

BMJ Open Healthcare experiences of patients with chronic heart failure in Germany: a scoping review

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ABSTRACT

Objectives To review systematically the past 10 years of research activity into the healthcare experiences (HCX) of patients with chronic heart failure (CHF) in Germany, in order to identify research foci and gaps and make recommendations for future research.

Design In this scoping review, six databases and grey literature sources were systematically searched for articles reporting HCX of patients with CHF in Germany that were published between 2008 and 2018. Extracted results were summarised using quantitative and qualitative descriptive analysis.

Results Of the 18 studies (100%) that met the inclusion criteria, most were observational studies (60%) that evaluated findings quantitatively (60%). HCX were often concerned with patient information, global satisfaction as well as relationships and communication between patients and providers and generally covered ambulatory care, hospital care and rehabilitation services. Overall, the considerable heterogeneity of the included studies' outcomes only permitted relatively trivial levels of synthesis.

Conclusion In Germany, research on HCX of patients with CHF is characterised by missing, inadequate and insufficient information. Future research would benefit from qualitative analyses, evidence syntheses, longitudinal analyses that investigate HCX throughout the disease trajectory, and better reporting of sociodemographic data. Furthermore, research should include studies that are based on digital data, reports of experiences gained in under-investigated yet patient-relevant healthcare settings and include more female subjects.

INTRODUCTION

Patients with chronic heart failure (CHF) have to cope with immense workloads. They may view both their disease(s) and their treatment as a burden when engaging in self-care and seeking help from a range of healthcare providers and services. To manage their condition, patients and their social networks are required to make lifestyle changes, to know when and how to seek help in acute situations and to initiate contact with and choosing between providers of long-term

Strengths and limitations of this study

- By systematically mapping the research field around healthcare experience of patients with chronic heart failure, we find that, for Germany, research is characterised by missing, insufficient and inadequate information.
- We were able to infer targeted recommendations for future primary research on healthcare experiences in patients with chronic heart failure and encourage replication of the fully published searches for contexts other than Germany.
- This review includes both, grey literature sources and published research articles detected through searching multiple electronic databases.
- As of yet, heterogeneous outcomes of healthcare experiences in the included studies allow only for relatively trivial levels of synthesis.
- Although a patient representative was involved, integrating the patient perspective further in the review process could have helped to understand which research gaps were most relevant to the patient and should be given priority in future research.

psychosocial, mental and physical support. They also commonly face tasks such as doing paperwork and communicating with funding bodies, becoming tech-savvy or comprehending complex medical information and its multitude of sources.¹

Burden of treatment as well as minimally disruptive medicine are concepts that have gained research momentum in the past decade.^{2–7} Perceived treatment burden negatively impacts on adherence, damage the health of patients and their families reduce employment among chronically ill patients and hinder effective resource use.^{6,8} A recently developed situation-specific theory of self-care in heart failure suggests that past experiences influence decision-making processes with respect to a patient's ability to care for himself or herself. Importantly, experiences

in healthcare settings may act as both, barriers and facilitators and thus influence self-care behaviours and self-efficacy in positive and negative ways.⁸

The literature suggests that ‘treatment burden is concerned with the negative experiences resulting from the process of undertaking treatment’.⁹ We have, however, chosen to use the more neutral term, patient healthcare experiences (HCX). HCX ‘consists of the multitudinous interactions originating at the interface between disease-specific, subjective healthcare needs and the healthcare services used by patients. They encompass various dimensions—whether they be relational, organisational or functional in nature—either obtained from the patients themselves, or otherwise accurately reflecting the patient’s views’.¹⁰ This working definition shifts the focus from an investigation of experiences of self-care and monitoring tasks towards examining experiences concerned with help-seeking and, more specifically, encounters with the healthcare system.

Investigating encounters between patients and healthcare systems, especially from the point of view of patients with multimorbidity, has received much attention in the USA and the UK.¹¹ Nevertheless, little is known about the subjective HCX of patients with CHF that are specifically confronted with the complex German healthcare infrastructure.

The scoping review methodology is particularly well-suited to broad research concepts.^{12–14} Correspondingly, HCX as a concept of interest has not yet been uniformly defined in the literature, and we anticipated that evidence would be many-sided and based on diverse research areas. Unlike qualitative evidence syntheses, a scoping review’s focus rather is on mapping the presence and extent of available research and can therefore act as a precursor to full systematic reviews.¹⁴

This scoping review is the first in Germany to systematically investigate research into HCX of patients with CHF, with the aim of developing recommendations for targeted future research in the field. Specifically, it seeks to summarise:

- ▶ the number of publications that report HCX of patients with CHF in Germany;
- ▶ the thematic dimensions of HCX that are addressed;
- ▶ the range of publications, study designs and academic disciplines that deal with HCX in patients with CHF in Germany;
- ▶ the demographics of patients included in the primary studies;
- ▶ research activity across healthcare services;
- ▶ methods used to assess and evaluate HCX;
- ▶ the context of rurality and urbanity in studies of HCX.

METHODS

Details on the methodological procedure have been published elsewhere.¹⁰ Reporting complies with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews.¹⁵

Study selection, literature searches and screening process

Papers were eligible for inclusion in this review when they investigated adult patients with CHF, reported any outcome related to patient healthcare experience in the context of the German healthcare environment and were published between 2008 and 2018 in either English or German.

We conducted systematic literature searches in six electronic databases (CINAHL, MEDLINE, EMBASE, PsycINFO, PSYINDEX and the Cochrane Database of Systematic Reviews) in May 2018. A full search strategy for each database is provided in online supplementary appendix 1. Additionally, the following grey literature sources were searched: ProQuest and DART-Europe (January 2019), German National Library (April 2019), as well as the homepages of relevant German organisations (June 2019) (see online supplementary appendices 2,3). Experts were not personally contacted. Finally, we hand-searched reference lists of included publications. Searching indexes of key journals was not necessary, as the key journals identified by the review team were indexed in electronic databases. Database searches are detailed in the protocol.

Two reviewers (MD and EB) screened publications on a Ti/Ab-level and a full-text level (MD and JP) using Covidence software.¹⁶ Conflicts were resolved by majority vote (MD, JP, JJP/FR).

Data extraction and synthesis

In accordance with the study protocol, data were extracted using a charting form developed by a multidisciplinary team and a patient representative (see online supplementary appendix 4) and entered in Microsoft Excel¹⁷ and MAXQDA¹⁸ software (MD). The following revisions were made to the protocolled data charting process. We extracted patient data on the living area (rural vs urban), employment status, educational background and state of mental health. Furthermore, since information from primary studies did not always fit into positive/negative/bivalent experience categories, we extracted the main results of reported experiences verbatim, whenever possible.

Population and study characteristics were summarised quantitatively using both tabular formats and narrative description. We calculated means for metric data and frequencies for nominal data. Where extracted nominal data from primary studies did not allow obvious categorisation, we developed inductive categories (MD). Information on the professional background of the author(s), the journal and the study objective was used to allocate primary studies to research areas.

Healthcare services were reported in accordance with the European Health Observatory on Health Systems categorisation,¹⁹ which allows replication of this work in the healthcare contexts of other countries. We expanded these categories to include healthcare services that were rated important by the patient representative and

mentioned in German clinical practice guidelines on CHF.²⁰

Following the approach of textual narrative synthesis,²¹ we grouped the included studies into subgroups according to the primary healthcare context under review. Within subgroups, we then produced commentaries for each individual study using direct quotes when possible.

Thematic dimensions of HCX were developed both, inductively and deductively using the 12 categories of patient-centred care published by Scholl *et al.*²² In order to identify research foci and research gaps regarding the range of HCX studied, deductive categories pragmatically served to ‘set the scene’. Main results of the individual studies extracted included the authors’ conclusions on HCX studied, reported findings on HCX derived from the results section or individual patient data in the format of quotes. All textual material was paraphrased and, if adequate, allocated to 12 deductive categories: essential characteristics of the clinician, clinician-patient relationship, patient as a unique person, biopsychosocial perspective, clinician-patient communication, integration of medical and non-medical care, teamwork and teambuilding, access to care, coordination and continuity of care, patient information, patient involvement in care, involvement of family and friends, patient empowerment, physical support and emotional support.²¹ As some textual material describing HCX did not fall into these categories, thematic codes further emerged from paraphrases during a second and third run through the material.

