

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Chronic Heart Failure Patients' Experiences of German Health-Care Services: A Protocol for a Scoping Review
AUTHORS	Dieckelmann, Mirjam; Reinhardt, Felix; Jeitler, Klaus; Semlitsch, Thomas; Plath, Jasper; Gerlach, Ferdinand; Siebenhofer, Andrea; Petersen, Juliana J.

VERSION 1 – REVIEW

REVIEWER	Dr Rachel Stocker Newcastle University, UK
REVIEW RETURNED	27-Sep-2018

GENERAL COMMENTS	<p>Thank you for the opportunity to review this study protocol. I think it is of interest to your readership and recommend publication subject to minor changes, which I have summarised below.</p> <p>The authors state that experience of CHF in a German context has not been studied systematically (page 3, line 12). I am not sure what this means – does this mean that a review of the evidence has not been conducted, or that the evidence is not available? I would also recommend that the authors consider which aspects of health services in other countries could be applicable to CHF experiences in Germany – whilst the setup is undoubtedly different, symptom profiles will mostly be similar.</p> <p>The methods appear to be comprehensive and the databases to be searched make sense for the research question. I cannot see dates for the study (e.g. start date) – please add.</p> <p>I note that the authors are to exclude papers which report patient experience from the view of other parties such as carers (page 7 lines 29-32). May I suggest either re-considering this or strengthening the rationale for this decision? Carers, such as spousal carers, are often instrumental in managing patient access to health care, and patient experience is very much influenced by the role of any carer in their life, particularly towards end of life when patients access health services more frequently. (See [1])</p> <p>The strengths and limitations section state that a patient representative will be involved in developing the research questions. But the research questions are presented on page 6. Please clarify. I also do not feel that the final bullet point in this section (non-research sources of information) is necessary, as these sources would not normally be included in such a review anyway.</p> <p>Typing errors: Page 3 line 27</p>
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	[1] Stocker R, Close H, Hancock H, et al. Should heart failure be regarded as a terminal illness requiring palliative care? A study of heart failure patients', carers' and clinicians' understanding of heart failure prognosis and its management. BMJ Supportive & Palliative Care 2017;7:464-469.
REVIEWER	Karin Hellström Ångerud Department of Nursing, Umeå University, Sweden
REVIEW RETURNED	19-Oct-2018
GENERAL COMMENTS	<p>This protocol for a scoping review addresses an interesting and important subject and it is well written, but, some revision would be necessary to overcome some weaknesses. People with heart failure have frequent contacts with different health care services. Patients' experiences are important to provide improvements in quality of care, not least because health care professionals' and patients' perceptions of quality might differ. Research in this area is sparse and this scoping review will contribute to the existing knowledge.</p> <p>Comments on the protocol:</p> <p>Throughout the manuscript, both heart failure and CHF are used. A consistent use of one of these should be applied.</p> <p>References 8 and 11 are in German and incomplete. Can they be replaced by references in English and/or are there URLs to add? A description of how the search in different databases will be performed needs to be developed in the section "# 2 Identifying relevant studies". A search strategy for this scoping review with keywords, MESH terms, filters and limits should be added (as appendix in supplementary file).</p> <p>Comment on ethical approval is missing in the ethics section. If ethical approval is not required, it should be mentioned in the ethics section.</p>

VERSION 1 – AUTHOR RESPONSE

REVIEWER 1

Reviewer Name: Dr Rachel Stocker

Institution and Country: Newcastle University, UK

1.1 Thank you for the opportunity to review this study protocol. I think it is of interest to your readership and recommend publication subject to minor changes, which I have summarised below.

Thank you very much for your detailed review. Your helpful comments are very much appreciated.

1.2 The authors state that experience of CHF in a German context has not been studied systematically (page 3, line 12). I am not sure what this means – does this mean that a review of the evidence has not been conducted, or that the evidence is not available?

We intended to say that to the best of our knowledge a systematic review on the topic has never been conducted. As the sentence you mentioned is not precise enough, we have now changed the wording to clarify this (page 2, line 8).

1.3 I would also recommend that the authors consider which aspects of health services in other countries could be applicable to CHF experiences in Germany – whilst the setup is undoubtedly different, symptom profiles will mostly be similar.

Thank you for your valuable recommendation. In response to your comment, we have added a paragraph (page 6, lines 36-40) in which we explain how we intend to categorize different health care services. Based on this categorization, comparability of different countries' health services will be facilitated

1.4 The methods appear to be comprehensive and the databases to be searched make sense for the research question. I cannot see dates for the study (e.g. start date) – please add.

We have added dates of coverage to both the methods section (page 6, lines 6-9) and the supplementary file (line 27).

