

## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Do chronic heart failure symptoms interact with burden of treatment? Qualitative literature systematic review.
<b>AUTHORS</b>	Austin, Rosalynn; Schoonhoven, Lisette; Clancy, Mike; Richardson, Alison; Kalra, Paul R; May, Carl

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Ellen Hummel University of Michigan , Palliative Care Program
<b>REVIEW RETURNED</b>	04-Jan-2021

<b>GENERAL COMMENTS</b>	<p>For this review article, the authors performed a mixed-method content analysis based on Burden of treatment (BoT) theory to systematically examine all relevant published qualitative studies to determine whether or not symptoms in CHF interact with BoT. After systematically reviewing 35 salient articles, they found that CHF symptoms impact BoT by increasing illness workload and decreasing patient capacity to perform treatment related tasks. For approximately 90% of the patients in these studies, CHF symptoms formed a barrier to or impeded patient engagement in self-care. This important review article points to an association between CHF symptoms and BoT that should be further investigated, especially given the current emphasis in CHF treatment on patient self-management. It also explores the many and far reaching ways that CHF symptoms negatively impact BoT, pointing for possible areas of future intervention. One of the implications is that it may be possible that decreasing CHF symptom burden may improve treatment engagement and adherence, although this needs to be looked at in further studies.</p>
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<b>REVIEWER</b>	Maddi Olano-Lizarraga University of Navarra, School of Nursing
<b>REVIEW RETURNED</b>	22-Jan-2021

<b>GENERAL COMMENTS</b>	<p>Thank you very much for giving me the opportunity to review this interesting article. It addresses an interesting topic that could have important implications for the care of people with CHF. However, the article requires several modifications to improve its clarity and coherence.</p> <ol style="list-style-type: none"> <li>1. The abstract should be revised. In particular, I recommend structuring the results section better, based on the structure of the results presented in the manuscript.</li> <li>2. I consider that, being the Burden of treatment (BoT) theory the conceptual framework of this study, you should better justify the choice of it, what are its origins, what is its objective and in what</li> </ol>
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contexts it has been applied so far. As well as a brief explanation of the Sankey diagram in Figure 3.

3. The authors state that they have conducted a review of qualitative research studies. As such, and taking into account the nature of qualitative studies, the analysis in this paper is striking. The application of the Thomas & Harden guide is very timely; however, I believe that to quantify exactly how many times the term "symptom" is mentioned and to base much of the analysis on this numerical quantification may be too rigid as well as superficial. As the authors will be aware, in qualitative research, the meaning of words is more important than the number of times they are used. Within the studies reviewed, there may be sentences or quotes that make direct reference to the impact of these symptoms on patients' lives, without explicitly mentioning that word. I consider it important that the authors clarify why they decided to conduct the analysis in this way and how they have controlled for this possible limitation.

4. I consider that the appendices they present on the Literature Synthesis Search strategies are very unclear. However, they should include a figure/table showing the combination of the search keywords and how they have been combined with the Booleans. This is of interest, as it may give more clarity to the process by showing the essence of the searches performed. On the other hand, it is striking, how the authors have not identified certain literature that matches the described search, as is the case of:

Jeon YH, Kraus SG, Jowsey T & Glasgow NJ (2010) The experience of living with chronic heart failure: a narrative review of qualitative studies. *BioMed Central Health Services Research* 10, 1-9.

Yu DSF, Lee DTF, Kwong ANT, Thompson DR & Woo J (2008) Living with chronic heart failure: a review of qualitative studies of older people. *Journal of Advanced Nursing* 61, 474-483.

Rodriguez KL, Appelt CJ, Switzer GE, Sonel AF & Arnold RM (2008) "They diagnosed bad heart": a qualitative exploration of patients' knowledge about and experiences with heart failure. *Heart and Lung* 37, 257-265.

Thornhill K, Lyons AC, Nouwen A & Lip GYH (2008) Experiences of living with congestive heart failure: a qualitative study. *British Journal of Health Psychology* 13, 155-175.

Olano-Lizarraga, M., Orovioigoicoechea, C., Errasti-Ibarrondo, B., & Saracíbar-Razquin, M. (2016). The personal experience of living with chronic heart failure: A qualitative metasynthesis of the literature. *Journal of Clinical Nursing*, 25(17-18), 2413-2429.

5. You should make the selection criteria more explicit. I recommend that you attach them in a table or if there are already too many tables/figures, describe them better in the manuscript.