However, since reports of healthcare services varied, a subgroup synthesis was not performed. However, a frequency analysis of healthcare services and thematic

dimensions of HCX was performed across all included publications and shown graphically.

Patient and public involvement

Unlike research on patient experiences derived from secondary data sources such as health claims data, this scoping review aims at mapping literature on HCX in patients with CHF from a genuine patients’ perspective. Consequently, we partnered with a patient representative to specify outcome variables to be extracted and to refine the research question. This research is part of a wider research project that includes online dissemination of a healthcare report to lay audiences with the purpose of providing patients with accessible information to start engaging in future patient and public involvement initiatives.

RESULTS

Number of publications that report healthcare experiences of patients with chronic heart failure in Germany

Following deduplication, our search of electronic databases and grey literature resulted in 1489 references. Of these, 1384 references were excluded based on information in title and abstract, so that 105 references were assessed for eligibility based on their full texts. Of these, 87 were excluded, mainly because publications did not report patient experiences related to healthcare services, information was not provided by the patient or studies did not (separately) examine the German context. Figure 1 provides details of the screening process. Ultimately, 18 publications were included in this review.

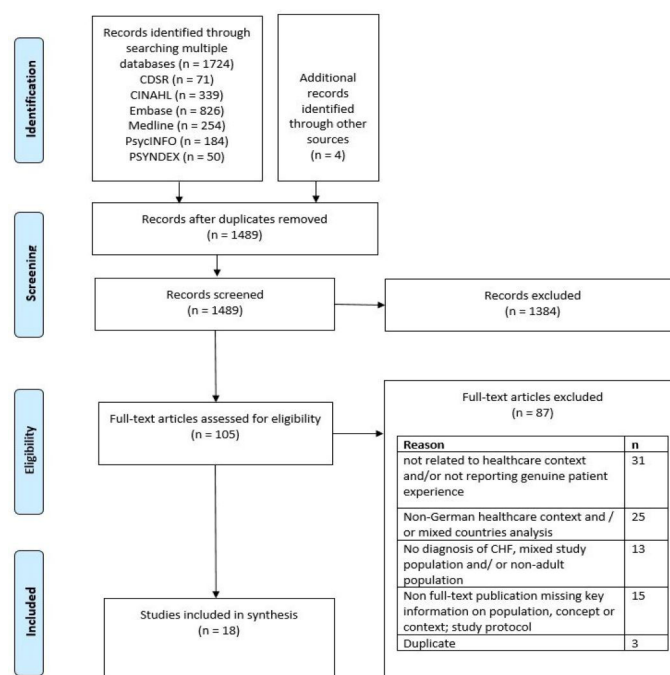


Figure 1 Study selection process. CHF, chronic heart failure.

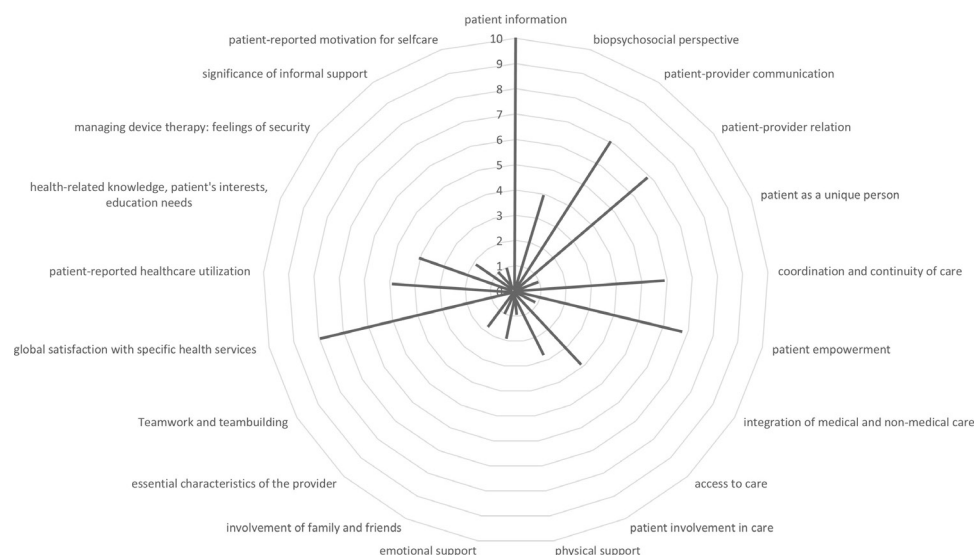


Figure 2 Number of times specific topics associated with healthcare experiences were described.

Thematic dimensions of healthcare experience addressed

The objectives of the studies varied (see online supplementary appendix 5). The majority of studies aimed to evaluate the relational aspects of how patients experience the interaction with providers.^{23–33} Some assessed, for instance, patients' utilisation of healthcare services,^{28 31 34–36} or the knowledge they gained by using certain services,^{23 28 37 38} others collected less impersonal data.

Figure 2 depicts the number of times specific topics associated with HCX were described in the included studies. In the majority of cases, a single study addressed multiple topics. Over half of the studies reported experiences with patient information.^{23–26 28 31–33 36 38} These included topics such as the kind of information patients were interested in,^{23 28 33 38} information seeking,^{23 25 28 31} the emotional response to information^{26 38} and the quality of available information.^{23 28 32} Global satisfaction with providers, technical devices, therapies, financial support and educational programmes was the second most commonly reported topic in the studies.^{23 26 28 30 32 38 39} Experiences of patient-provider communication,^{24 25 27 28 31 32 36} relationships^{23 27 28 30 32 33 36} as well as patient empowerment,^{24 25 27 30 36 38 39} were addressed in seven of the 18 studies, thus focusing on relational aspects of experiences, while coordination and continuity of care were reported in one-third of studies,^{26 28 29 31 32 36} reflecting a focus on the organisational dimensions of HCX. Little research explored experiences with emotional or physical support,^{30 32 38} the integration of medical and non-medical care,³¹ essential characteristics of the provider,^{27 28} patient perceptions of being a unique person²⁷ and the involvement of family and friends.³⁸ No study investigated experiences of patients with teamwork and teambuilding of healthcare providers.

The range of publications, study designs and academic discipline that deal with healthcare experiences in patients with CHF in Germany

The majority of studies were published in international and German academic peer-reviewed journals.^{23–27 29–34 38–40}

As we also performed grey literature searches, one in five references were doctoral theses.^{28 35–37} The included references were published between 2008 and May 2018, with approximately half having been published within the past 3 years, possibly indicating a slight upward trend in publication activity. With regard to study design, most publications were designed as observational studies (61%)^{23–26 30 31 34 35 37 38 40} followed by qualitative (22%)^{27 28 32 33} and interventional studies (18%).^{29 36 39} We found no systematic reviews or non-clinical study designs, such as preference-based experiments. Accordingly, sample sizes varied substantially, ranging from 17 to 475 subjects per study. The majority of research stemmed from the health and medical sciences. Table 1 summarises the synthesised study characteristics, while online supplementary appendix 5 details study characteristics for each included reference. The studies' objectives varied substantially, reflecting diversity in study design and research area.

Demographics of patients included in the primary studies

Table 2 summarises synthesised findings of the study populations, while online supplementary appendix 6 details population characteristics for each included reference. Overall, 1868 patients were included in the primary studies of this review. One-third of patients were women. No study reported information on ethnicity or insurance status of patients, and fewer than half the studies reported data on relationship status,^{23–26 28 35 37 39} housing situation,^{24 26 28 29 31 34} employment status^{23 25 31 32 35 39} and educational background.^{23–25 31 37 39} Forty-four per cent of studies provided no data on comorbidities, risk factors and mental health. CHF was not further specified in the majority of studies.

