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Heart Failure Patients' Experiences of German Health-Care Services: A Protocol for a Scoping Review

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025685
Article Type:	Protocol
Date Submitted by the Author:	26-Jul-2018
Complete List of Authors:	Dieckelmann, Mirjam; Goethe-University Frankfurt am Main, Institute of General Practice Reinhardt, Felix; Goethe-University Frankfurt am Main, Institute of General Practice Jeitler, Klaus; Medical University of Graz, Institute of General Practice and Evidence-based Health Services Research Semlitsch, Thomas; Institute of General Practice and Evidence-based Health Services Research, Medical University Graz Plath, Jasper; Goethe-University Frankfurt am Main, Institute of General Practice Gerlach, Ferdinand; Goethe-University Frankfurt am Main, Institute of General Practice Siebenhofer, Andrea; Medical University of Graz, Institute of General Practice and Evidence-based Health Services Research; Goethe-University Frankfurt am Main, Institute of General Practice Petersen, Juliana J.; Goethe-University Frankfurt am Main, Institute of General Practice
Keywords:	PRIMARY CARE, Heart failure < CARDIOLOGY, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, Patients' experience, Scoping review

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Title

Heart Failure Patients' Experiences of German Health-Care Services: A Protocol for a Scoping Review

Corresponding Author

Prof. Dr. med. Andrea Siebenhofer
Institute of General Practice and Evidence-based Health Services Research
Medical University of Graz
Auenbruggerplatz 2/9
8036 Graz, Austria
andrea.siebenhofer@medunigraz.at
Tel.: +43 316 385 73558

First Author

Mirjam Dieckelmann, Institute of General Practice, Goethe-University Frankfurt, Frankfurt, Germany

Co-Authors

Felix-Alexander Reinhardt, Institute of General Practice, Goethe-University Frankfurt, Frankfurt, Germany

Dr. med. univ. Klaus Jeitler, Institute of General Practice and Evidence-based Health Services Research,
Medical University of Graz, Graz, Austria

Mag. rer. nat. Thomas Semlitsch, Institute of General Practice and Evidence-based Health Services Research,
Medical University of Graz, Graz, Austria

Jasper Plath, Institute of General Practice, Goethe-University Frankfurt, Frankfurt, Germany

Prof. Dr. med. Ferdinand M. Gerlach, Institute of General Practice, Goethe-University Frankfurt, Frankfurt,
Germany

Prof. Dr. med. Andrea Siebenhofer, Institute of General Practice and Evidence-based Health Services
Research, Medical University of Graz, Graz, Austria and Institute of General Practice, Goethe-University
Frankfurt, Frankfurt, Germany

Dr. med. Juliana J. Petersen, Institute of General Practice, Goethe-University Frankfurt, Frankfurt, Germany

Abstract

Introduction

Chronic heart failure (CHF) is a heterogeneous condition requiring complex medical treatment from diverse health care services. An increasingly holistic understanding of health care has resulted in contextual factors such as perceived quality of care, as well as patients' acceptance, preferences and subjective expectations of health services, all gaining in importance. How patients with CHF experience the use of health care services has not been studied systematically in a German health care context. The aim of this scoping review is therefore to review systematically the experiences of patients affected by CHF with health care services in Germany in the literature and to map the research foci. Further objectives are to identify gaps in evidence, develop further research questions, and to inform decision-makers concerned with improving health care of patients living with CHF.

Methods and analysis

This scoping review will be based on a broad search strategy involving systematic and comprehensive electronic database searches in MEDLINE, EMBASE, PsycINFO, PSYINDEX, CINAHL and Cochrane's CDSR, grey literature searches, as well as hand searches through references lists and non-indexed key journals. The methodological procedure will be based on an established six-stage framework for conducting scoping reviews that includes two independent reviewers. Data will be systematically extracted, qualitatively and quantitatively analyzed, and summarized in narratively and visually. To ensure the research questions and extracted information are meaningful, a patient representative will also be involved.

Ethics and dissemination

Ethical approval will not be required to conduct this review. Results will be disseminated through a clearly illustrated report that will be part of a wider research project. Furthermore, it is intended that the review's findings should be made available to relevant stakeholders through publication in peer-reviewed journals and presentations at conferences ('knowledge transfer'). Protocol registration in PROSPERO is not applicable for scoping reviews.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This scoping review will be the first to systematically map the past 10 years of research activity surrounding heart failure patients' experiences of using health care services in Germany, and to genuinely explore the consumer perspective
- The research will be limited to Germany but will allow the replication of findings for other health care systems with their specific geographical and institutional health care features
- All health care settings and study designs will be relevant for inclusion in this review to provide an overview of the entire range of German health services
- A patient representative will be involved in developing the research questions and defining the outcome variables to be extracted
- Non-research sources of information on patient experience, such as consumer blogs and social media will not be included in this scoping review

INTRODUCTION

Heart failure is a major chronic condition affecting a growing number of people in Germany, most of whom are older adults.[1] A diagnosis of heart failure (ICD-I50) is the second most common cause of death amongst women and is one of the top four causes of death amongst men in Germany.[2] Due to the bidirectional interplay between somatic and psychosocial factors, patients with heart failure experience both reduced survival and quality of life.[3] Evidence suggests that with increasing severity of clinical symptoms, quality of life decreases disproportionately in hospitalized[4], and primary care patients.[5]

In Germany, approximately € 5.3 billion were spent on treating heart failure in 2015[6]. Having doubled over the past two decades, heart failure is the most common primary reason for hospital admission in Germany [2], and is a major cause of in-hospital mortality.[7]

Both the overall economic burden of the disease and the individual physical, mental and psychosocial impact on heart failure patients' lives mean health services must coordinate their services well if patients' complex health care needs are to be managed effectively and efficiently. However, repeated hospital admissions following acute decompensation are characteristic of patients with CHF and make it difficult for in- and out-patient care sectors to coordinate their activities.[8]

The management of heart failure should be minimally disruptive and involve multidisciplinary health care services, both in formal health care facilities and the patient's environment.[9] The European Society of Cardiology has identified the following as areas in which health care provision can potentially be improved: discharge planning, lifestyle advice, exercise training, follow-up and monitoring, palliative and end-of-life-care as well as self-care in elderly, frail or cognitively impaired heart failure patients.[9]

In modern health care systems, CHF patients find themselves managing their condition both at home and, when seeking help from the confusing range of health care providers and their various services, externally. The burden of treatment may be perceived as challenging as a result of the need to adhere to complex pharmaceutical therapies, manage co-morbidities that interfere with CHF, physically and psychologically cope with symptoms that may severely interfere with everyday life activities, continuously monitor one's own health status, operate technical devices, understand complex disease mechanisms and interact with different health professionals.[10]

To help patients cope with such immense workloads, a disease management program for heart failure patients is scheduled for implementation in Germany in 2018.[11] Against this background, this review's findings may help policy-makers, health care providers and decision-makers concerned with inter- or intra-

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3 sectoral management of care to gain a comprehensive overview of what is known about the individual
4 health care needs of CHF patients and their experiences and satisfaction with the health care they receive in
5 Germany.

