

**Appendix 1: Search strategy for electronic database searches**

<b>Search Strategy for MEDLINE and EMBASE</b>	
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??nich* 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"

<b>Search Strategy for CINAHL, PSYINDEX and PsycINFO</b>	
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 #fer* 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 #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
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 <sup>21</sup> 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 <sup>19</sup> and extended to include health care settings mentioned in German clinical practice guidelines <sup>20</sup> 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"> <li>• Mean age</li> </ul>
<ul style="list-style-type: none"> <li>• Sex</li> </ul>
<ul style="list-style-type: none"> <li>• Ethnicity</li> </ul>
<ul style="list-style-type: none"> <li>• Insurance status</li> </ul>
<ul style="list-style-type: none"> <li>• Relationship status</li> </ul>
<ul style="list-style-type: none"> <li>• Housing situation</li> </ul>
<ul style="list-style-type: none"> <li>• Employment status</li> </ul>
<ul style="list-style-type: none"> <li>• Educational background</li> </ul>

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

## 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 <sup>21</sup> )	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"> <li>The newly developed heart failure rehabilitation program helps patients improve knowledge of their condition, reduce anxiety and depression and improve their quality of life.</li> <li>Patients reported a high subjective training need and interest in medical information on the disease and treatment.</li> <li>For the majority of patients, the information gain primarily provides security</li> <li>Some negative statements related to the room and the "less realistic dietary advice"</li> <li>An appointment with the partner was proposed</li> </ul> <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"> <li>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 -</li> <li>"[...] significant small between-group intervention effect on certain dimension of patients' self-management competence"</li> </ul> <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"> <li>High subjective training need of patients</li> <li>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</li> <li>Interest in psychocardiological knowledge from educational training programs was more diversified and is associated with patients' psychological burden.</li> <li>On average, patients rated the educational training program they received to be good or very good</li> <li>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.</li> <li>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</li> <li>Half the patients actively searched for disease-related information themselves</li> <li>Patients explicitly expressed the wish for SDM (n=44), better quality information (n=11) and more positive patient-doctor relationships</li> </ul> <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"> <li>• Patients rated the one-hour self-care training on heart failure as helpful and good</li> <li>• Younger patients and single patients are less likely to keep a journal than older people and patients living with someone</li> <li>• 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</li> <li>• 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%)</li> </ul> <p><i>Patient information, patient empowerment (symptom control), provider-patient communication, motivation for self-care</i></p>	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	<p>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</p> <p><i>Provider-patient communication, patient information, patient empowerment, patient involvement in care</i></p>	
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"> <li>• 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</li> <li>• The support of relatives at home was important to patients</li> <li>• With regard to application, patients felt confident using the device. Over 80% of patients felt they had been well-informed.</li> <li>• 80% of the patients told nurses they were confident using the device</li> <li>• About half the patients stated that the support of case managers and social services was helpful</li> <li>• Approx. 70% of patients were satisfied with physiotherapy and rehabilitation after surgery</li> <li>• 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</li> </ul> <p><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></p>	
Meyer / 2010 [40]	"[...] to evaluate the quality of two different [LVAD] systems based on patients' perspective [...]".	Cross-sectional design / 27 / Questionnaire / Quantitative	<p>"Overall patients' satisfaction was high [despite] dissatisfaction with: loudness of the power base unit &amp; length of the driveline"</p> <p><i>Satisfaction (with technical device)</i></p>	Palliative care and older adults with CHF
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"> <li>• 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).</li> <li>• Patients view ACP consultations as an open process: Willingness to participate in such conversations must be given to the individual.</li> <li>• 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</li> </ul> <p><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></p>	
Klindtworth / 2015 [28]	"[...] to understand how old and very old patients with advanced HF perceive	Qualitative study/ 25 /	<p>"[...] 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</p>	