Research activity across healthcare services

The evidence map in figure 3 shows the number of studies that reported HCX for different healthcare services and according to study design. It is of note that

Table 1 Study characteristics of included studies

Study characteristics (n=18)	Number (%)
Year of publication	
2008–2012	5 (28)
2013–2018	13 (72)
Type of publication	
Journal article	14 (78)
Doctoral thesis	4 (22)
Study design	
RCT	3 (17)
Longitudinal study	6 (33)
Cross-sectional study	5 (28)
Qualitative study	4 (22)
Research area*	
Health services research	8 (44)
Health education	6 (33)
Psychosomatic medicine	5 (28)
Geriatrics	3 (17)
Family medicine	3 (17)
Cardiac surgery	3 (17)
Rehabilitation science	3 (17)
Palliative medicine	2 (11)
Pharmaceutical care	2 (11)
Nursing	1 (6)
Telemedicine	1 (6)
Sample size	
10<n≤25	3 (17)
25<n≤100	10 (56)
100<n<200	3 (17)
200<n<500	2 (11)
Methods of assessment	
Interviews	5 (28)
Survey	12 (67)
Group discussion	1 (6)
Method of evaluation	
Qualitative	4 (22)
Quantitative	12 (67)
Mixed	2 (11)

*Multiple selection possible.
RCT, randomised controlled trial.

most studies could not be exclusively allocated to one healthcare context, and HCX was reported for multiple healthcare services within a single study. For example, 7 of 18 studies reported patient experiences with hospital care,^{24–26 28 32 33 36} of which one study was a randomised controlled trial (RCT)³⁶ (from a total of 3 RCTs identified in this review, see figure 3). Overall, research activity was spread non-uniformly across healthcare

Table 2 Population characteristics of included studies

Population characteristics (n=1868)	Outcome	Reported in n studies
Mean age	67 years	16
Age range	23–100 years	6
Sex (% female)	31%	18
Ethnicity	–	0
Insurance status	–	0
Relationship status		8
Married, steady relationship	64%	
Single, divorced, widowed, others	36%	
Housing situation		6
Living together	56%	
Living alone	23%	
Assisted living, nursing home, home care	21%	
Employment status		6
Employed	27%	
Non-employed, retired, others	73%	
Educational background		6
Minimum of 10 school years completed	84%	
Minimum of 13 school years completed	16%	
Severity of symptoms		15
NYHA I	8%	
NYHA II	43%	
NYHA III	35%	
NYHA IV	14%	
Comorbidities, risk factors, state of mental health	Diverse	10
Type of heart failure		8
Aetiology	Diverse	3
Pathophysiology	HFrEF, HFpEF	6
Localisation	Global failure, left ventricular failure	1
Therapeutic characteristics	Diverse	16

HFpEF, heart failure with preserved ejection fraction; HFrEF, heart failure with reduced ejection fraction; NYHA, New York Heart Association.

services and study designs, indicating gaps and foci in research activity. Research was mostly undertaken to investigate HCX in ambulatory care settings (11/18 studies),^{24–26 28 31–36} and predominantly based on qualitative^{28 32 33} and cross-sectional evidence.^{24–26 35} Hospital care (7/18 studies),^{24–26 28 32 33 36} rehabilitation and

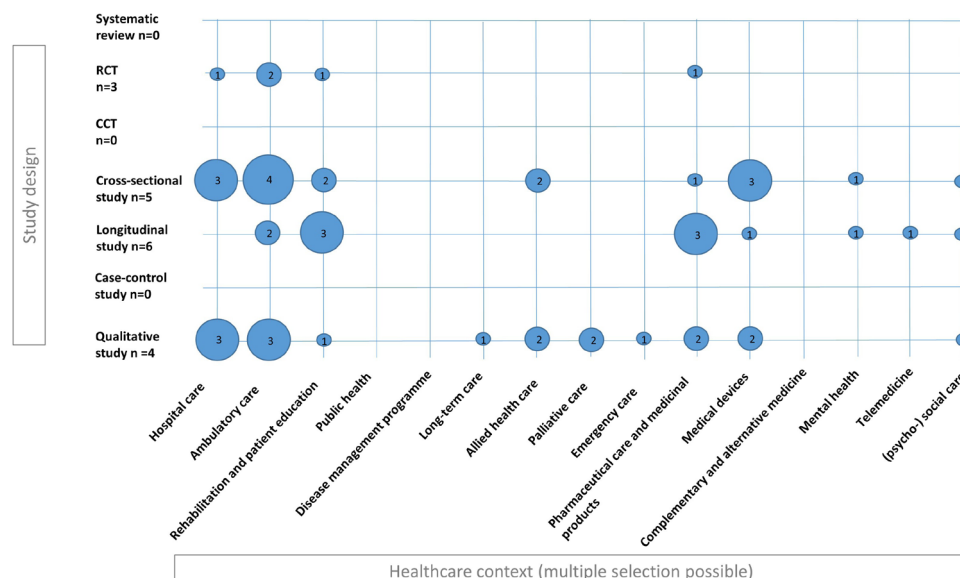


Figure 3 Number of publications according to healthcare context and study design. CCT, clinically controlled trial; RCT, randomised controlled trial.

patient education,^{23 24 26 31 32 38 39} pharmaceutical care and medicinal products^{23 25 31–33 36 37} as well as medical devices^{25 26 30 32 33 40} (the majority of which were investigated using observational studies) were less frequently investigated. Little research activity was observed for HCX with emergency care services,²⁸ allied healthcare,^{26 32 33 35} long-term care (1/18 studies),²⁸ mental healthcare (2/18 studies),^{31 35} psychosocial healthcare (3/18 studies)^{26 31 32} and telemedical care.³⁰ No research investigated HCX with public health, disease management programmes and complementary and complementary medicine. Qualitative studies covered the widest range of healthcare services.

Methods of assessing and evaluating healthcare experiences

Surprisingly, HCX was mostly evaluated quantitatively (10/18 studies) using questionnaires,^{23–25 29 30 35 36 38 40} of which most were self-developed, as well as one interview.³⁴ Only six studies used qualitative evaluation (interviews,^{27 28 31 32} group discussion³³ and questionnaire³⁹). Two of 18 studies used mixed methods analysis.^{26 37}

Rurality, urbanity and healthcare experiences

It was not possible to determine the geographical location of reported HCX precisely, as the individual studies did not report patient residence codes. Only one study specifically provided information on whether reported HCX were assessed in rural, suburban or urban areas.

DISCUSSION

The aim of this study was to systematically review the past 10 years of research activity into the HCX of patients with CHF in Germany. We identified the following research foci. HCX were generally evaluated quantitatively (60%). Most studies were observational (60%). Contributions came from health services research (44%), health

education (33%) and various medical disciplines. They primarily reported HCX in terms of patient information, global satisfaction, patient-provider relationships and communication. In descending order of frequency, HCX were reported for ambulatory care, hospital care, rehabilitation, pharmaceutical care and medicinal products, and the provision of medical devices. Overall, the heterogeneity of included studies' outcomes was substantial and permitted only relatively trivial levels of synthesis.

The investigation on patients' genuine views on healthcare services is an important goal in itself and must not exclusively be viewed as a means for healthcare systems to manage care more efficiently.¹¹ We therefore excluded papers that reported HCX only from a provider perspective, or that analysed only health claims data. In this way, we assessed actual and (lived) experience and how they expressed itself emotionally and cognitively. Studies of this review examined experiences in terms of satisfaction, preferences, knowledge and desires rather than actual experience. Actual experience was understood to refer to quantitative information (eg, number of consultations with the doctor), relational experience (eg, interaction with provider perceived to need improvement) or organisational experience (eg, too little time to communicate with doctor).

This review maps the body of literature on HCX in both a population-specific and a country-specific context. This was necessary because system design and a particular (set of) condition(s) determine the healthcare realities that patients face. Results of this review may therefore not be transferable to different countries or patients with different conditions straightforwardly. The synthesis of qualitative evidence investigating experiences of patients with multimorbidity around the globe has found that the magnitude of perceived treatment burden is determined, among other things, by contextual factors such as the

healthcare system and social environment.⁴¹ However, transferring this research to other care contexts can be performed by adjusting the search strategy.

A recently published scoping review reported ways to describe gaps and research priorities in health literature and found that research gaps mainly fell into three categories: missing information, inadequate information and insufficient information—all of which the present scoping review confirms.⁴²

Missing information

Our results suggest that information on HCX in patients with CHF from systematic reviews and meta-research does not exist. The paucity of research in this field either suggests the phenomenon of HCX lacks the theoretical substantiation that is required before empirical research can be undertaken, or it may indicate that in Germany, the development of this particular research field is in its infancy.