6
7 The literature on measuring quality of care suggests that no consensus has yet been reached on which
8 patient-relevant aspects should be included in the development of quality indicators.[12] Identification of
9 the scope of evidence will therefore help to understand what is most important to the patient receiving
10 health care. Health care organizations concerned with improving the quality of services in CHF care may use
11 this knowledge to define what constitutes a positive patient experience and infer factors that may improve
12 health care provision for this target group.
13

14 Furthermore, this knowledge may lay the groundwork for the development of a disease-specific assessment
15 tool to measure how CHF patients experience their treatment in Germany. Different approaches to
16 measuring patients' experiences have been reviewed in literature, suggesting that there is no gold standard
17 for such an assessment.[13, 14] Hence, this evidence map seeks to review a wide array of methodological
18 study designs that report on patients' experiences.
19

20 Emphasis on a holistic approach to understanding health care makes it particularly important not only to
21 review the effectiveness of medical interventions, but also to take into account contextual factors such as
22 patients' lived experiences, their acceptance and expectations of health care services. A meta-synthesis of
23 qualitative reviews has found that patients' experiences along with rational choices establish how patients
24 make decisions relating to self-care and help-seeking behavior in the management of their complex chronic
25 conditions.[15] For the chronic condition of heart failure, prior experiences can be expected to influence
26 decisions concerning management of the disease, implementation of a healthy lifestyle, effective
27 cooperation with health professionals and adherence to treatment regimens, all of which ultimately affect
28 mortality, quality of life, and other relevant outcomes.[16]
29
30

31 However, little is known about the subjective experiences of CHF patients that are specifically confronted
32 with the German health care infrastructure, and seeking and receiving health care services. A preliminary
33 search for existing and registered reviews revealed no such evidence. Although a comprehensive scoping
34 study exploring the literature on patients' experiences is underway, it focuses on integrated care settings
35 rather than a country-specific health care landscape.[17] To the best of our knowledge, this is the first
36 scoping review conducted to ask what existing literature can tell us about the experiences of CHF patients
37 with the entire range of German health services in both formal and informal care settings.
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41 **METHODS AND ANALYSIS**

42 Since standard reporting guidelines for scoping reviews such as a PRISMA-ScR tool are currently being
43 developed,[18] the methodological procedure followed in this scoping review is based on the theoretical
44 framework of Arksey and O'Malley[19], and the complementary recommendations proposed by Levac and
45 colleagues.[20] This six-stage approach also complies with recommendations on conducting scoping reviews
46 published by The Joanna Briggs Institute.[21] The procedure consists of the following six steps: (#1)
47 Identifying the research question; (#2) Identifying relevant studies; (#3) Study selection; (#4) Charting the
48 data; (#5) Collating, summarizing, and reporting the results; (#6) Consultation.
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52 **#1 Identifying the research question**

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3 The aim of this review is to provide an accessible overview of what is known about CHF patients' experiences
4 of using health care services in Germany.

5
6 Following on from the above objective, the main research questions is:

- 7
8 1. What is the extent and range of available evidence addressing CHF patients' experiences of using
9 German health care services?

10
11 In order to understand patients' journeys through the German health care system and to shed light on their
12 subjective experiences on these journeys, secondary research questions are:

- 13
14 2. What health care services and settings, what geographical contexts and what dimensions of patient
15 experience are covered?
16 3. What methodological designs are used to assess patients' experiences?

17
18 To examine the full range of patients' experiences, we have defined the multidimensional concept of patient
19 experience rather broadly. Since a uniform definition of patients' experiences does not yet exist in the
20 literature, we have introduced the following working definition based on a narrative synthesis review by
21 Wolf and colleagues:[22] Patient experience is the multitude of interactions originating at the interplay
22 between disease-specific, subjective health care needs and the health care services used by patients. They
23 encompass various dimensions - whether they be relational, organizational or functional in nature – either
24 derived from the patient's voice or otherwise accurately reflecting the patient's views.
25

26
27 We applied the PCC-mnemonic (Population – Concept – Context) introduced by The Joanna Briggs
28 Institute[21] to develop the research question. For this scoping review, population (P) is defined as adults
29 living with the chronic condition of heart failure. The concept of interest (C) constitutes the experiences of
30 patients managing the complex condition of chronic heart failure that result from their disease-specific
31 health care needs on the one hand, and the health care they receive on the other. The context (C) of the
32 research question includes all formal and informal health care services provided in all health care settings in
33 Germany.
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36 #2 Identifying relevant studies

37
38 The search strategy will be broad and will aim to cover literature, including grey literature, from various
39 academic disciplines. This is necessary since investigating patients' experiences in different German health
40 care settings may involve research fields as diverse as psychology, medical sciences, health care
41 management, nursing, rehabilitation and e-health.
42

43
44 Consequently, we will conduct systematic literature searches in the following six databases: CINAHL,
45 Medline, Embase (all via Ovid), PsycINFO, PSYINDEX (both via Ebsco) and the Cochrane Database of
46 Systematic Reviews (CDSR) via Wiley.