1.5 I note that the authors are to exclude papers which report patient experience from the view of other parties such as carers (page 7 lines 29-32). May I suggest either re-considering this or strengthening the rationale for this decision? Carers, such as spousal carers, are often instrumental in managing patient access to health care, and patient experience is very much influenced by the role of any carer in their life, particularly towards end of life when patients access health services more frequently. (See Stocker R, Close H, Hancock H, et al. Should heart failure be regarded as a terminal illness requiring palliative care? A study of heart failure patients', carers' and clinicians' understanding of heart failure prognosis and its management. *BMJ Supportive & Palliative Care* 2017;7:464-469.)

As you say, consideration of the (in)formal care environment of patients is crucial to understanding their experiences with health services, especially in - but not limited to - terminally ill patients. We will take this into account by expanding the search to include studies which have reported patient experiences from the perspective of family and friends. We have made a change on page 6, lines 3034 accordingly.

We extensively discussed whether to include studies reporting patient experiences from the point of view of non-patients, as we are only too aware that the opinions of health professionals, as well as informal caregivers and members of patients' social networks, all play a role in shaping patients' experiences of health care services. We would like to emphasize that we will extract information on relationship status in order to catalogue the extent to which individual studies report on a patient's family situation, and describe the influence of close relatives on patient experiences.

However, we decided that for this review we would concentrate primarily on literature that focuses on how patients themselves perceive health service providers, structures and processes, as we consider this to be intrinsically linked with patient-centeredness. We therefore decided to exclude papers describing patients' experiences, as perceived by health professionals and experts, and as expressed

in routine data. Since perceptions are largely subjective in nature, the character of these experiences may be distorted if they are seen through the glasses of professional third parties. This may not affect factual experiences much, but the emotional and relational dimensions of patient experience may be more prone to bias if reported by them.

1.6 The strengths and limitations section state that a patient representative will be involved in developing the research questions. But the research questions are presented on page 6.

Please clarify.

We are sorry the sentence was misleading. It has now been corrected (page 3, line 9).

1.7 I also do not feel that the final bullet point in this section (non-research sources of information) is necessary, as these sources would not normally be included in such a review anyway.

It has now been removed. However, as we expect substantial study heterogeneity to make it difficult to summarize results, we have now included this factor as a limitation (page 3, lines 13-14).

1.8 Typing errors: Page 3 line 27

Corrected.

REVIEWER 2

Reviewer Name: Karin Hellström Ängerud

Institution and Country: Department of Nursing, Umeå University, Sweden

2.1 This protocol for a scoping review addresses an interesting and important subject and it is well written, but, some revision would be necessary to overcome some weaknesses. People with heart failure have frequent contacts with different health care services. Patients' experiences are important to provide improvements in quality of care, not least because health care professionals' and patients' perceptions of quality might differ. Research in this area is sparse and this scoping review will contribute to the existing knowledge.

Thank you very much for your detailed review. Your helpful comments are very much appreciated.

2.2 Throughout the manuscript, both heart failure and CHF are used. A consistent use of one of these should be applied.

Thank you for this important remark, we now use the term chronic heart failure consistently, and whenever possible in its abbreviated form (CHF). This also includes the title of our paper.

2.3 References 8 and 11 are in German and incomplete. Can they be replaced by references in English and/or are there URLs to add?

Reference number 8 refers to the national clinical practice guideline for CHF treatment in Germany. The original document has not been translated into English. However, an official summary has been published in English, which we have now cited along with the original reference (page 11, line 30).

Reference 11 is a press release from Germany's Federal Joint Committee (G-BA), which has unfortunately not been translated into English. Since this is the announcement of a DMP program that has not yet been launched, we could find no better English press release than that of the Federal Joint Committee. However, we have provided URL addresses for the references (page 11, line 39-40), and in response to your important comment, we have added English translations of all German references to the reference section.

2.4 A description of how the search in different databases will be performed needs to be developed in the section “# 2 Identifying relevant studies”. A search strategy for this scoping review with keywords, MESH terms, filters and limits should be added (as appendix in supplementary file).

We have added full search strategies for all databases as supplementary material. As it is also important, we have further mentioned the time span covered by the search and elaborated how it will be performed (page 6, lines 5-9).

2.6 Comment on ethical approval is missing in the ethics section. If ethical approval is not required, it should be mentioned in the ethics section.

We have added this information to the ethics and dissemination section of the main text (page 9, line 25).

VERSION 2 – REVIEW

REVIEWER	Karin Hellström Ångerud Department of Nursing, Umeå University, Sweden
REVIEW RETURNED	16-Dec-2018
GENERAL COMMENTS	My issues were satisfactorily addressed.
REVIEWER	Dr Rachel Stocker Newcastle University, UK
REVIEW RETURNED	17-Dec-2018
GENERAL COMMENTS	Thank you for the opportunity to review this re-submission. I am satisfied that my minor concerns with the paper have been addressed. I recommend accepting this paper.