Inadequate information

Surprisingly, despite increasing interest in patient experiences with quality of care, no study was carried out with the specific aim of assessing HCX. Individual studies tended rather to report HCX as an outcome that was not directly linked to their main objective, and was not mentioned in the title or abstract.

We found primary studies gave too little sociodemographic information (eg, insurance status, educational background or state of mental health) on the study population to provide the necessary context for a sound interpretation of HCX in the form of a full synthesis. For instance, patients with CHF are at considerable risk of cognitive decline and of having other mental health conditions,^{43 44} which can shape HCX. It is therefore essential that primary studies provide adequate information on such factors in the future.

The healthcare services studied in the included publications were not always congruent with the list of care providers provided by the patient representative. Specifically, disease management programmes and heart failure nurses that patients rated as important have not been adequately reflected in research. This may indicate a gap in the coverage of certain important healthcare services.

Insufficient information

The importance of rurality and urbanity in influencing HCX could not be assessed, as primary studies lack sufficient data on where patients live. However, the increasing prevalence of CHF in the rural population suggests that investigations of HCX should take into account where the patient resides.⁴⁵

Although 6 of the 18 studies were of a longitudinal nature, they provided little information on changes in HCX throughout the patient's lifetime and throughout the course of the illness. According to the theoretical framework of complex adaptive chronic care,⁴⁶ patients typically experience periods of stability, self-management

and routine care combined with acute exacerbations, as well as complex and unstable phases that often demand inpatient health services. Hence, patients journey through different stages of their disease and through diverse healthcare settings along their chronic illness trajectories.

Traditionally, HCX assessment has been extensively used in inpatient sectors, but patient-reported measures of HCX are increasingly being developed for multiple healthcare settings or specific populations.^{47 48} Such patient-reported outcome measures may be used to develop innovative reimbursement models or metrics to assess the performance of healthcare systems.⁴⁹ Against the background of such diverse opportunities for the application of HCX, we must consider the concept of patient experience as a source of information that can enable us to increase quality of care rather than as a tool to measure cost efficiency in competing healthcare providers.

This review also emphasises the dominant role of the application of quantitative methods in exploring patient experiences. However, the application of qualitative research (synthesis) may help explore and conceptually carve out phenomena such as patient experience with healthcare. Furthermore, HCX can be measured in many different ways and make use of varying levels of generalisability and information.⁵⁰ Nonetheless, in this review, we found that the methods used to assess HCX were mainly interviews, surveys and group discussions, indicating that the use of other methodologies may result in considerable gains.

LIMITATIONS

Overall, the considerable heterogeneity of the included studies' outcomes only permitted relatively trivial levels of synthesis. Moreover, data extraction was performed by a single researcher, so the generation of codes and allocation of data to inductive categories lacks triangulation and may therefore reflect the single researcher's perspective.

In retrospect, as burden of treatment is increasingly being investigated and is closely linked to the broad range of topics that comprise HCX, we may have missed some publications by not including this term in the search strategy.

Although a patient representative was involved in defining relevant extraction categories, we think that involving patients in the review process further would offer valuable insights into the identification of patient-relevant research gaps. The scoping review methodology may help in identifying these gaps.

Importantly, study quality of the included publications was not assessed. The outcomes of HCX reported herein may therefore be subject to methodological problems in the conduct of the primary studies included in this review, such as small sample sizes or bias introduced by interviewer effects. Appraising study quality would be a necessary step if full evidence synthesis was the aim.

CONCLUSION

Overall, research activity is characterised by substantial heterogeneity in formulated study aims and the reported outcomes of healthcare experience. Consequently, an in-depth thematic synthesis of the results is not indicated at this stage. However, more and precise primary research may provide information from (qualitative) systematic reviews that is focused on specific thematic dimensions of healthcare experience or a particular healthcare setting, and this may support the development of an evidence-based understanding of patient experiences with CHF-specific healthcare in Germany.

Research into the HCX of patients with CHF in Germany is characterised by missing, insufficient and inadequate information. Replication of this work with a focus on other countries' healthcare systems will help systematically investigate the HCX of patients with CHF. In Germany, future research should specifically address the following:

- ▶ Scientific analysis of patients' HCX based on data from digital sources such as consumer platforms, social media and patient's blogs, as these data sources may deliver insightful information to complement that gained using the traditional assessment methods that have been used so far.
- ▶ Investigation of HCX in understudied healthcare contexts to improve the patient experience holistically and not exclusively for individual providers and services.
- ▶ More evidence from qualitative studies for an in-depth understanding of the concept of HCX.
- ▶ If possible, sociodemographic patient information should be reported in detail in primary studies, as it provides an important context for the interpretation of HCX.
- ▶ Evidence from longitudinal studies should assess patient opinions at multiple time points along the disease trajectory, as experience is likely to shift in line with changing symptoms.
- ▶ Evidence of the HCX of female subjects, as they were not equally represented in the studies under review.

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Contributors JJP, AS and FMG conceptualised this work. KJ, TS, AS, JJP, FR and MD developed the search strategy. JJP, MD, FR and JP were involved in screening and selection processes. MD extracted data and analysed the extracted results together with CG. All authors critically revised and approved the manuscript.

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Competing interests JJP is a co-investigator in the PANORA study ('Prevalence of anticyclic 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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Appendix 1: Search strategy for electronic database searches

	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	(MH "Heart Failure+") [not applicable for PsycINFO and PSYINDEX]
2	TX ((myocard* OR cardia* OR heart) N3 (insufficien* OR failure OR incompeten* OR decompensat*))
3	TX HF?#EF
4	TX CHF
5	TX (NYHA OR (New York Heart Association Class))

6	TX (herzinsuffizien* OR herzversagen OR myokardinsuffizien*)
7	TX (ejektionsfraktion OR auswurfleistung)
8	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7
9	TX ((client* OR consumer* OR individu* OR klient* OR patient* OR pers* OR nlich* OR personal OR subje* OR user*) N3 (accept* OR attitude* OR barrier* OR bed* OR 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* OR ffer* OR report* OR satisf* OR sicht* OR stimme OR trust* OR understand* OR verst* OR ndnis OR verstehen OR vertrauen OR view* OR voice* OR zufrieden*))
10	TX (("health care" OR (health N2 service*)) N3 access*)
11	TX (patient* N3 (flow OR journey*))
12	TX (arzt-patient* N3 (beziehung* OR interaktion* OR kommunikation OR verh* OR tnis))
13	TX ((professional-patient OR nurse-patient OR physician-patient OR doctor-patient OR practitioner-patient) N3 (relation* OR communication OR interaction*))
14	TX (burden* N2 treatment)
15	TX (shared N1 decision-making)
16	TX ((partizipativ* OR gemeinsam* OR geteilt*) N1 entscheid*)
17	TX ((waiting N1 time*) OR wartezeit*)
18	TX (PREM OR "patient-reported experience measure*")
19	TX (care N3 (pathway* OR continuity OR transition* OR coordination))
20	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
21	(MH "Germany+") [not applicable for PsycINFO and PSYINDEX]
22	TX (german* OR deutsch*)
23	AF (german* OR deutsch*) AND LA (german OR ger)
24	S21 OR S22 OR S23
25	LA (english OR eng OR german OR ger)
26	S8 AND S20 AND S24 AND S25
27	Limiters - Published Date: 20080101-20181231

Search Strategy for Cochrane Database of Systematic Reviews (CDSR)	
1	MeSH descriptor: [Heart Failure] explode all trees
2	((myocard* OR cardia* OR heart) NEAR/3 (insuffizien* OR failure OR incompeten* OR decompensat*)):ti,ab,kw
3	(HF*EF):ti,ab,kw
4	(CHF):ti,ab,kw
5	(NYHA OR "New York Heart Association Class"):ti,ab,kw
6	(herzinsuffizien* OR herzversagen OR myokardinsuffizien*):ti,ab,kw
7	(ejektionsfraktion OR auswurfleistung):ti,ab,kw
8	{OR #1-#7}
9	((client* OR consumer* OR individu* OR klient* OR patient* OR pers* OR nlich* OR personal OR subje* OR user*) NEAR/3 (accept* OR attitude* OR barrier* OR bed* OR 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* OR ffer* 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
10	((("health care" or (health NEAR/2 service*)) NEAR/3 access*)):ti,ab,kw
11	(patient* NEAR/3 (flow or journey*)):ti,ab,kw
12	(arzt-patient* NEAR/3 (beziehung* or interaktion* or kommunikation or verh*tnis)):ti,ab,kw
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
14	(burden* NEAR/2 treatment):ti,ab,kw
15	(shared NEXT decision-making):ti,ab,kw
16	((partizipativ* or gemeinsam* or geteilt*) next entscheid*)):ti,ab,kw
17	((Waiting NEXT time*) or wartezeit*)):ti,ab,kw
18	(PREM or "patient-reported experience measure*"):ti,ab,kw
19	(care NEAR/3 (pathway* or continuity or transition* or coordination)):ti,ab,kw
20	{or #9-#19}
21	{and #8, #20}
22	[Using Custom Range for specifying years of publication 2008-2018]