47
48 Additionally, a non-systematic search of grey literature will be undertaken using Google Scholar, Open Grey
49 and ProQuest, since research articles that have not been peer-reviewed will also be relevant. The same holds
50 true for experts and organizations involved in the field of patient-experienced health care, whom we also
51 intend to contact.
52

53 Finally, we will hand-search the reference lists of included studies and search the indexes of key journals.

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55 We intend to report detailed search strategies for all databases. A first step in developing the systematic
56 search strategy will be to use the PCC-mnemonic to brainstorm for search terms that well describe the
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3 population, the concept under investigation, and the context of the research question. Additional search
4 terms will be extracted from scans of titles and abstracts in an initial non-exhaustive search. Once the search
5 strategy has been well refined through the incorporation of feedback from our research team members,
6 searches will be run electronically and identified articles exported and converted into the standard file
7 format RIS. Subsequently, we will merge all identified studies into Covidence software[23] for deduplication
8 and the selection of further studies.
9

10 11 12 **#3 Study selection**

13
14 Two independent reviewers will screen titles, abstracts and full texts of the articles. A majority vote involving
15 a third reviewer will resolve any disagreements on which studies to include on all levels of the search. The
16 PRISMA flow diagram will be used to give an overview of the number of studies throughout the study
17 selection process.[24]
18

19 All research articles that address the experiences of using health care services of adults receiving treatment
20 in Germany after a diagnosis of chronic heart failure (as defined in the individual studies) will be eligible for
21 this review.
22

23 All clinical forms of CHF are relevant for inclusion, regardless of etiology or classification of severity. Studies
24 dealing with patients with multiple chronic conditions or co-morbidities will also be eligible for inclusion if
25 patients' experiences specifically relate to CHF.
26

27 For the review, patient experience will be defined broadly and include neighboring concepts such as
28 patients' preferences, needs, values, satisfaction, burden of treatment and expectations of health care
29 services. Study designs assessing patients' experiences indirectly - i.e. patients' experiences are described by
30 another party - will only be considered eligible for inclusion if patients were unable to self-report due to
31 their state of health.
32

33 All health care settings will be relevant for this review, including traditional settings of inpatient and
34 outpatient care as well as other health services that patients use to manage their CHF.
35

36 We will exclude publications that involve data from multiple countries unless the study design allows the
37 separate analysis of data for Germany. Studies investigating patients' experiences of using non-medical and
38 social services, as well as non-research publications such as online ratings and consumer blogs, will not be
39 considered eligible for this review. Furthermore, when patients' experiences focus on perceived burden of
40 disease, rather than directly relating to the use of health care services, they will also be excluded. The search
41 will be limited to publications in German and English that have been published within the last 10 years.
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45 **#4 Charting the data**

46
47 A data-charting form will be used for all eligible full texts. The development of the data-charting forms will
48 involve all multidisciplinary research team members. A patient representative will also be involved to discuss
49 the importance of outcome variables from a health care user perspective. Data extraction will be piloted
50 using two relevant studies to ensure applicability and will be updated if necessary. In the next step, data will
51 be extracted based on the three categories listed in table 1.
52

Study Characteristics	First Author
	Year of Publication

	Type of Publication
	Academic Discipline
	Sample Size
	Study Objective
	Authors' Main Conclusion
Key Findings	Thematic Dimension of Patient Experience
	Experience : Positive/Negative/Both
	Geographical Setting (i.e. federal state, area code, urban vs rural area)
	Institutional Setting or Health Care Service Used (i.e. inpatient hospital care, informal home care, rehabilitation services)
	Methodology Used to Assess Patients' Experiences
Population Characteristics	Age
	Sex
	Ethnicity
	Insurance Status
	Relationship Status
	Severity of Symptoms (NYHA)
	Co-morbidities
	Type of Heart Failure (in terms of localization, etiology or pathophysiology)
	Therapeutic Characteristics (i.e. implanted device therapy, pharmacological therapy)

Table1: Data charting form used to extract information to answer the scoping review's questions.

Firstly, study characteristics will be extracted, including data on the first author's name, year and type of publication, academic discipline, sample size, study objective as well as the main conclusion.

Secondly, key findings will be extracted, depending on their relevance to the research questions. The findings will be described in terms of whether they can be categorized as positive, negative or both, the geographical setting (i.e. federal state, area code, urban vs rural area), the institutional setting or health care service used (i.e. inpatient hospital care, informal home care, rehabilitation services), and the methodology used to assess patients' experiences.

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3 Thirdly, population characteristics will be charted. These will include data on age, sex, ethnicity, insurance
4 and relationship status, severity of symptoms/NYHA, comorbidities, type of heart failure as well as
5 therapeutic characteristics (i.e. implanted device therapy, pharmacological therapy).
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8 **#5 Collating, summarizing, and reporting the results**

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10 First of all, information on study and population characteristics from the data-charting form will be
11 summarized using basic descriptive statistics and descriptive narration. Subsequently, key findings including
12 information on study methodology, categories of patient experience, authors' conclusions, types of health
13 care service, the institutional setting under investigation as well as the geographical setting of the study will
14 be summarized narratively and tabulated.
15

16 To visually depict the quantity of research across various study designs and health care settings, an evidence
17 map will be created in a second step. If appropriate, the evidence map will be a bubble diagram that includes
18 the following reported information: type of studies, number of eligible studies, geographical setting, health
19 care service and institutional setting.
20

21 Both the visual and narrative presentation of results will provide information on the breadth of knowledge
22 available on the experiences of CHF patients with German health care services. A basic thematic analysis of
23 what was reported in eligible studies will be undertaken by summarizing key findings, while the creation of a
24 bubble plot will highlight gaps in the evidence. The kinds of study that are relevant to the field will be listed
25 on the bubble plot's x-axis, and the types of health care service relevant to CHF patients in Germany on the
26 y-axis. These specifications will be refined by research staff in consultation with a patient representative.
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31 **#6 Consultation**

32

33 The aim of the review is to provide an accessible overview of CHF patients' experiences of using different
34 kinds of health care services in Germany, as portrayed in the literature.
35

36 Investigating patients' experiences requires consultation with patients to ensure extraction of both
37 appropriate and meaningful outcome variables. A patient representative will therefore be involved in
38 refining the research questions, and developing a data-charting form and the matrix for a bubble plot. For
39 this purpose, we will conduct semi-structured telephone interviews with the patient representatives, or send
40 them questionnaires with open-questions via email.
41

42 Further, we will make use of end-of-project knowledge translation by incorporating stakeholders with
43 backgrounds in health care research, clinical practice, nursing and the organization of patient support
44 groups. These stakeholders will form an advisory board that is part of a wider research project, whereby
45 board meetings will serve as a platform to elucidate which key messages most appropriately address end-
46 users' information needs.
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50 **ETHICS AND DISSEMINATION**

