Author’s response to reviews

Title: Balancing the struggle to live with dementia: A systematic meta-synthesis of coping

Authors:
Guro Bjørkløf (guro.bjorklof@aldringoghelse.no)
Anne-Sofie Helvik (anne-sofie.helvik@ntnu.no)
Tanja Ibsen (tanja.ibsen@aldringoghelse.no)
Elisabeth Telenius (elisabeth.w.telenius@aldringoghelse.no)
Ellen Grov (ellgro@oslomet.no)
Siren Eriksen (siren.eriksen@aldringoghelse.no)

Version: 2 Date: 21 Jun 2019

Author’s response to reviews:

We would like to thank the editor and all the referees for constructive comments and advices.

A description of changes of the manuscript are shown below and is also added in a separate file.

Yours sincerely

Prof. Siren Eriksen

FOLLOWING CHANGES HAVE BEEN DONE AS RECOMMENDED:

I have some minor and some major comments, which might improve the manuscript.

1. Abstract

P.2 line 29 and line 34: The authors assessed 83 articles but included 74 in the meta-synthesis. The difference in numbers needs an explanation.

We did read 163 full text articles. Of those, eighty were excluded due to the exclusion criteria. We assessed the remaining eighty-three using the nine objective criteria of CASP in which nine
articles were excluded due to low quality and seventy-four were included. The explanation has been changed and clarified in the abstract.

P. 2 line 30: The authors are requested to describe how they synthesized their findings. We changed the sentence to “The analysis was conducted in line with qualitative content analysis”. The topic is further described under the method section in the article.

P.2 line 50: The authors concluded that people with dementia cope in different ways and use several strategies. Implications for healthcare professionals and decision makers must be added.

A sentence has been added to the abstract: “This insight is essential in dementia care to facilitate a supportive environment”. The topic is further described in the Discussion-section.

2. Background

P. 3 line 11-13: Please correct the writing of "…, The World Health… and The Norwegian…”

The required corrections have been made.

P.3 line 16: The term "right treatment" is difficult to understand. Person-centered care aims to provide "individual treatment", which should be highlighted here.

We agree that the term “right treatment” is not a good term to use and we have changed it into “appropriate treatment”. We agree that person-centered care /Individual care is essential but believe that the last part of the sentence describes this argument.

New:

Thus, in providing the appropriate treatment and support in accordance to people with dementia’s own needs and fundamental human rights, knowledge about how people with dementia experience and cope with their current and future life-situation is fundamental.

P.3 line 54: A short description should be added about what "a global coping response" means.

An explanation has been added.

New: A global coping response is defined as a response in acute and severe stress, where you use: “combinations of almost all of the problem-focused and emotion-focused coping strategies at every stage of the exam, indicating the use of a substantial global coping response.”[17, p. 949].

P.4 line 1: Target groups of this meta-synthesis are healthcare professionals and decision makers. However, the subject will be important for informal carers of people with dementia, too. Therefore, I suggest adding informal carers as a further target group.
We agree. The term “informal carers” has been added to the sentence.

New:

A review of the scientific literature on coping and dementia is therefore warranted and can help to advice and inform healthcare personnel and decision makers on how they can support and plan for appropriate healthcare services for people with dementia. In addition, informal carers may find such synthesized knowledge helpful to facilitate for their family member with dementia.

3. Methods

P. 4 line 10: The design must be described with only a few sentences.

A sentence describing design has been added.

New:

An interpretative qualitative meta-synthesis was conducted [21, 22]. The review includes cross-sectional and longitudinal qualitative interview-studies describing coping in different ways.

P.4 line 29: The correct term of the database PsycINFO must be used (https://www.apa.org/pubs/databases/psycinfo). A correction is also needed in the abstract section.

The correction has been made throughout the whole manuscript.

P.4 line 53: Correction is needed for "…and (3) The paper…".

The correction has been made.

P.5 line 2: The CASP checklist includes 10 questions (https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf). The authors excluded question 10: "How valuable is the research?" Reasons should be given because this question is important with regard to issues of external validity of the included studies.

This is an interesting comment and we agree that this part needs a further explanation. For this review we have chosen to use the nine criteria assessing the quality of the structure and the objective elements of the articles. The last and 10th question has not been included, as this question of the value of the research and the article for the society, including external validity, includes a subjective appraisal. Our main concern was to find moderate and high methodological quality describing the experience of coping in different ways that we could use. We have added some changes in the manuscript.