Appendix 2: List of organizations whose webpages were searched for grey literature sources

Deutscher Paritätischer Wohlfahrtsverband, Gesamtverband e.V. (DPWV)

<https://www.der-paritaetische.de/verband/ueber-uns/>

Deutsche Arbeitsgemeinschaft Selbsthilfegruppen e.V. (DAG SHG)

<https://www.dag-shg.de/>

Bundesverband der Organtransplantierten

<https://bdo-ev.de/bdo/>

Deutsche Gesellschaft für Prävention und Rehabilitation von Herz-Kreislaufkrankungen e.V.

<https://www.dgpr.de/home/>

Deutsche Gesellschaft für Verhaltensmedizin und Verhaltensmodifikation e.V.

<https://www.dgvm-online.de/index.php>

Deutsche Gesellschaft für Kardiologie (DGK)

<https://dgk.org/>

KBV Versichertenbefragung

<http://www.kbv.de/html/versichertenbefragung.php>

Institut für angewandte Qualitätsförderung und Forschung im Gesundheitswesen

<https://www.aqua-institut.de/>

Deutsche Zentrum für Herzinsuffizienz (DZHI)

<http://www.chfc.ukw.de/startseite.html>

Kompetenznetz Herzinsuffizienz

<http://knhi.de/network/>

Bundesarbeitsgemeinschaft Pflegeexperten Herzinsuffizienz

<http://www.pflegeexperten-herzinsuffizienz.de/>

Dt. Zentrum für Herz-Kreislauf-Erkrankung e.V.

<https://dzhk.de/>

Verbraucherzentrale

<https://www.verbraucherzentrale.de/>

Bertelsmann Stiftung

<https://www.bertelsmann-stiftung.de>

Wissenschaftliches Institut der AOK

<https://www.wido.de/>

Wissenschaftliches Institut der PKV

<http://www.wip-pkv.de>

Deutsche Krankenhausgesellschaft

<https://www.dkgev.de/>

IQWiG

<https://www.iqwig.de/>

IQTIG

<https://iqtig.org/>

DIMDI

<https://www.dimdi.de/dynamic/de/weitere-fachdienste/versorgungsdaten/>

BZgA

<https://www.bzga.de/>

Zentralinstitut für die kassenärztliche Versorgung in der Bundesrepublik Deutschland

<https://www.zi.de/>

Dipex Germany

<http://www.krankheitserfahrungen.de/>

Appendix 3: Search terms used to identify grey literature sources in the following databases

- ProQuest, 02 Jan 2019, 40 hits
("heart failure" OR CHF OR cardiac failure) AND (germany OR deutschland)
- DART-Europe, 02 Jan 2019, 127 hits

Country: Germany, “Herzinsuffizienz”, “patient*”

- Deutsche Nationalbibliothek [German National Library], 17 Apr 2019, 284 hits

herzinsuffizienz and patient* and (diss* or habil*)

Appendix 4: Data charting form

First author
Year of publication
Type of publication
Academic discipline/ research area
Sample size
Study objective
Authors’ main conclusion with regard to HCX
Thematic dimension of patient experience (based on dimensions of patient-centered care developed by Scholl et al., 2014 ²¹ and extended to include inductive categories)
Study design
Geographical setting (i.e. federal state, area code, urban vs rural area) where patients experienced care
Healthcare context (based on an outline by Busse and Blümel ¹⁹ and extended to include health care settings mentioned in German clinical practice guidelines ²⁰ and considered relevant by a patient representative)
Methodology used to assess patients’ experiences
Method of assessment (qualitative, quantitative, mixed-methods)
Study population
<ul style="list-style-type: none"> • Mean age
<ul style="list-style-type: none"> • Sex
<ul style="list-style-type: none"> • Ethnicity
<ul style="list-style-type: none"> • Insurance status
<ul style="list-style-type: none"> • Relationship status
<ul style="list-style-type: none"> • Housing situation
<ul style="list-style-type: none"> • Employment status
<ul style="list-style-type: none"> • Educational background

<ul style="list-style-type: none">• State of mental health
<ul style="list-style-type: none">• Severity of symptoms (NYHA)
<ul style="list-style-type: none">• Co-morbidities or risk factors
<ul style="list-style-type: none">• Type of CHF (in terms of localization, etiology or pathophysiology)
<ul style="list-style-type: none">• Therapeutic characteristics (i.e. implanted device therapy, pharmacological therapy)

Appendix 5: Study characteristics and results

First Author / Year /	Study objective (where possible verbatim)	Study design / n / Method of Assessment / Method of Evaluation	Reported healthcare experiences and their <i>thematic dimension</i> (arrived at both inductively and deductively according to Scholl et al's dimensions of patient-centered health care ²¹)	Main theme
Muschalla / 2011 [38]	To test a "newly developed patient education program [concerning] patients' acceptance, changes in disease-related knowledge, perceived health- and illness-related quality of life, and mental symptoms".	Longitudinal design / 64 / Questionnaire / Quantitative	<ul style="list-style-type: none"> • The newly developed heart failure rehabilitation program helps patients improve knowledge of their condition, reduce anxiety and depression and improve their quality of life. • Patients reported a high subjective training need and interest in medical information on the disease and treatment. • For the majority of patients, the information gain primarily provides security • Some negative statements related to the room and the "less realistic dietary advice" • An appointment with the partner was proposed <i>Patient empowerment, patient information, involvement of family and friends, emotional support, increase in knowledge, need for health education, global satisfaction (with an education program)</i>	Rehabilitation, patient education
Meng / 2016 [39]	Evaluation of "[...] a patient-centered self-management educational group program for patients with chronic systolic heart failure as compared to usual care education during inpatient cardiac rehabilitation".	RCT / 475 / Questionnaire / Qualitative	<ul style="list-style-type: none"> • Compared to a standard lecture-based program, the patient-centered training program increased patient satisfaction with treatment in terms of content and group interaction, but not in terms of materials -. • "[...] significant small between-group intervention effect on certain dimension of patients' self-management competence" <i>Patient empowerment (adherence to medication and exercise; symptom control), global satisfaction (with an education program: education materials, group interaction, program content)</i>	
Meng / 2009 [23]	To explore the subjective needs of CHF patients for health-related educational training (existing level of knowledge, interest in educational training, interest in participating in educational training programs) within the context of rehabilitation and to evaluate an educational training program.	Longitudinal design / 106 / Questionnaire / Quantitative	<ul style="list-style-type: none"> • High subjective training need of patients • Patients were very interested in basic medical knowledge on heart failure and information on CHF therapy (including nutrition, symptom control, exercise, alcohol) as well as information on how to transfer information into everyday life, but less interested in information about smoking behavior and coping strategies • Interest in psychocardiological knowledge from educational training programs was more diversified and is associated with patients' psychological burden. • On average, patients rated the educational training program they received to be good or very good • Approx. 75% of patients preferred to be involved in shared decision making than a paternalistic patient-doctor relationship (for younger patients, no gender differences). This patient collective had greater interest in educational programs. • 43% of patients said they had been well informed about the disease by doctors, 20% rated the information provided by doctors to be of bad quality • Half the patients actively searched for disease-related information themselves • Patients explicitly expressed the wish for SDM (n=44), better quality information (n=11) and more positive patient-doctor relationships <i>Provider-patient relationship, patient involvement in care, patient information, need for health education, increase in knowledge, global satisfaction with education program)</i>	