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52 Using scoping review methodology, we aim to systematically and comprehensively map available literature
53 on heart failure patients' experiences of using health care services in Germany. The rationale for choosing
54 the scoping review methodology and deciding against undertaking a critical appraisal of included studies is
55 twofold. Firstly, clustering research patterns and gaps in patient-centered CHF health services research will
56 provide valuable information for the development of further research questions for primary research, or full
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3 systematic research syntheses, regardless of whether they take a qualitative, quantitative or mixed-methods
4 approach. Secondly, decision-makers and practitioners in health care will be provided with a comprehensive
5 overview of the extent and nature of the past decade's research activity that relates to their specific health
6 care context.
7

8 This scoping review will be conducted by a multidisciplinary research team that includes members with
9 diverse backgrounds such as health services research, psychology, health care management and public
10 health. This scoping review will be embedded within a wider research project that aims to develop a clearly
11 illustrated report on current structures of CHF management within the German health care system. As such,
12 its results will be disseminated in this report and presented to relevant stakeholders at the advisory board
13 meeting. Moreover, we intend to present findings from this scoping review at research conferences and to
14 publish them in a peer-reviewed journal.
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Acknowledgements

We would like to thank Phillip Elliott for proof-reading the manuscript.

Contributors

JJP, AS and FG developed the concept and acquired funding for this review. MD, KJ, TS and FR developed the search strategy. MD drafted the first version of the manuscript. JJP, KJ, TS, FR and JP finalized this manuscript.

Funding

This work was supported by the Robert Bosch Foundation ('Robert Bosch Stiftung').

Competing interests

JJP is a co-investigator in the PANORA study ('Prevalence of anti-cyclic citrullinated peptide (CCP) positivity in patients with new non-specific onset of musculoskeletal symptoms, possibly related to early rheumatoid arthritis in general practices in Germany'), which is being conducted by the Fraunhofer Institute and financed by Bristol-Meyer Squibb. She is employed by the Institute of General Practice of Goethe University Frankfurt and has never personally received financial remuneration from a pharmaceutical company. The other authors report no conflict of interest.

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BMJ Open

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Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-025685.R1
Article Type:	Protocol
Date Submitted by the Author:	26-Nov-2018
Complete List of Authors:	Dieckelmann, Mirjam; Goethe-University Frankfurt am Main, Institute of General Practice Reinhardt, Felix; Goethe-University Frankfurt am Main, Institute of General Practice Jeitler, Klaus; Medical University of Graz, Institute of General Practice and Evidence-based Health Services Research Semlitsch, Thomas; Institute of General Practice and Evidence-based Health Services Research, Medical University Graz Plath, Jasper; Goethe-University Frankfurt am Main, Institute of General Practice Gerlach, Ferdinand; Goethe-University Frankfurt am Main, Institute of General Practice Siebenhofer, Andrea; Medical University of Graz, Institute of General Practice and Evidence-based Health Services Research; Goethe-University Frankfurt am Main, Institute of General Practice Petersen, Juliana J.; Goethe-University Frankfurt am Main, Institute of General Practice
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Patient-centred medicine, Evidence based practice
Keywords:	PRIMARY CARE, Heart failure < CARDIOLOGY, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, Patients' experience, Scoping review

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Title

Chronic Heart Failure Patients' Experiences of German Health-Care Services: A Protocol for a Scoping Review

Corresponding Author

Mirjam Dieckelmann
Institute of General Practice
Goethe University Frankfurt
Theodor-Stern-Kai 7
60590 Frankfurt am Main, Germany
dieckelmann@allgemeinmedizin.uni-frankfurt.de
Tel.: +49 69 6301 80442

First Author

Mirjam Dieckelmann, Institute of General Practice, Goethe University Frankfurt, Frankfurt, Germany

Co-Authors

Felix-Alexander Reinhardt, Institute of General Practice, Goethe University Frankfurt, Frankfurt, Germany

Dr. med. univ. Klaus Jeitler, Institute of General Practice and Evidence-based Health Services Research,
Medical University of Graz, Graz, Austria

Mag. rer. nat. Thomas Semlitsch, Institute of General Practice and Evidence-based Health Services Research,
Medical University of Graz, Graz, Austria

Jasper Plath, Institute of General Practice, Goethe University Frankfurt, Frankfurt, Germany

Prof. Dr. med. Ferdinand M. Gerlach, Institute of General Practice, Goethe University Frankfurt, Frankfurt,
Germany

Prof. Dr. med. Andrea Siebenhofer, Institute of General Practice and Evidence-based Health Services
Research, Medical University of Graz, Graz, Austria and Institute of General Practice, Goethe University
Frankfurt, Frankfurt, Germany

Dr. med. Juliana J. Petersen, Institute of General Practice, Goethe University Frankfurt, Frankfurt, Germany

Word Count: 2997 words

Abstract

Introduction

Chronic heart failure (CHF) is a heterogeneous condition requiring complex treatment from diverse health care services. An increasingly holistic understanding of health care has resulted in contextual factors such as perceived quality of care, as well as patients' acceptance, preferences and subjective expectations of health services, all gaining in importance. How patients with CHF experience the use of health care services has not been studied within the scope of a systematic review in a German health care context. The aim of this scoping review is therefore to review systematically the experiences of patients affected by CHF with health care services in Germany in the literature and to map the research foci. Further objectives are to identify gaps in evidence, develop further research questions, and to inform decision-makers concerned with improving health care of patients living with CHF.

Methods and analysis

This scoping review will be based on a broad search strategy involving systematic and comprehensive electronic database searches in MEDLINE, EMBASE, PsycINFO, PSYINDEX, CINAHL and Cochrane's CDSR, grey literature searches, as well as hand searches through reference lists and non-indexed key journals. The methodological procedure will be based on an established six-stage framework for conducting scoping reviews that includes two independent reviewers. Data will be systematically extracted, qualitatively and quantitatively analyzed, and summarized both narratively and visually. To ensure the research questions and extracted information are meaningful, a patient representative will be involved.