New in “Assessment of the quality of the studies”: 
We used the following nine criteria of CASP appraisal: (1) a clear statement of aims; (2) appropriate choice of the method; (3) appropriate research design; (4) congruence between the recruitment strategy, aims and research; (5) the data collection method addresses the research issue; (6) a relationship between the researcher and the participant was considered; (7) ethical issues were considered; (8) the process of data analysis was sufficiently rigorous; and (9) a clear statement of the findings.

New in “Strengths and limitations”:

The CASP criteria for qualitative studies consist of ten questions in which we have chosen to use the first nine. These nine criteria are assessing the quality of the structure and the objective elements of the articles. The last and 10th question has not been included, as this has a subjective appraisal of the value of the research and the importance of the particular article with its scope for the society. Thus, this 10th question is important for the external validity of the single studies in their original form. However, we used CASP to include studies with sound methodological approach describing experience of coping in different ways. This said, CASP’s 10th question have high importance for a regular quality assessment and a broad description of quality of studies.

P.5 line 19: The number of studies needs checking. The authors reported 83 reviewed studies, and that they excluded seven studies for low quality issues. The meta-synthesis included 74 studies. Table 1 includes 75 studies. In table 1

As described earlier, we did read 163 full text articles. Of those, eighty were excluded due to the exclusion criteria. The remaining eighty-three were assessed using the nine objective criteria of CASP in which nine articles were excluded due to low quality and seventy-four were included.

The explanation has been changed and hopefully clarified.

As far as we understand, table 1 do consist of the 74 included articles.

P.6 line 9: The authors described as the first analytic step the reading and analyzing of one-third of the papers. Please explain whether the categories were derived from this one-third of the papers. I wonder how the authors handled aspects of coping in the remaining two-thirds of the papers, which did not fit in the four categories?

Pair of authors read all the seventy-four articles and descriptions of coping from all included articles were extracted into meaning units. The extraction of meaning units were conducted by TLI and SE in cooperation.

New:

In the first step, at least two of the authors (TLI, EKG, EWT, SE) read all the seventy-four papers. Results from the papers related to coping, were extracted as direct citations into
“meaning units” (TLI and SE); a form created for further analysis [99].

4. Results

P.6 line 31-60: References must be added.

References are added.

P.7 line 28: The identified latent theme "Balancing the struggle of living with dementia" should be added here.

We can see that the identified latent theme could have been added here, but due to the method chosen for this research and the logical structure of our article, we prefer to end our Result-section with describing the latent theme.

P.9 line 1-12: This category accepting the situation has only one subcategory, i.e. position in life. Social and emotional support was described as one of the two main coping resources (P.7 line 7). What was reported within the studies about the use of social and emotional support by people with dementia to accept the situation? Who helps the people with dementia to accept their situation?

This is indeed interesting questions. Unfortunately, our data material did not report the influence of other people in relation to accepting the situation. Accepting the situation was more an individual attitude and choice. Most of the studies described family members as the most important relations due to social and emotional support. But some studies also emphasized friendship and relation to others.

Which strategies are useful? Answers to these questions are important results, because healthcare professionals and decision makers must improve their understanding of successful strategies to support people with dementia.

We agree that the understanding of successful strategies could be of importance, but for this article, we did not consider whether the different strategies were useful or not. The aim of our work was to describe the strategies used. Furthermore, it could for most of the descriptions be difficult to judge whether the strategies were successful or not to reduce stress

P.9 line 20: A reference must be added to the quotation "the end of the world".

The reference is Tolhurst & Weicht, 2017 and has been added.

P.9 line 30-46: The category Avoiding the situation has two subcategories, i.e. Direct avoiding strategies and Indirect avoiding strategies. It is difficult to see a clear distinction of these two
subcategories. Maybe it is important to differentiate the avoiding strategies; however, there is a need for explanation.