Köberich / 2016 [24]	"[...] to investigate heart failure patients' attitudes towards and the factors influencing diary use".	Cross-sectional design / 53 / Questionnaire / Quantitative	<ul style="list-style-type: none"> • Patients rated the one-hour self-care training on heart failure as helpful and good • Younger patients and single patients are less likely to keep a journal than older people and patients living with someone • Only about half the patients still used the diary 3 months after the intervention; body weight and blood pressure were recorded more frequently than edema. The diary was used for personal reasons and not primarily because the doctor requested it. Among diary-users, most patients stated that it was suitable for everyday use and as a structuring tool, and that it was useful for informing health professionals about their current state of health • Reasons not to use the diary were: no perceived need for it, stable vital parameters, ability to recognize symptoms of exacerbation without it, good subjective well-being. Patients did not use the diary because their doctor regularly collected the data anyway (27.3%) because the family doctor did not ask for a diary (27.3%) because the cardiologist did not ask (22.7%) because the nurse did not ask (4.5%) <i>Patient information, patient empowerment (symptom control), provider-patient communication, motivation for self-care</i>	Device therapy (VAD)
Dahrmann / 2017 [25]	"This study evaluated health-related QoL with both therapy options [LVAD vs optimised medical management]"	Cross-sectional design / 100 / Questionnaire / Quantitative	No significant group differences between LVAD therapy vs. optimal medical therapy in terms of information and communication, need for participation, patient activation, information-seeking behavior, and shared decision-making <i>Provider-patient communication, patient information, patient empowerment, patient involvement in care</i>	
Berg / 2017 [26]	To study "the requirements for outpatient care [...] from the perspective of VAD patients".	Cross-sectional design / 30 / Questionnaire/ Mixed Methods	<ul style="list-style-type: none"> • VAD patients and their relatives feel confident using the device after an initial phase of habituation. Information, accessibility and regular contact, even without a specific reason (e.g. routine visit to the polyclinic), convey the feeling of being able to cope with living with a VAD system • The support of relatives at home was important to patients • With regard to application, patients felt confident using the device. Over 80% of patients felt they had been well-informed. • 80% of the patients told nurses they were confident using the device • About half the patients stated that the support of case managers and social services was helpful • Approx. 70% of patients were satisfied with physiotherapy and rehabilitation after surgery • Good support at home and regular contact with the polyclinic - without regular appointments – was considered more important than good accessibility to the clinic and outpatient practices <i>Perceived safety of technical device, informal home support from case manager or social health service, professional handling of device by nurses and patient, global satisfaction (with rehabilitation and physiotherapy after surgery), access to care, coordination and continuity of care, patient information</i>	
Meyer / 2010 [40]	"[...] to evaluate the quality of two different [LVAD] systems based on patients' perspective [...]".	Cross-sectional design / 27 / Questionnaire / Quantitative	"Overall patients' satisfaction was high [despite] dissatisfaction with: loudness of the power base unit & length of the driveline" <i>Satisfaction (with technical device)</i>	
Werdecker / 2018 [27]	To analyze perceptions of ACP consultations in patients with advanced heart failure.	Qualitative study / 67 / Interviews / Qualitative	<ul style="list-style-type: none"> • In an ACP consultation, patients view the following as success factors: atmosphere, time allowed, respectful interaction and mutual communication, trust as well as consideration of individual patient needs (e.g., information needs, worries, and fears). • Patients view ACP consultations as an open process: Willingness to participate in such conversations must be given to the individual. • Five different types were identified empirically: 1) patients refused further involvement in ACP, 2) decision-making concerning end-of-life issues was encouraged, 3) decision were made 4) patients confirmed or reevaluated their existing ACP, 5) patients avoided engaging further with the topic and relied on their existing ACP <i>Essential characteristics of the clinician (respect), provider-patient communication (mutual conversation, time for communication), provider-patient relationship (trust), patient as an empowered person (consideration of patient preferences)</i>	Palliative care and older adults with CHF
Klindtworth / 2015 [28]	"[...] to understand how old and very old patients with advanced HF perceive	Qualitative study/ 25 /	"[...] older patients do not experience HF as a life-limiting disease. [...] The needs and priorities of older HF patients vary depending on their disease status and individual preferences. [...] Many older HF patients lack sufficient knowledge about their condition and its prognosis, particularly with regard to emergency situations and end of life issues, and many expressed	

	their disease and to identify their medical, psychosocial and information needs, focusing on the last phase of life."; "[...] explore the needs of older patients with advanced heart failure, and their experiences with health care delivery in Germany".	Interviews / Qualitative	a wish for open discussions. From the patients' perspective, there is a need for improvement in interaction with health care professionals, and limits in treatment and medical care are not openly discussed" <i>Provider-patient communication (prognosis, time for communication), patient information (quality of information, prognosis, information-overload, comprehensibility, GP as main source of information, coordination and continuity of care (dissatisfaction with inpatient sector), provider-patient relationship (respect), essential characteristics of the provider (empathy, friendliness, competence), access to care (financial burden), knowledge (prognosis, emergency situation, end-of-life), healthcare utilization (palliative care, outpatient cardiologist, GP), global satisfaction (regarding ambulant nursing, financial support for informal caregiving)]</i>	
Scherer / 2008 [34]	"[...] to determine which psychosocial factors influence primary care patients' consultation frequency in the case of heart failure"	Longitudinal design / 310 / Interview / Quantitative	<ul style="list-style-type: none"> • patients visited their family doctor an average of 8.2 times over 9 months • "Low self-rated severity of heart failure was associated with infrequent attendance [...] women and patients living alone were more likely to consult their GP at least twice per month" • "[...] High primary care utilization was also influenced by anxiety and depression as well as by physical problems" <i>Healthcare utilization (GP visits)</i>	Family practice
Peters-Klimm / 2010 [29]	"[...] explore the effectiveness of a new model of CHF case management conducted by doctors' assistants (DAs, equivalent to a nursing role) and supported by general practitioners (GPs)."	RCT / 199 / Questionnaire / Quantitative	Improvements in quality of care as a result of a case management program (outpatient-primary care setting) compared to standard care <i>Coordination and continuity of care, biopsychosocial perspective, patient involvement in care</i>	
Knoll / 2013 [36]	"Investigates the extent to which a structured, interdisciplinary program between primary care physicians and pharmacists in the care of patients with [...] chronic heart failure, by means of improved adherence, can lead to a measurable improvement in therapeutic success (weekly visits to the pharmacist)"	RCT / 50 / Questionnaire / Quantitative	<ul style="list-style-type: none"> • At the end of the intervention, 20% of patients decided to continue using the weekly dosing service provided by the pharmacy at their own expense • The program did not affect hospital admissions • In the intervention group, patients were more satisfied with pharmacist care than they were at first <i>Coordination and continuity of care, provider-patient communication, patient empowerment (adherence to medication), patient information, provider-patient relationship, healthcare utilization (hospital admissions)</i>	Pharmaceutical care