Ethics and dissemination

Ethical approval will not be required to conduct this review. Results will be disseminated through a clearly illustrated report that will be part of a wider research project. Furthermore, it is intended that the review's findings should be made available to relevant stakeholders through conference presentations and publication in peer-reviewed journals ('knowledge transfer'). Protocol registration in PROSPERO is not applicable for scoping reviews.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- This scoping review will be the first to systematically map the past 10 years of research activity surrounding CHF patients' experiences of using health care services in Germany, and to genuinely explore the consumer perspective
- The research will be limited to Germany but will allow the replication of findings for other health care systems with their specific geographical and institutional health care features
- All health care settings and study designs will be relevant for inclusion in this review to provide an overview of the entire range of German health services
- A patient representative was involved in refining the research questions and defining the outcome variables to be extracted
- Since patient experience is a broad concept, we expect study heterogeneity to lead to potential difficulties summarizing extracted data

INTRODUCTION

Heart failure is a major chronic condition affecting a growing number of people in Germany, most of whom are older adults.[1, 1] A diagnosis of heart failure (ICD-I50) is the second most common cause of death amongst women and is one of the top four causes of death amongst men in Germany.[2] Due to the bidirectional interplay between somatic and psychosocial factors, patients with CHF experience both reduced survival and quality of life.[3] Evidence suggests that with increasing severity of clinical symptoms, quality of life decreases disproportionately in hospitalized[4], and primary care patients.[5]

In Germany, approximately € 5.3 billion were spent on treating heart failure in 2015[6]. Having doubled over the past two decades, it is the most common primary reason for hospital admission in Germany [2], and is a major cause of in-hospital mortality.[7]

Both the overall economic burden of the disease and the individual physical, mental and psychosocial impact on CHF patients' lives mean health services must coordinate their services well if patients' complex health care needs are to be managed effectively and efficiently. However, repeated hospital admissions following acute decompensation are characteristic of patients with CHF and make it difficult for in- and out-patient care sectors to coordinate their activities.[8, 9]

The management of CHF should be minimally disruptive and involve multidisciplinary health care services, both in formal health care facilities and the patient's environment.[10] The European Society of Cardiology has identified the following as areas in which health care provision can potentially be improved: discharge planning, lifestyle advice, exercise training, follow-up and monitoring, palliative and end-of-life-care as well as self-care in elderly, frail or cognitively impaired CHF patients.[10]

In modern health care systems, CHF patients find themselves managing their condition both at home and, when seeking help from the confusing range of health care providers and their various services, externally. The burden of treatment may be perceived as challenging as a result of the need to adhere to complex pharmaceutical therapies, manage co-morbidities that interfere with CHF, physically and psychologically cope with symptoms that may severely interfere with everyday life activities, continuously monitor one's own health status, operate technical devices, understand complex disease mechanisms and interact with different health professionals.[11]

To help patients cope with such immense workloads, a disease management program for CHF patients is scheduled for implementation in Germany in 2018.[12] Against this background, this review's findings may help policy-makers, health care providers and decision-makers concerned with inter- or intra-sectoral

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3 management of care to gain a comprehensive overview of what is known about the individual health care
4 needs of CHF patients and their experiences and satisfaction with the health care they receive in Germany.
5

6 The literature on measuring quality of care suggests that no consensus has yet been reached on which patient-
7 relevant aspects should be included in the development of quality indicators.[13] Identification of the scope
8 of evidence will therefore help to understand what is most important to the patient receiving health care.
9 Health care organizations concerned with improving the quality of services in CHF care may use this knowledge
10 to define what constitutes a positive patient experience and infer factors that may improve health care
11 provision for this target group.
12
13

14 Furthermore, this knowledge may lay the groundwork for the development of a disease-specific assessment
15 tool to measure how CHF patients experience their treatment in Germany. Different approaches to measuring
16 patients' experiences have been reviewed in literature, suggesting that there is no gold standard for such an
17 assessment.[14] Hence, this evidence map seeks to review a wide array of methodological study designs that
18 report on patients' experiences.
19
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21 Emphasis on a holistic approach to understanding health care makes it particularly important not only to
22 review the effectiveness of medical interventions, but also to take into account contextual factors such as
23 patients' lived experiences, as well as their acceptance and expectations of health care services. A meta-
24 synthesis of qualitative reviews has found that patients' experiences along with rational choices establish how
25 patients make decisions relating to self-care and help-seeking behavior in the management of their complex
26 chronic conditions.[15] For CHF, prior experiences can be expected to influence decisions concerning
27 management of the disease, implementation of a healthy lifestyle, effective cooperation with health
28 professionals and adherence to treatment regimens, all of which ultimately affect mortality, quality of life, and
29 other relevant outcomes.[16]
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31

32 However, little is known about the subjective experiences of CHF patients that are specifically confronted with
33 the German health care infrastructure, and seeking and receiving health care services. A preliminary search
34 for existing and registered reviews revealed no such evidence. Although a comprehensive scoping study
35 exploring the literature on patients' experiences is underway, it focuses on integrated care settings rather
36 than a country-specific health care landscape.[17] To the best of our knowledge, this is the first scoping review
37 conducted to ask what existing literature can tell us about the experiences of CHF patients with the entire
38 range of German health services in both formal and informal care settings.
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43 **METHODS AND ANALYSIS**

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45 Since standard reporting guidelines for scoping reviews such as a PRISMA-ScR tool are currently being
46 developed,[18] the methodological procedure followed in this scoping review is based on the theoretical
47 framework of Arksey and O'Malley[19], and the complementary recommendations proposed by Levac and
48 colleagues.[20] This six-stage approach also complies with recommendations on conducting scoping reviews
49 published by The Joanna Briggs Institute.[21] The procedure consists of the following six steps: (#1) Identifying
50 the research question; (#2) Identifying relevant studies; (#3) Study selection; (#4) Charting the data; (#5)
51 Collating, summarizing, and reporting the results; (#6) Consultation.
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56 **#1 Identifying the research question**

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58 The aim of this review is to provide an accessible overview of what is known about CHF patients' experiences
59 of using health care services in Germany.
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3 Following on from the above objective, the main research questions is:
4

- 5 1. What is the extent and range of available evidence addressing CHF patients' experiences of using
6 German health care services?
7

8 In order to understand patients' journeys through the German health care system and to shed light on their
9 subjective experiences on these journeys, secondary research questions are:
10

- 11 2. What health care services and settings, what geographical contexts and what dimensions of patient
12 experience are covered?
13
- 14 3. What methodological designs are used to assess patients' experiences?
15

