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

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ABSTRACT

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Professor Andrea Siebenhofer; andrea.siebenhofer@ medunigraz.at **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.⁶⁸ A recently developed situation-specific theory of selfcare 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 selfefficacy 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 wellsuited 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, PSYNDEX 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 $\mathrm{CHF.}^{20}$

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 $2^{6.38}$ 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,^{2425 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 onethird 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, 303238 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 $(22\%)^{27283233}$ and interventional studies $(18\%)^{293639}$ 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<="" td=""><td>3 (17)</td></n≤>	3 (17)		
25 <n≤100< td=""><td>10 (56)</td></n≤100<>	10 (56)		
100 <n<200< td=""><td>3 (17)</td></n<200<>	3 (17)		
200 <n<500< td=""><td>2 (11)</td></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

Population characteristicsReported in subsetMean age67 years16Age range23–100 years6Sex (% female)31%18Ethnicity-0Insurance status-0Relationship status4%-Married, steady relationship64%-Single, divorced, widowed, others36%-Itving together56%-Living together23%-Assisted living, nursing home, shome care1Employed27%-Runament, Status-6Mon-employed, retired, others3%-Single, divorced, widowed, shome care16%Employed27%-Runament, Status-6Mon-employed, retired, others16%Status3%-Status16%-Status3%-Minimue of 13 school years18NTHA I3%-NYHA II35%-NYHA II35%-NyHA IV14%-AtiologyNierse3Type of heart failore-8AtiologyNierse3AtiologyNierse3AtiologyNierse3AtiologyNierse3AtiologyNierse3AtiologyNierse3AtiologyNierse3AtiologyNierse3	Table 2 Population characteristics of included studies		
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	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 products²³ ²⁵ ^{31–33} ³⁶ ³⁷ as well as medical devices²⁵ 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 HXC 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 HXC 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 evidencebased understanding of patient experiences with CHFspecific 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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