Rohlehr / 2017 [37]	To assess patients knowledge regarding medication and self-reported medication adherence.	Longitudinal design / 111 / Questionnaire/ Mixed Methods	<ul style="list-style-type: none"> • Self-reported adherence was good to mediocre in most patients • Inadequate knowledge about disease-specific drugs overall. In declining order, patients knew about medication effects, administration time, drug name and dose • Declining knowledge after discharge • Women had more advanced knowledge • Socio-demographic factors such as education or family status correlated with drug knowledge • Medication knowledge correlates positively with the use of a medication plan and self-preparation of the medication • Drug knowledge of patients with acutely decompensated heart failure needs improvement • Despite a slight increase in knowledge about ongoing therapy, the long-term results over the course of the disease were sometimes worse than a state of acute decompensation <i>Knowledge, self-reported adherence</i>	
Müller / 2013 [30]	"[...] a concept using a telemedical service center to manage [home monitoring] data was developed and investigated regarding patients' satisfaction, physicians' satisfaction, and alert filtering."	Longitudinal design / 55 / Questionnaire / Quantitative	The majority of patients stated that the telemedicine home monitoring program did not result in improved drug intake, but provided feelings of security, increased treatment satisfaction, and improved the relationship with the physician <i>Provider-patient relationship, physical support (medication adherence), patient empowerment, global satisfaction (with eHealth program)</i>	Telemedicine
Lossnitzer / 2015 [31]	"[...] to analyse the preferences and objections of CHF patients suffering from depressive symptoms regarding various psychosocial treatment options. After a period of three months we analysed how many patients had actually participated in a treatment."	Longitudinal design / 85 / Interview/ Qualitative	<ul style="list-style-type: none"> • "The most favoured treatment option was a low-threshold service with supportive talks [...] 64.7% [of respondents] [...] concerning topics such as quality of life, financial stressors, overall health, and/or social relationships – ideally in conjunction with appointments in the CHF Outpatient Department." • Preferences for treatment with psychotropic drugs were lower (34.1% of respondents) • "[...] 47.1% [of respondents] reported that they could not envision adhering to regular weekly psychotherapy sessions." • "[...] 14.1% [of respondents] reported that they would like more time with their treating cardiologist to address questions concerning their heart disease." • The most commonly used treatment options were cardiac exercise groups and supportive talks <i>Patient information, integration of medical and non-medical care, access to care, coordination and continuity of care, provider-patient communication, biopsychosocial perspective, healthcare utilization (psychosocial care)</i>	Social care and mental healthcare
Naumann / 2014 [35]	To study the influence of heart failure on the socioeconomic situation of the patient.	Cross-sectional design / 72 / Questionnaire / Quantitative	<ul style="list-style-type: none"> • The majority of patients visited their GPs 0-8 times a year and their cardiologists 0-2 times a year, with mental factors such as anxiety and anxiety associated with more frequent consultations. • Few patients were offered psychotherapeutic care. If offered, the offer was generally taken up. Few patients organized psychotherapy by themselves. About one third of patients were offered cardiac exercise programs to complement their treatment, which only half took advantage of <i>Healthcare utilization (GP and specialist services, psychotherapy and cardiac exercise therapy)</i>	

Baudendistel / 2015 [32]	"[...] to explore patient perspectives on guided treatment of CHF across multiple health care sectors. Furthermore, it was investigated to what extent patient perspectives are represented by quality indicators of the German National Disease Management Guideline."	Qualitative study / 17 / Interviews / Qualitative	<ul style="list-style-type: none"> • "[...] patients were mostly satisfied with their health care [...] especially in primary care" • "However, deficits were identified, especially related to communication and cooperation across health care sectors, especially at the transition between hospital and outpatient care." • "Patient experiences within the inpatient sector were often reported to be less positive, whereas most patients had good experiences with the GP's treatment in primary care." • "Patient needs focused primarily on doctor-patient relationship, communication, quality of information, and professional advice, as well as psychological support." • "However, patients also expressed relevant deficits regarding their health care. Particularly, patients reported shortcomings related to cooperation between health care professionals within the whole range of treatment across multiple health care sectors. Furthermore, they described structural deficits with regard to area-wide available services (e.g., patient education, counseling, and programs on physical exercise)." • Cooperation between the medical disciplines & health care sectors" was perceived important • "Pharmacological treatment was relevant to the interviewees, especially the quality of professional counselling was central [...]. Thereby, comprehensibility of the information provided was considered as important." • " [...] the provision of exercise training as a health service to patients did not get enough attention [...]." • "The need for psychosocial support, e.g., in coping with illness experiences, was addressed by several interviewees." • "Mostly, the GP was described as the primary contact person. He often was perceived as a coordinator." • "Deficits in information exchange and communication, especially on behalf of the inpatient sector, were expressed by the interviewees." • "Joint discussion of medical findings or fast information exchanges between, e.g., GPs and cardiologists were mentioned to be positive." • "Clear responsibilities and organizational processes, e.g., in case of application for a rehabilitation were relevant to the interviewees." • "The need for support in the community setting to cope with challenges in everyday life was a further important point [...]." • "Care in the advanced phase of chronic illness, respectively palliative care, was mentioned by some interviewees, especially in elderly. Issues like increasing dependency on care and the need to be under care at home were addressed." • "[...] having a contact partner, e.g. a GP or a health care assistant, and getting timely appointments [were] indicators for a good quality of health care [...]." <p><i>Global satisfaction (inpatient care and GP services in primary care), coordination and continuity of care, provider-patient communication, provider-patient relationship, patient information (comprehensibility, quality, professional counselling), emotional support, biopsychosocial perspective</i></p>	Overlapping themes
Herzberg / 2016 [33]	"[...] it was investigated [...] how relevant the existing quality indicators of the National Disease Management Guidelines for Chronic Heart Failure are being estimated [by patients]."	Qualitative study / 22 / group discussion / Qualitative	<ul style="list-style-type: none"> • Patients emphasize the social dimension of sports to belong to high-quality treatment • Patients mentioned a lack of information on cardiac rehabilitation through exercise from doctors and a lack of support by statutory health insurers • Patients spoke negatively about pharmaceutical care since drug administration was not sufficiently monitored by doctors • Patients accepted that surgical treatments were necessary interventions, but complained about a lack of information on the risk of complications and expressed a fear of being instrumentalized • Patients accepted the technical nature and the doctor's additional knowledge about diagnostic care, but said that knowledge was not communicated and diagnostic results not explained adequately • Regular follow-up visits were considered important, but patients wished to receive more support from doctors without having to insist themselves • Patients complained about difficulties gaining timely access to both inpatient and ambulatory cardiac health care <p><i>Patient information (cardiac rehabilitation, surgery-induced complications, medication, diagnosis, waiting times), biopsychosocial perspective, provider-patient relationship (fear of being instrumentalized), access to care</i></p>	

RCT: Randomized controlled trial; CHF: Chronic heart failure; SDM: Shared decision making; QoL: Quality of life; (L)VAD: (Left) ventricular assist device; ACP: Advanced care planning; GP: General practitioner; Approx.: Approximate

Appendix 6: Study and population characteristics of included studies

First author / Year / Type of publication / Location of healthcare services studied	Academic discipline(s)	Healthcare context	Mean age / Women % / Ethnicity / Insurance status / relationship status / housing situation / employment / educational background	Severity (NYHA) / type of CHF / somatic comorbidities & risk factors / state of mental health / therapeutic characteristics
Muschalla [38] / 2011 / Journal article / Longitudinal design / BW, Brandenburg	Health education, rehabilitation science, psychosomatic medicine	Rehabilitation and patient education	53 y. / 30% / NR / NR / NR / NR / NR / NR	mean NYHA 2.4 / EF≤ 40 %, 42.2% (Ischemic cardiomyopathy) / mean BMI (29.0), Overweight / HADS anxiety score > 10 (26%), HADS depressions score > 8 (36%) / mean duration cardiac Rehabilitation 27.2 days
Meng [39] / 2016 / Journal article, RCT / NS, NRW, Hessen, SH	Health education, rehabilitation science	Rehabilitation and patient education	62 y. / 22% / NR / NR / 13.6% (Single), 79.7% (married/partner), 12.0% (divorced/ separated), 11.4%(widowed) / NR / 39.6% (employed), 44.4% (retired), 8% (unemployed), 7.3% (other), 50.1% <10 SY, 23.7% (10 SY), 21.6% (13 SY)	NYHA II-III / chronic systolic heart failure / 77.4% (arterial hypertension); 57.2% (cholesterol); 31.1% (smokers); 28.2% (diabetes); 22.7%(positive family history) / Depression 24.1%, anxiety 24.6% / education program during inpatient cardiac rehabilitation (medical treatment, exercise therapy, psychological support, relaxation, social counselling), 33.9% with implanted device
Meng [23] / 2009 / Journal article / Longitudinal design / NRW	Health education, rehabilitation science	Rehabilitation and patient education, pharmaceutical care and medicinal products	69 y. / 16% / NR / NR / 82.9% (married), 10.5% (widowed), 2.9% (divorced), 3.8% (single) / NR / 88.6% (retired), 9.5% (working) / secondary education ≤ 10 years 92.3%, Secondary education 13 years 6.7%	NYHA I-IV / 1.9%(EF<25%); 59.2%(EF 25-39%); 37.9% (EF 40-55%); 1.0% (EF>55%) / Mean number of cardiac risk factors 3.4 / Approx. 75% of patients reported to feel under psychological pressure from the condition of heart failure / Patients received an educational training program in a rehabilitation clinic
Köberich [24] / 2016 / Journal Article / Cross-sectional design / South Germany	Health education, nursing	Hospital care, ambulatory care, rehabilitation and patient education	67 y. / 21% / NR / NR / 9.4% (single/unmarried); 64.2% (married); 15.1% (widowed); 7.5% (divorced) / 75.5% (living with someone); 17.0% (living alone) / NR / Educational level: 35.8% (≤9 SY); 26.4% (10 SY); 7.5%(13 SY); 22.6% (university degree)	NYHA I-IV / NR / NR / NR / patients received a one-hour education session on self-care
Dahrmann [25] / 2017 / Journal article / Cross-sectional design / NRW	Cardiac surgery, psychosomatic medicine	Hospital care, ambulatory care, pharmaceutical care and medicinal products, medical devices	54 y. / 23% / NR / NR / 74% (married) / NR / 47% (retired) / 23% Higher Education	NYHA III-IV / Dilatative (42%), Ischemic (45%), other causes (13%) / mean number of risk factors 10.9 / self-rated psychological health status on a scale from 1-5 (2.45), mean HADS depression score (6.5), anxiety score (7.9) / left ventricular assist device, optimal medication