16 To examine the full range of patients' experiences, we have defined the multidimensional concept of patient
17 experience rather broadly. To the best of our knowledge, a uniform definition of patients' experiences does
18 not yet exist in the literature. Based on narrative synthesis reviews, we have therefore developed the following
19 working definition:[22, 23] Patient experience consists of the multitudinous interactions originating at the
20 interface between disease-specific, subjective health care needs and the health care services used by patients.
21 They encompass various dimensions - whether they be relational, organizational or functional in nature -
22 either obtained from the patients themselves, or otherwise accurately reflecting the patient's views.
23
24

25 We applied the PCC-mnemonic (Population – Concept – Context) introduced by The Joanna Briggs Institute[21]
26 to develop the research question. For this scoping review, population (P) is defined as adults living with CHF.
27 The concept of interest (C) constitutes the experiences of patients managing the complex condition of chronic
28 heart failure that result from their disease-specific health care needs on the one hand, and the health care
29 they receive on the other. The context (C) of the research question includes all formal and informal health
30 care services provided in all health care settings in Germany.
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35 #2 Identifying relevant studies

36 The search strategy will be broad and will aim to cover literature, including grey literature, from various
37 academic disciplines. This is necessary since investigating patients' experiences in different German health
38 care settings may involve research fields as diverse as psychology, medical sciences, health care management,
39 nursing, rehabilitation and e-health.
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42 Consequently, we will conduct systematic literature searches in the following six databases: CINAHL, Medline,
43 Embase (all via Ovid), PsycINFO, PSYINDEX (both via Ebsco) and the Cochrane Database of Systematic Reviews
44 (CDSR) via Wiley.
45

46 Additionally, a non-systematic search of grey literature will be undertaken using platforms such as Google
47 Scholar, Open Grey and ProQuest, since research articles that have not been peer-reviewed will also be
48 relevant. The same holds true for experts and organizations involved in the field of patient-experienced health
49 care, whom we also intend to contact.
50
51

52 Finally, we will hand-search the reference lists of included studies and search the indexes of key journals.
53

54 A first step in developing the systematic search strategy was to use the PCC-mnemonic to brainstorm for
55 search terms that well describe the population, the concept under investigation, and the context of the
56 research question. Additional search terms were extracted from scans of titles and abstracts in an initial non-
57 exhaustive search.
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3 Search strategies for all databases and publication dates of coverage are provided in a supplementary file in
4 the appendix. They comprise three search blocks that reflect the PCC-scheme. In addition, searches will be
5 limited to publications in German and English that have been published within the last 10 years (2008-present).
6 Preliminary searches across all databases were conducted in April 2018. Final searches are scheduled to be
7 finished by the end of 2018 (database searches and grey literature searches). Once the search strategy has
8 been refined through the incorporation of feedback from our research team members and run electronically,
9 identified articles will be exported and converted into the standard file format RIS. Subsequently, we will
10 merge all identified studies into Covidence software[24] for deduplication and the selection of further studies.
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14 15 **#3 Study selection**

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17 Two independent reviewers will screen titles, abstracts and full texts of the articles. A majority vote involving
18 a third reviewer will resolve any disagreements on which studies to include on all levels of the search. The
19 PRISMA flow diagram will be used to give an overview of the number of studies throughout the study selection
20 process.[25]
21

22
23 All research articles that address the experiences of using health care services of adults receiving treatment in
24 Germany after a diagnosis of CHF (as defined in the individual studies) will be eligible for this review.
25

26 All clinical forms of CHF are relevant for inclusion, regardless of etiology or classification of severity. Studies
27 dealing with patients with multiple chronic conditions or co-morbidities will also be eligible for inclusion if
28 patients' experiences specifically relate to CHF.
29

30 For the review, patient experience will be defined broadly and include neighboring concepts such as patients'
31 preferences, needs, values, satisfaction, burden of treatment and expectations of health care services. Study
32 designs assessing patients' experiences indirectly i.e. expert opinion, routine data that was not obtained from
33 patients directly, or came from health professionals, will not be eligible for inclusion. On the other hand, since
34 informal caregivers play a significant role in shaping patients' experiences of health care services, studies that
35 report patient experiences from the perspective of a patient's close social network will be eligible for inclusion
36 – especially towards end of life and when patients are unable to self-report their experiences.[26]
37
38

39 All health care settings will be considered relevant for this review, including traditional settings of inpatient
40 and outpatient care, as well as other health services that patients use to manage their CHF. As we are aware
41 that health systems differ substantially between countries, we intend to classify health care services based on
42 Busse and Blümel's categorization of provision of services, as reported in a series published by the European
43 Observatory on Health Systems and Policies.[27] In this way, it will be possible to draw conclusions from the
44 review's results for health care systems in different countries.
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47 We will exclude publications that involve data from multiple countries unless the study design allows the
48 separate analysis of data for Germany. Studies investigating patients' experiences of using non-medical and
49 social services, as well as non-research publications such as online ratings and consumer blogs, will not be
50 considered eligible for this review. Furthermore, when patients' experiences focus on perceived burden of
51 disease, rather than directly relating to the use of health care services, they will also be excluded.
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55 **#4 Charting the data**

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57 A data-charting form will be used for all eligible full texts. The development of the data-charting forms will
58 involve all multidisciplinary research team members. A patient representative will also be involved to discuss
59 the importance of outcome variables from a health care user perspective. Data extraction will be piloted using
60

two relevant studies to ensure applicability and will be updated if necessary. In the next step, data will be extracted based on the three categories listed in table 1.

Study Characteristics	First author
	Year of publication
	Type of publication
	Academic discipline
	Sample size
	Study objective
	Authors' main conclusion
Key Findings	Thematic dimension of patient experience
	Experience : positive/negative/both
	Geographical setting (i.e. federal state, area code, urban vs rural area)
	Institutional setting or health care service used (i.e. inpatient hospital care, informal home care, rehabilitation services)
	Methodology used to assess patients' experiences
Population Characteristics	Age
	Sex
	Ethnicity
	Insurance status
	Relationship status
	Severity of symptoms (NYHA)
	Co-morbidities
	Type of CHF (in terms of localization, etiology or pathophysiology)
	Therapeutic Characteristics (i.e. implanted device therapy, pharmacological therapy)

Table1: Data charting form used to extract information to answer the scoping review's questions.

Firstly, study characteristics will be extracted, including data on the first author's name, year and type of publication, academic discipline, sample size, study objective as well as the main conclusion.