	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"> <li>patients visited their family doctor an average of 8.2 times over 9 months</li> <li>"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"</li> <li>"[...] High primary care utilization was also influenced by anxiety and depression as well as by physical problems" <i>Healthcare utilization (GP visits)</i></li> </ul>	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"> <li>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</li> <li>The program did not affect hospital admissions</li> <li>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></li> </ul>	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"> <li>• Self-reported adherence was good to mediocre in most patients</li> <li>• Inadequate knowledge about disease-specific drugs overall. In declining order, patients knew about medication effects, administration time, drug name and dose</li> <li>• Declining knowledge after discharge</li> <li>• Women had more advanced knowledge</li> <li>• Socio-demographic factors such as education or family status correlated with drug knowledge</li> <li>• Medication knowledge correlates positively with the use of a medication plan and self-preparation of the medication</li> <li>• Drug knowledge of patients with acutely decompensated heart failure needs improvement</li> <li>• 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</li> </ul> <p><i>Knowledge, self-reported adherence</i></p>	
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"> <li>• "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."</li> <li>• Preferences for treatment with psychotropic drugs were lower (34.1% of respondents)</li> <li>• "[...] 47.1% [of respondents] reported that they could not envision adhering to regular weekly psychotherapy sessions."</li> <li>• "[...] 14.1% [of respondents] reported that they would like more time with their treating cardiologist to address questions concerning their heart disease."</li> <li>• The most commonly used treatment options were cardiac exercise groups and supportive talks</li> </ul> <p><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></p>	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"> <li>• 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.</li> <li>• 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</li> </ul> <p><i>Healthcare utilization (GP and specialist services, psychotherapy and cardiac exercise therapy)</i></p>	

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"> <li>• "[...] patients were mostly satisfied with their health care [...] especially in primary care"</li> <li>• "However, deficits were identified, especially related to communication and cooperation across health care sectors, especially at the transition between hospital and outpatient care."</li> <li>• "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."</li> <li>• "Patient needs focused primarily on doctor-patient relationship, communication, quality of information, and professional advice, as well as psychological support."</li> <li>• "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)."</li> <li>• Cooperation between the medical disciplines &amp; health care sectors" was perceived important</li> <li>• "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."</li> <li>• "[...] the provision of exercise training as a health service to patients did not get enough attention [...]."</li> <li>• "The need for psychosocial support, e.g., in coping with illness experiences, was addressed by several interviewees."</li> <li>• "Mostly, the GP was described as the primary contact person. He often was perceived as a coordinator."</li> <li>• "Deficits in information exchange and communication, especially on behalf of the inpatient sector, were expressed by the interviewees."</li> <li>• "Joint discussion of medical findings or fast information exchanges between, e.g., GPs and cardiologists were mentioned to be positive."</li> <li>• "Clear responsibilities and organizational processes, e.g., in case of application for a rehabilitation were relevant to the interviewees."</li> <li>• "The need for support in the community setting to cope with challenges in everyday life was a further important point [...]."</li> <li>• "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."</li> <li>• "[...] 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 [...]."</li> </ul> <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"> <li>• Patients emphasize the social dimension of sports to belong to high-quality treatment</li> <li>• Patients mentioned a lack of information on cardiac rehabilitation through exercise from doctors and a lack of support by statutory health insurers</li> <li>• Patients spoke negatively about pharmaceutical care since drug administration was not sufficiently monitored by doctors</li> <li>• 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</li> <li>• 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</li> <li>• Regular follow-up visits were considered important, but patients wished to receive more support from doctors without having to insist themselves</li> <li>• Patients complained about difficulties gaining timely access to both inpatient and ambulatory cardiac health care</li> </ul> <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**

<b>First author / Year / Type of publication / Location of healthcare services studied</b>	<b>Academic discipline(s)</b>	<b>Healthcare context</b>	<b>Mean age / Women % / Ethnicity / Insurance status / relationship status / housing situation / employment / educational background</b>	<b>Severity (NYHA) / type of CHF / somatic comorbidities &amp; risk factors / state of mental health / therapeutic characteristics</b>
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 $\leq$ 40 %, 42.2% (Ischemic cardiomyopathy) / mean BMI (29.0), Overweight / HADS anxiety score > 10 (26%), HADS depression 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 $\leq$ 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% ( $\leq$ 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 (multimedication), 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)