicide" may enhance the findability of the article.
The Dutch word "naasten" is often translated as "family caregivers", even if these persons are not providing actual care to the patient.

Q 6   Is the English language of sufficient quality?

Yes, although the journal editor may be able to correct a few small things in the main text and the quotations.

Q 7   Is the quality of the figures and tables satisfactory?

Yes.

Q 8   Does the reference list cover the relevant literature adequately and in an unbiased manner?)

Yes.

QUALITY ASSESSMENT

Q 9   Originality

Q 10   Rigor

Q 11   Significance to the field

Q 12	Interest to a general audience
Q 13	Quality of the writing
Q 14	Overall scientific quality of the study

| **Q 15** | Please make a recommendation based on your comments: |

Major revisions.