Secondly, key findings will be extracted, depending on their relevance to the research questions. The findings will be described in terms of whether they can be categorized as positive, negative or both, the geographical

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3 setting (i.e. federal state, area code, urban vs rural area), the institutional setting or health care service used
4 (i.e. inpatient hospital care, informal home care, rehabilitation services), and the methodology used to assess
5 patients' experiences.
6

7 Thirdly, population characteristics will be charted. These will include data on age, sex, ethnicity, insurance and
8 relationship status, severity of symptoms/NYHA, comorbidities, type of CHF as well as therapeutic
9 characteristics (i.e. implanted device therapy, pharmacological therapy).
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12 13 **#5 Collating, summarizing, and reporting the results**

14
15 First of all, information on study and population characteristics from the data-charting form will be
16 summarized using basic descriptive statistics and descriptive narration. Subsequently, key findings including
17 information on study methodology, categories of patient experience, authors' conclusions, types of health
18 care service, the institutional setting under investigation as well as the geographical setting of the study will
19 be summarized narratively and tabulated.
20
21

22 To visually depict the quantity of research across various study designs and health care settings, an evidence
23 map will be created in a second step. If appropriate, the evidence map will be a bubble diagram that includes
24 the following reported information: type of studies, number of eligible studies, geographical setting, health
25 care service and institutional setting.
26

27 Both the visual and narrative presentation of results will provide information on the breadth of knowledge
28 available on the experiences of CHF patients with German health care services. A basic thematic analysis of
29 what was reported in eligible studies will be undertaken by summarizing key findings, while the creation of a
30 bubble plot will highlight gaps in the evidence. The kinds of study that are relevant to the field will be listed
31 on the bubble plot's x-axis, and the types of health care service relevant to CHF patients in Germany on the y-
32 axis. These specifications will be refined by research staff in consultation with a patient representative.
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36 37 **#6 Consultation**

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39 The aim of the review is to provide an accessible overview of CHF patients' experiences of using different kinds
40 of health care services in Germany, as portrayed in the literature.
41

42 In line with this objective, we will make use of end-of-project knowledge translation by incorporating
43 stakeholders with backgrounds in health care research, clinical practice, nursing and the organization of
44 patient support groups. These stakeholders will form an advisory board that is part of a wider research project,
45 whereby board meetings will serve as a platform to elucidate which key messages most appropriately address
46 end-users' information needs.
47
48
49

50 51 **Patient and public involvement**

52 Investigating patients' experiences requires consultation with patients to ensure extraction of both
53 appropriate and meaningful outcome variables. A patient representative was therefore involved in refining
54 the research questions and developing a data-charting form, and the matrix for a bubble plot. For this purpose,
55 we conducted semi-structured telephone interviews with the patient representative, or sent the
56 representative questionnaires with open-questions via email. Apart from the specification of outcome
57 variables and research questions, patients will not be involved in the overall design of the study, conducting
58 review processes, data extraction and the representation of results.
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ETHICS AND DISSEMINATION

Using scoping review methodology, we aim to systematically and comprehensively map available literature on CHF patients' experiences of using health care services in Germany. The rationale for choosing the scoping review methodology and deciding against undertaking a critical appraisal of included studies is twofold. Firstly, clustering research patterns and gaps in patient-centered CHF health services research will provide valuable information for the development of further research questions for primary research, or full systematic research syntheses, regardless of whether they take a qualitative, quantitative or mixed-methods approach. Secondly, decision-makers and practitioners in health care will be provided with a comprehensive overview of the extent and nature of the past decade's research activity that relates to their specific health care context. This study will not require ethical approval.

This scoping review will be conducted by a multidisciplinary research team that includes members with diverse backgrounds such as health services research, psychology, health care management and public health. This scoping review will be embedded within a wider research project that aims to develop a clearly illustrated report on current structures of CHF management within the German health care system. As such, its results will be disseminated in this report and presented to relevant stakeholders at the advisory board meeting. Moreover, we intend to present findings from this scoping review at research conferences and to publish them in a peer-reviewed journal.

Acknowledgements

We would like to thank Phillip Elliott for proof-reading the manuscript. Furthermore, we would like to gratefully acknowledge the valuable advice provided by the patient representative, Helmuth Bundschuh.

Contributors

JJP, AS and FG developed the concept and acquired funding for this review. MD, KJ, TS and FR developed the search strategy. MD drafted the first version of the manuscript. JJP, KJ, TS, FR and JP finalized this manuscript.

Funding

This work was supported by the Robert Bosch Foundation ('Robert Bosch Stiftung').

Competing interests

JJP is a co-investigator in the PANORA study ('Prevalence of anti-cyclic citrullinated peptide (CCP) positivity in patients with new non-specific onset of musculoskeletal symptoms, possibly related to early rheumatoid arthritis in general practices in Germany'), which is being conducted by the Fraunhofer Institute and financed by Bristol-Meyer Squibb. She is employed by the Institute of General Practice of Goethe University Frankfurt and has never personally received financial remuneration from a pharmaceutical company. The other authors report no conflict of interest.

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Search Strategy for MEDLINE and EMBASE

1	exp Heart Failure/
2	((myocard* or cardia* or heart) adj3 (insufficien* or failure or incompeten* or decompensat*)).mp.
3	HF??EF.mp.
4	CHF.mp.
5	(NYHA or "New York Heart Association Class").mp.
6	(herzinsuffizien* or herzversagen or myokardinsuffizien*).mp.
7	(ejektionsfraktion or auswurfleistung).mp.
8	or/1-7
9	((client* or consumer* or individu* or klient* or patient* or pers??nlich* or personal or subje* or user*) adj3 (accept* or attitude* or barrier* or bed??rfnis* or bedarf* or belief* or believ* or beobacht* or bericht* or burden or challenge* or confiden* or einsicht* or einstellung* or emotion* or empathy or empfind* or erfahrung* or erkenntnis* or erleb* or erwart* or evaluat* or expect* or experience* or feedback or feeling* or herausforderung* or insight* or involve* or knowledge or meinung* or need* or observation* or opinion* or participat* or perceiv* or perception* or perspectiv* or prefer* or pr??fer* or report* or satisf* or sicht* or stimme or trust* or understand* or verst??ndnis or verstehen or vertrauen or view* or voice* or zufrieden*)).mp.
10	((("health care" or (health adj2 service*)) adj3 access*).mp.
11	(patient* adj3 (flow or journey*)).mp.
12	(arzt-patient* adj3 (beziehung* or interaktion* or kommunikation or verh??tnis)).mp.
13	((professional-patient or nurse-patient or physician-patient or doctor-patient or practitioner-patient) adj3 (relation* or communication or interaction*)).mp.
14	(burden* adj2 treatment).mp.
15	(shared adj1 decision-making).mp.
16	((partizipativ* or gemeinsam* or geteilt*) adj1 entscheid*).mp.
17	((Waiting adj1 time*) or wartezeit*).mp.
18	(PREM or "patient-reported experience measure").mp.
19	(care adj3 (pathway* or continuity or transition* or coordination)).mp.
20	Or/9-19
21	exp Germany/
22	(german* or deutsch*).mp.
23	(german* or deutsch*).in. and (german or ger).lg.
24	or/21-23
25	(english or eng or german or ger).lg.
26	and/8,20,24-25
27	limit 26 to yr="2008 -Current"