6. In figure 1 the "P" for PRISMA is missing.

7. I think figure 4 is not relevant and could be deleted.

	<p>8. In the discussion section, there is little comparison with the rest of the published literature on the topic. The similarities and differences with respect to previous literature should be presented in greater depth.</p> <p>9. The results of this study are very directly related to practice. Therefore, the implications section should present this aspect more concretely.</p>
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**VERSION 1 – AUTHOR RESPONSE**

Reviewer: 1

Dr. Ellen Hummel, University of Michigan

Comments to the Author:

For this review article, the authors performed a mixed-method content analysis based on Burden of treatment (BoT) theory to systematically examine all relevant published qualitative studies to determine whether or not symptoms in CHF interact with BoT. After systematically reviewing 35 salient articles, they found that CHF symptoms impact BoT by increasing illness workload and decreasing patient capacity to perform treatment related tasks. For approximately 90% of the patients in these studies, CHF symptoms formed a barrier to or impeded patient engagement in self-care. This important review article points to an association between CHF symptoms and BoT that should be further investigated, especially given the current emphasis in CHF treatment on patient self-management. It also explores the many and far reaching ways that CHF symptoms negatively impact BoT, pointing for possible areas of future intervention. One of the implications is that it may be possible that decreasing CHF symptom burden may improve treatment engagement and adherence, although this needs to be looked at in further studies.

*Thank you for your kind comments. We too are excited by these findings as like you suggested it points to possible areas for future interventions. We are in the process of analysing the results of our empirical study that explores this relationship and look forward to sharing more of our research with you.*

Reviewer: 2

Dr. Maddi Olano-Lizarraga, University of Navarra

Comments to the Author:

Thank you very much for giving me the opportunity to review this interesting article. It addresses an interesting topic that could have important implications for the care of people with CHF. However, the article requires several modifications to improve its clarity and coherence.

*Thank you for your kind comments. We have answered all your questions below.*

1. The abstract should be revised. In particular, I recommend structuring the results section better, based on the structure of the results presented in the manuscript.

*Thank you for highlighting this inconsistency. We have reframed the abstract to match the structure of the results section in the manuscript.*

2. I consider that, being the Burden of treatment (BoT) theory the conceptual framework of this study, you should better justify the choice of it, what are its origins, what is its objective and in what contexts it has been applied so far.

*Justification for the choice of conceptual framework has now been updated (page3). The origins of this thinking was outlined in a previous paper which we have referenced in this work. Highlighting the context in which BoT has been applied is not the purpose of this article. However, some of such work was highlighted in the discussion of this paper and includes work in lung cancer, COPD, chronic kidney disease, and other chronic illnesses.*

As well as a brief explanation of the Sankey diagram in Figure 3.

*A sentence explaining Sankey diagrams was added in the methods section (page 5).*

3. The authors state that they have conducted a review of qualitative research studies. As such, and taking into account the nature of qualitative studies, the analysis in this paper is striking. The application of the Thomas & Harden guide is very timely; however, I believe that to quantify exactly how many times the term "symptom" is mentioned and to base much of the analysis on this numerical quantification may be too rigid as well as superficial. As the authors will be aware, in qualitative research, the meaning of words is more important than the number of times they are used. Within the studies reviewed, there may be sentences or quotes that make direct reference to the impact of these symptoms on patients' lives, without explicitly mentioning that word. I consider it important that the authors clarify why they decided to conduct the analysis in this way and how they have controlled for this possible limitation.

*The work presented is secondary analysis of published primary quantitative research, it was important to demonstrate that the key features of the phenomena identified in this work are in fact typical of the literature. Thus, we chose to use a mixed methods approach as this facilitated including simple descriptive counts to highlight the frequency and consistency of these features. We argue that using the simple counts around the coding, in addition to the more thorough qualitative analysis reassures the reader that we have established that the new phenomena we present is representative of the included articles.*

4. I consider that the appendices they present on the Literature Synthesis Search strategies are very unclear. However, they should include a figure/table showing the combination of the search keywords and how they have been combined with the Booleans. This is of interest, as it may give more clarity to the process by showing the essence of the searches performed.

*The full search strategies were presented in Supplemental Material 1, as requested by the PRISMA reporting guidelines. The full strategies for each database searched was provided including all keywords and Booleans. Further the search strategies were adapted from previously published work outlining these strategies which was referenced.*

On the other hand, it is striking, how the authors have not identified certain literature that matches the described search, as is the case of:

Jeon YH, Kraus SG, Jowsey T & Glasgow NJ (2010) The experience of living with chronic heart failure: a narrative review of qualitative studies. *BioMed Central Health Services Research* 10, 1-9.