The category Avoiding the situation has been rewritten

New: Avoiding the situation

People with dementia may experience challenging situations in which they feel unskilled or inadequate due to the cognitive decline. In addition, having a diagnosis of dementia and experience the condition develop can be stressful and threatening to the experience of security and sense of self. Coping by trying to avoid stressful situations could concern an active resistance to adaption, change or to accepting help because this may imply accepting dementia and the progression of the symptoms over again. The person with dementia can use strategies that actively redirects focus or refrain from the exposed situations. For instance, this by changing subject in a conversation or avoiding situations by using distractions such as being active, keeping occupied or compensate. The focus is less on handling a “threat” that emerges, but more on keeping a distance and avoiding it in advance. This can include not thinking and talking about the future, withdrawal and not taking initiative because this could mean being exposed as cognitively impaired.

P.9 line 52- P.10 line 7: The latent theme Balancing the struggle of living with dementia can be enhanced by including aspects of the identified main resources Humour and Social and emotional support.

We have included the aspects of humour end social and emotional support.

New: Balancing the struggle to live with dementia:

The four categories of strategies presented in the material do not necessarily follow each other in a linear process of coping ending in acceptance of the situation. Instead, they should be seen as potential strategies when meeting challenges and stress following dementia. The participants reported using several strategies at the same time and they employed different strategies depending on appraisals of the demands from the situation they encountered. Hence, the choice of strategies will be influenced by not only available resources of coping, but also the situation and context, and several strategies can be used for the same situation and challenge. The coping process and the four strategies described by people with dementia can be summed up in the overall theme balancing the struggle of living with dementia.

5. Discussion

The section needs a discussion about the influence of the main coping resources Humour and Social and emotional support on the coping strategies and capabilities of people with dementia.
This is an interesting topic, but the material does not answer how the resources influence the coping strategies. Instead, we have emphasized the topic theoretically. See the rewritten discussion.

P.10 line 27-42: These are results, which should be part of the Results section.

Yes, we agree that this topic should be mentioned in the Result section.

New Coping with dementia (Results):

It is interesting to note that only two of the 74 included studies explicitly aimed to explore coping [18; 45].

New Discussion:

The two studies in our data material explicitly exploring coping in people with dementia had different perspectives. Frazer et al. [45] studied how women who live alone with dementia cope in their everyday lives. They found that their participants were actively engaged in reconstructing their sense of self, using a variety of coping strategies. Sharp [18] described how people with dementia cope with the stress they experienced. The author highlighted the topic of learning to do things differently and establishing coping strategies that provide control. Her participants described individual potential for adapting and coping with the stressful aspects of living with dementia. Even though the two papers do not present their interview guides, there are reason to believe that the participants have been asked to describe their ways of coping.

P.10 line 50-52: The authors stated that their findings describe problem- and emotion-focused coping strategies. It should be discussed whether the categories Keep going and holding on to life as usual and Adapting and adjusting to demands from the situation are coping strategies that are more problem-focused, and whether the other two categories are more emotion-focused strategies. It should be discussed why it is important for professionals and decision makers (and informal carers) to consider the different needs regarding problem-focused aspects and emotion-focused aspects of coping in living with dementia.

A more thorough discussion of these aspects is implemented now. We have made changes throughout the whole Discussion-section.

6. Limitation

P.12 line 8: The limitation section should include the modified application changed use of the original CASP checklist.

A description of the use of CASP has been added to the Strengths and limitation-section.
New:

The CASP criteria for qualitative studies consist of ten questions in which we have chosen to the first nine. These nine criteria are assessing the quality of the structure and the objective elements of the articles. The last and 10th question has not been considered as this is a subjective appraisal of the value of the research and this particular article as a whole. This 10th question could be seen as important for the external validity of single study as a whole. This said, in our review we used parts of the articles describing the experience of coping and we re-analyzed and synthesized the material. We do agree that a broader description of context could have strengthened the review.

7. Conclusion

This section needs major revision, because this is a short summary of the findings, but not a conclusion with a clear take-home message for readers.

The Conclusion-section has been rewritten.

References

4. Livingstone et al.: There is an error in the title of this paper.

The error has been corrected.

Table 1: Authors should check the headings.

The errors have been corrected.

Table 2: This table includes 74 studies, but table 3 includes 75 studies.

To our concern there are 74 studies included in both tables.

Table 3: This table includes sociodemographic information for some studies. The information can be removed with the exception of the information regarding the cognitive status because the authors mentioned these aspects in the result section, and it seems to be an important influencing factor regarding the abilities of people with dementia to communicate their coping strategies.