	Search Strategy for CINAHL, PSYINDEX and PsycINFO
1	
2	
3	
4	1 (MH "Heart Failure+") [not applicable for PsycINFO and PSYINDEX]
5	2 TX ((myocard* OR cardia* OR heart) N3 (insufficien* OR failure OR incompeten* OR decompensat*))
6	3 TX HF?#EF
7	4 TX CHF
8	5 TX (NYHA OR (New York Heart Association Class))
9	6 TX (herzinsuffizien* OR herzversagen OR myokardinsuffizien*)
10	7 TX (ejektionsfraktion OR auswurfleistung)
11	8 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
12	
13	9 TX ((client* OR consumer* OR individu* OR klient* OR patient* OR pers??nlich* OR personal OR subje* OR user*) N3 (accept* OR attitude* OR barrier* OR bed??rfnis* OR bedarf* OR belief* OR believ* OR beobacht* OR bericht* OR burden OR challenge* OR confiden* OR einsicht* OR einstellung* OR emotion* OR empathy OR empfind* OR erfahrung* OR erkenntnis* OR erleb* OR erwart* OR evaluat* OR expect* OR experience* OR feedback OR feeling* OR herausforderung* OR insight* OR involve* OR knowledge OR meinung* OR need* OR observation* OR opinion* OR participat* OR perceiv* OR perception* OR perspectiv* OR prefer* OR pr?#fer* OR report* OR satisf* OR sicht* OR stimme OR trust* OR understand* OR verst?#ndnis OR verstehen OR vertrauen OR view* OR voice* OR zufrieden*))
14	
15	
16	
17	
18	
19	
20	
21	10 TX (("health care" OR (health N2 service*)) N3 access*)
22	11 TX (patient* N3 (flow OR journey*))
23	12 TX (arzt-patient* N3 (beziehung* OR interaktion* OR kommunikation OR verh?#tnis))
24	13 TX ((professional-patient OR nurse-patient OR physician-patient OR doctor-patient OR practitioner-patient) N3 (relation* OR communication OR interaction*))
25	
26	
27	14 TX (burden* N2 treatment)
28	15 TX (shared N1 decision-making)
29	16 TX ((partizipativ* OR gemeinsam* OR geteilt*) N1 entscheid*)
30	17 TX ((waiting N1 time*) OR wartezeit*)
31	18 TX (PREM OR "patient-reported experience measure*")
32	19 TX (care N3 (pathway* or continuity or transition* OR coordination))
33	
34	20 S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
35	21 (MH "Germany+") [not applicable for PsycINFO and PSYINDEX]
36	22 TX (german* OR deutsch*)
37	23 AF (german* OR deutsch*) AND LA (german OR ger)
38	24 S21 OR S22 OR S23
39	25 LA (english OR eng OR german OR ger)
40	26 S8 AND S20 AND S24 AND S25
41	
42	27 Limiters - Published Date: 20080101-20181231
43	
44	

Search Strategy for Cochrane Database of Systematic Reviews (CDSR)

1	
2	1 MeSH descriptor: [Heart Failure] explode all trees
3	2 ((myocard* or cardia* or heart) NEAR/3 (insufficien* or failure or incompeten* or decompensat*)):ti,ab,kw
4	3 (HF*EF):ti,ab,kw
5	4 (CHF):ti,ab,kw
6	5 (NYHA or "New York Heart Association Class"):ti,ab,kw
7	6 (herzinsuffizien* or herzversagen or myokardinsuffizien*):ti,ab,kw
8	7 (ejektionsfraktion or auswurfleistung):ti,ab,kw
9	8 {or #1-#7}
10	9 ((client* or consumer* or individu* or klient* or patient* or pers* nlich* or personal or subje* or user*) NEAR/3 (accept* or attitude* or barrier* or bed* rfnis* or bedarf* or belief* or believ* or beobacht* or bericht* or burden or challenge* or confiden* or einsicht* or einstellung* or emotion* or empathy or empfind* or erfahrung* or erkenntnis* or erleb* or erwart* or evaluat* or expect* or experience* or feedback or feeling* or herausforderung* or insight* or involve* or knowledge or meinung* or need* or observation* or opinion* or participat* or perceiv* or perception* or perspectiv* or prefer* or pr* fer* or report* or satisf* or sicht* or stimme or trust* or understand* or verst* ndnis or verstehen or vertrauen or view* or voice* or zufrieden*)):ti,ab,kw
11	10 (("health care" or (health NEAR/2 service*)) NEAR/3 access*):ti,ab,kw
12	11 (patient* NEAR/3 (flow or journey*)):ti,ab,kw
13	12 (arzt-patient* NEAR/3 (beziehung* or interaktion* or kommunikation or verh* tnis)):ti,ab,kw
14	13 ((professional-patient or nurse-patient or physician-patient or doctor-patient or practitioner-patient) NEAR/3 (relation* or communication or interaction*)):ti,ab,kw
15	14 (burden* NEAR/2 treatment):ti,ab,kw
16	15 (shared NEXT decision-making):ti,ab,kw
17	16 ((partizipativ* or gemeinsam* or geteilt*) next entscheid*):ti,ab,kw
18	17 ((Waiting NEXT time*) or wartezeit*):ti,ab,kw
19	18 (PREM or "patient-reported experience measure*"):ti,ab,kw
20	19 (care NEAR/3 (pathway* or continuity or transition* or coordination)):ti,ab,kw
21	20 {or #9-#19}
22	21 {and #8, #20}
23	22 [Using Custom Range for specifying years of publication 2008-2018]