*Review article (not eligible—review paper), was returned in search but excluded. Relevant conclusions from this article have been cited within the discussion.*

Yu DSF, Lee DTF, Kwong ANT, Thompson DR & Woo J (2008) Living with chronic heart failure: a review of qualitative studies of older people. *Journal of Advanced Nursing* 61, 474-483.

*Review article (not eligible—review paper), was returned in search but excluded. Relevant conclusions from this article have been cited within the discussion.*

Rodriguez KL, Appelt CJ, Switzer GE, Sonel AF & Arnold RM (2008) "They diagnosed bad heart": a qualitative exploration of patients' knowledge about and experiences with heart failure. *Heart and Lung* 37, 257-265.

*Returned in search but was excluded as was not about general experience of living with heart failure. Focus of this paper was on communication between patients and healthcare professionals. Thank you for highlighting this article, we have re-read the work. Main themes were: Diagnostic process, self-monitoring/ self-care, treatments, and advanced planning (end-of-life). Depending on a reader's interpretation I can understand why reviewer 2 has highlighted it as on reflection I can see how it could be included. However, as the focus of the article is primarily on healthcare interactions rather than the patients experience in general, it was excluded. Retrospectively, we argue if it was included, it wouldn't have changed the results of our work. The data that would have been extracted fits in with existing conclusions. Relevant conclusions from this article have been cited within the discussion.*

Thornhill K, Lyons AC, Nouwen A & Lip GYH (2008) Experiences of living with congestive heart failure: a qualitative study. *British Journal of Health Psychology* 13, 155–175.

*Returned in search but was excluded as was not about general experience of living with heart failure. Focus of article was on diagnostic process, changes after diagnosis, and role of others in adjusting to life with chronic illness. Thank you for highlighting this article, we have re-read the work. Focus of this work was around beliefs, impact on everyday life, impact on perceptions of the future, and of others (family, friends, and healthcare providers), as well as beliefs about causes of heart failure. As such we did not feel that the work fit within the eligibility criteria of "descriptions of living with, and managing, CHF from the patient perspective" as it centred around participant thoughts and beliefs rather than the practical day to day management. Like the above article, it could be argued that this is the interpretation of the reader. Retrospectively I can see how it could be included, but the main data that we would have extracted again wouldn't change our conclusions. However, it is mainly focused on the "impact" of the illness not the day to day living with HF thus we argue that it remains as excluded.*

Olano-Lizarraga, M., Oroviogicoechea, C., Errasti-Ibarrondo, B., & Saracíbar-Razquin, M. (2016). The personal experience of living with chronic heart failure: A qualitative metasynthesis of the literature. *Journal of Clinical Nursing*, 25(17-18), 2413-2429.

*Review article (not eligible—review paper), was returned in search but excluded. Relevant conclusions from this article have been cited within the discussion.*

5. You should make the selection criteria more explicit. I recommend that you attach them in a table or if there are already too many tables/figures, describe them better in the manuscript.

*Added a table to make eligibility criteria more explicit, as well as minor changes within the manuscript. Table numbers have been adjusted.*

6. In figure 1 the "P" for PRISMA is missing.

*Thank you for highlighting, this typographical error has now been fixed.*

7. I think figure 4 is not relevant and could be deleted.

*We believe figure 4 is relevant as it highlights the strength of the metaphors used by participants (from original articles) to describe the intense nature of the interaction between symptoms and the various aspects of the BoT framework and self-care. We feel that this is important as it illustrates the depth of the symptoms impact from patients' perspective on how symptoms form a barrier to*

*engagement with desired and required self-care activities. We note that Reviewer 1 did not share Reviewer 2's view that this was irrelevant.*

8. In the discussion section, there is little comparison with the rest of the published literature on the topic. The similarities and differences with respect to previous literature should be presented in greater depth.

*Thank your for highlighting this. Some of the above-mentioned review papers along with other key review papers have now been added to the discussion adding greater depth to the discussion and demonstrating the original findings of our work.*

9. The results of this study are very directly related to practice. Therefore, the implications section should present this aspect more concretely.

*Thank you for highlighting this, edits have been made within the conclusion and clinical implications section which hopefully highlights the relation of the study results to clinical practice.*

#### **VERSION 2 – REVIEW**

<b>REVIEWER</b>	Maddi Olano-Lizarraga University of Navarra, School of Nursing
<b>REVIEW RETURNED</b>	17-May-2021
<b>GENERAL COMMENTS</b>	would like to congratulate the authors for the work they have done in making the requested changes. I believe that the authors have responded to all the comments suggested.