In this table we have been true to the information presented in each study. Transparency has been an important principle strengthening the external validity of the present study.

New Table 3.

*Sociodemographic information is described for those studies presenting such information.*
Table 4: The category Social and emotional support includes reference 93, but this was not part of the Condensed meaning units. Reference 98 is included in the Condensed meaning units, but this is not part of the first category mentioned above. The reference should be 93 (not 98) and has been corrected.

Richard Fortinsky (Reviewer 2): Strengths of this paper include the importance of the topic, a thorough presentation of all articles included in the systematic review, the methodology which adhered quite well to the PRISMA criteria, and conclusions that were adequately supported by the qualitative analysis.

Several limitations or inadequate explanations are notable:

1. In the methods section, it is unclear what is meant by "pure sample" of persons living with dementia. Does this refer to the type of dementia or to something regarding the sampling procedures used in the studies reviewed?

   The description of selection has been clarified.

   New: The 164 articles were read in full text and included according the following inclusion criteria: (1) the sample consist of people with dementia only (..)

2. Among exclusion criteria, "mixed sample" was mentioned. It is unclear what this term refers to, so this must be further elaborated.

   The sample consisting of people with dementia only and not people with for instance MCI, probably dementia, Huntington disease or other cognitive impairment.

   New: Exclusion criteria: (1) dementia was described as probable or possible; (2) it was a mixed sample with people with dementia and people with other diagnosis (..)

3. In the section on data abstraction, it is noted that pairs of authors each read and reread one-third of papers. It is unclear how many total authors were engaged in the article reviews, and also why pairs of authors read only a portion of the articles. This section requires greater elaboration and clarification to fully understand the article review process.
Pair of authors read all the seventy-four articles and descriptions of coping from all included articles were extracted into meaning units. The extraction of meaning units were conducted by TLI and SE in cooperation.

New:

In the first step, at least two of the authors (TLI, EKG, EWT, SE) read all the seventy-four papers. Results from the papers related to coping, were extracted as direct citations into “meaning units” (TLI and SE); a form created for further analysis [99].

4. In the results section, different numbers of articles reviewed are mentioned than in the section on assessment of the quality of studies. The true number must be reconciled and used consistently wherever mentioned in the paper.

We did read 163 full text articles. Of those, eighty were excluded due to the exclusion criteria. We assessed the remaining eighty-three using the nine objective criteria of CASP in which nine articles were excluded due to low quality and seventy-four were included. The explanation has been changed and clarified in result section.

5. The data abstraction and synthesis section is quite cursory and provides only a sketch of the steps in this process. Greater elaboration of each step would help strengthen the paper by explaining the multi-step process of data synthesis.

Each step of the analysis process has been further elaborated.

New:

In the first step, at least two of the authors (TLI, EKG, EWT, SE) read all the seventy-four papers. Results from the papers describing coping, were extracted as direct citations into “meaning units” (TLI and SE); a form created for further analysis [99]. In the second step, meaning units were condensed (TLI and SE) and controlled (ASH). This is a process were the content of the direct citation is being extracted using the meaning units own language. We then labelled the condensed meaning units with codes in order to organize the material (GHB and ASH). The third step consisted of comparing codes, identifying similarities and differences in order to structure and gather the codes into subcategories (all authors). In the fourth step, the eight subcategories identified through this process were ultimately gathered into four categories with subcategories presenting the manifest meaning of the material. Finally, in the fifth step, the comprehensive understanding phase, we summarized and reflected upon the results consisting of resources and strategies, in order to reach a presentation of the text as one overall latent theme [99].
6. Given that some studies included persons with dementia living in private homes and others included persons living in nursing homes or other care facilities, the paper would be strengthened by drawing comparisons between strategies used by persons living in each type of setting. For example, was humor used more commonly in one setting or the other, and what this might mean for potential interventions to help persons with dementia live better lives in the settings where they reside.

We agree. This is a very interesting topic, but the material does not provide possibilities for comparisons between strategies used by persons living in each type of setting.

7. Even though the number of studies that were longitudinal was quite small, any evaluation of changes over time in strategies would make a new contribution to the literature. Authors should consider commenting on themes found regarding changes over time if at all possible.

We agree, this is a very interesting topic, but the material does not provide possibilities for evaluating changes over time.