Berg [26] / 2017 / Journal Article / Cross-sectional design / NRW	Cardiac surgery, health services research	Hospital care, ambulatory care, rehabilitation and patient education, (psycho-) social care, medical devices, allied health care	62 y. / 10% / NR / NR / 70% (married) / Primarily cared for by spouse (62%), partner (4%), children (19%), care service (15%) NR / NR	Severely ill, VAD-patients bridge-to-transplantation or candidacy (67%) / NR / NR / NR / implanted VAD therapy
Meyer [40] / 2010 / Journal article / Cross-sectional design / NS	Cardiac surgery	Medical devices	23-64 y. / 11% / NR / NR / NR / NR / NR / NR	NR / NR / NR / NR / 598.5 (median days on device)
Werdecker [27] / 2018 / Journal article / Qualitative study / NS	Geriatrics, palliative care, health services research	Palliative care	83 y. / 52% / NR / NR / NR / NR / NR / NR	NYHA IV / NR / NR / NR / NR
Klindtworth [28] / 2015 / Doctoral Thesis incl. Journal Articles / Qualitative study / NS, BW	General practice, geriatrics, palliative care	Hospital care, ambulatory care, palliative care, long-term care, emergency care	71-98 y. / 56% / NR / NR / 80% single or widowed / living at home 72%, assisted living/nursing home 28% / NR / NR	NYHA III-IV / NR / NR / NR / in-patient or ambulatory geriatric treatment
Scherer [34] / 2008 / Journal article / Longitudinal design / NS	Psychosomatic medicine, general practice, health services research	Ambulatory care	73 y. / 53% / NR / NR / NR / 41.6% living alone / NR / NR	NYHA I-IV / NR / NR / HADS Anxiety score (5.7 - 7.2), HADS Depression score (6.0 - 7.4) / NR
Peters-Klimm [29] / 2010 / Journal article / RCT / BW (48% rural, 17% suburban, 35% urban)	Health services research, general practice	Ambulatory care	70 y. / 28% / NR / NR / NR / 26.6% (living alone) / NR / SES 30.9% (lower), 60% (middle), 9% (upper)	NYHA I-III / main cause of CHF: 46.7% (ischemic); 52.2% (non-ischemic); mean duration CHF: 6.5 y.; localization CHF: 64.3% (left); 32.1% (left & right); 2.5% unknown; mean LVEF: 36.7 / atrial fibrillation, peripheral artery disease, cerebrovascular disease, asthma, COPD, diabetes, hypertension, dyslipidemia, infarction before age of 60, smoker / depression 22.1 % / therapies: 32.6% (Stent); 21.1% (bypass); 23.6% (pacemaker); 16.0% (ICD); 6% (prosthetic heart valve); 7% (reanimation/ defibrillation), various medication and patients received either regular ambulatory care or case management + telemonitoring + home visits
Knoll [36] / 2013 / Doctoral thesis / RCT / Saarland, NRW	Pharmaceutical care, geriatrics, health education	Hospital care, ambulatory care, pharmaceutical care and medicinal products	76 y. / 44% / NR / NR / NR / NR / NR / NR	Mean NYHA 2,5 / NR / 60.9% hypertension, 58.7% diabetes mellitus type II, 54.3% coronary heart disease, 30.4% cerebrovascular diseases, 28.3% hyperlipidemia, 26% heart valve disease, less than 20%: COPD, atrial fibrillation, malignancy, hyperuricemia, depression and dementia / NR / patients received pharmaceutical care (multimедication), primary care

Rohlehr [37] / 2017 Doctoral thesis Longitudinal design / Saarland	Pharmaceutical care, health education	Pharmaceutical care and medicinal products	78 y. / 44% / NR / NR / 50.5% married, 37.8% widowed, 5% in a partnership, 6% single or divorced / NR / NR / 77.5% ≤ 9 SY, 7.2% (10 SY), 15.3% (13+ SY)	NYHA I-IV / 29% non-reduced EF / hypertension 52,3 %, coronary heart disease 50,5%, atrial fibrillation 46,9 %, 36,0 % chronic kidney disease, 28,8 % Diabetes mellitus type II, 9,9 % COPD / NR / mean number of drugs 7,7
Müller [30] / 2013 / Journal article / Longitudinal design / Germany-wide, telemedical center in BW	Telemedicine	Telemedical care, medical devices	65 y. /16% / NR / NR / NR / NR / NR / NR	NYHA II-III / LVEF of 40% or less and indication for ICD or CRT-D / NR / NR / various medication: b-blockers, diuretics, angiotensin converting enzyme inhibitors, digitalis, ICD or ICD+CRT-D therapy
Lossnitzer [31] / 2015 / Journal article / Longitudinal study / BW	Health services research, psychosomatic medicine	Ambulatory care, rehabilitation and patient education, pharmaceutical care and medicinal products, (psycho-) social care, mental health care	59 y. / 26% / NR / NR / NR / Living alone (17.6%) / not employed (75.3%) / Primary school education (63.5%), Secondary school education (34.1%)	NYHA I-IV / 47.1% (dilative myopathy); 38.8% (coronary artery disease); 14.1% (other) / NR / depressive disorder according to the PHQ-9 (sum-score 12.52) / psychotherapeutic treatment 9.4%, antidepressant (SSRI/SNRI) or sedative medication (18.8%), various medication: b-blockers, ACE, diuretics, ARB, cardiac glycosides, antidepressant
Naumann [35] / 2014 / Doctoral thesis / Cross-sectional design / Sachsen	Health services research, psychosomatic medicine	Ambulatory care, mental health care, allied health care	52 y. / 15% / NR / NR / 83% (married or in partnership), 17% (widowed, single, divorced) / NR / 54% (employed), 46% (non- employed) / NR	NYHA I-III / NR / NR / HADS anxiety score increased (34%), HADS depression score increased (26%), 20% reported anxiety due to their cardiac condition / 28% device therapy (ICD)
Baudendistel [32] / 2015 / Journal article, Qualitative study / BW	Health services research	Hospital care, ambulatory care, rehabilitation and patient education, pharmaceutical care and medicinal products, (psycho-) social care, medical devices, allied health care	72 y. / 29% / NR / NR / NR / NR / 82.4% (retiree), 5.9% (housewife), 11.8% (others) / NR	NR / chronic systolic heart failure EF<35% / mean number of additional chronic conditions 4.4 / NR / 76.5% took more than 7 drugs per day, 23.5% took less than 7 drugs per day
Herzberg [33] / 2016/ Journal article / Qualitative study / MV	Health services research	Hospital care, ambulatory care, pharmaceutical care and medicinal products, medical devices, allied health care	52-85 y. / 56% / NR / NR / NR / NR / NR / NR	NR / NR / NR / NR / cardiac exercise therapy

NYHA: New York Heart Association; NR: not reported ; (LV)EF: (Left ventricular) ejection fraction; BMI: Body mass index; HADS: ; y: years, BW: Baden-Wuerttemberg; RCT: Randomized controlled trial, NRW: North Rhine-Westphalia; NS: Lower Saxony; SH: Schleswig-Holstein; SY: school years; VAD: Ventricular assisted device; MV: Mecklenburg-Western Pomerania; COPD: Chronic obstructive pulmonary disease; ICD: Implanted Cardioverter Defibrillator; CRT(-D): Cardiac resynchronization therapy (defibrillator)