*Review Article*

European Journal of Cardiovascular Nursing

ESC European Society of Cardiology

# Symptom perception in heart failure: a scoping review on definition, factors and instruments

European Journal of Cardiovascular Nursing
2020, Vol. 19(2) 100–117

DOI: 10.1177/1474515119892797
journals.sagepub.com/home/cnu
SAGE

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## Abstract

**Background:** Symptom perception in heart failure has been identified as crucial for effective self-care that is a modifiable factor related to decreased hospital readmission and improved survival.

**Aims:** To review systematically the heart failure symptom perception literature and synthesise knowledge on definition, description, factors and instruments.

**Methods:** We conducted a scoping review including studies reporting patient-reported symptom perception in adults with heart failure. Structured searches were conducted in Medline, PubMed, Embase, CINAHL, PsychINFO, Web of Science, Cochrane, JBI and grey literature. Two authors independently reviewed references for eligibility. Data were charted in tables and results narratively summarised.

**Results:** The search yielded 3057 references, of which 106 were included. The definition of heart failure symptom perception comprised body listening, monitoring signs, recognising, interpreting and labelling symptoms, and furthermore awareness of and assigning meaning to the change. Symptom monitoring, recognition and interpretation were identified as challenging. Symptom perception facilitators include prior heart failure hospitalisation, heart failure self-care maintenance, symptom perception confidence, illness uncertainty and social support. Barriers include knowledge deficits, symptom clusters and lack of tools/materials. Factors with inconsistent impact on symptom perception include age, sex, education, experiences of living with heart failure, comorbidities, cognitive impairment, depression and symptom progression. One instrument measuring all dimensions of heart failure symptom perception was identified.

**Conclusion:** Heart failure symptom perception definition and description have been elucidated. Several factors facilitating or hampering symptom perception are known. Further research is needed to determine a risk profile for poor symptom perception – which can then be taken into consideration when supporting heart failure self-care.

## Keywords

Heart failure, symptom perception, body observation, body analysis, facilitators, barriers

Date received: 27 May 2019; revised: 22 October 2019; accepted: 14 November 2019

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## Introduction

Symptom perception is a necessary antecedent of self-care management and has emerged as essential for effective heart failure (HF) self-care (i.e. patient activities to maintaining physiological stability, perceiving and responding to symptoms).[1] Symptom perception has been described as involving body listening, monitoring signs to detect physical sensations and recognising, interpreting and labelling symptoms.[1] Symptom perception is challenging for patients with HF,[2, 3] and failure to detect or interpret symptoms appropriately can result in inappropriate[3, 4] or delayed responses (e.g. seeking care),[4] and prolonged hospitalisation.[5] In contrast, symptom recognition combined with appropriate responses decrease emergency room visits, HF hospitalisation and all-cause mortality.[6] Self-care in HF remains suboptimal worldwide.[7] Symptom perception needs to be operationalised. Understanding the factors influencing symptom perception may help identify patients at risk of poor symptom perception and develop tailored strategies for improving symptom perception. Reviewing the available instruments for assessing symptom perception may help in measuring this construct.

HF self-care theory,[1, 8] modifying factors[9–11] and instruments measuring HF self-care[12–15] have been summarised. However, an overview focusing specifically on symptom perception is missing as the literature is embedded in the larger body of work on self-care. Two integrative reviews[16, 17] have synthesised the literature on symptom recognition, interpretation and response.[16, 17] These reviews identify some factors associated with symptom recognition,[17] yet gaps remain regarding symptom perception definition, modifying factors and instruments measuring this construct.

This study aims to operationalise symptom perception by examining the scope of work on HF symptom perception relating to four research questions:

- How has HF symptom perception been defined?
- How has HF symptom perception been described?
- What factors are associated with HF symptom perception?
- What instruments have been used to measure HF symptom perception?

## Methods

We conducted a scoping review and followed standard reporting guidelines for scoping reviews.[18] The sequential process included identifying the research question, identifying and selecting relevant studies, data charting and comprehensively summarising results.[19] The protocol is available on request from the corresponding author. Studies of symptom perception in adults living with HF were considered for inclusion along with expert opinion and position papers. Article eligibility criteria are detailed in Table 1.

Literature searches were developed with a medical librarian (CJ). An initial limited search was conducted in Medline OvidSP. Relevant articles were identified (GCS) and discussed with the second reviewer (ML). Subsequently, keywords and index terms of the retrieved papers were analysed and finalised for a full search in eight bibliographic databases and five unpublished grey literature databases in October 2017 (Table 2). Full descriptions including keywords and search strategies are provided in the Supplementary files. The search was actualised on 21 August 2018 in the seven major bibliographic databases (Medline, PubMed, Embase, CINAHL, PsychINFO, Web of Science, Cochrane). During article review and data charting, additional articles were identified in the reference lists of retrieved articles and included in the review process. Authors were contacted to obtain full text articles as needed.

References were imported into citation management software (Endnote X7.7.1, Clarivate Analytics) and duplicates

**Table 1.** Eligibility criteria applied to the scoping review.

| Inclusion criteria | Exclusion criteria |
|---|---|
| **Population** | **Concept** |
| Adults with HF | Studies limited to symptom intensity, symptom severity or distress description |
| **Concept** | Studies of interventions supporting symptom perception |
| Studies reporting on symptom perception or related elements, i.e. symptom recognition, symptom detection, symptom awareness, somatic perception or somatic awareness | Studies of symptom perception outcomes |
| Studies on symptom perception definition or description | **Context** |
| Studies reporting barriers or facilitators to HF symptom perception | Remote monitoring |
| Studies on instruments measuring HF symptom perception (regardless of reported psychometric properties) | Symptoms monitored by healthcare professionals |
| **Design** | |
| Any study design including opinion and position papers | |
| **Language** | |
| English, French, Swedish, German, Italian and Spanish | |

HF: heart failure.

**Table 2.** Literature search sources.

| Bibliographic databases | Grey literature databases |
|---|---|
| **Medline OvidSP Epub** ahead of print, in-process and other non-indexed citations, Ovid MEDLINE(R) daily and Ovid MEDLINE(R) 1946 to present<br>**PubMed**<br>Search limited to the references not indexed for Medline<br>**Embase.com**<br>**CINAHL full text Ebsco**<br>**PsycINFO OvidSP**<br>1806 to August week 2 2018<br>**Web of Science core collection**<br>**Cochrane Library Wiley**<br>Cochrane Database of systematic reviews issue 8 of 12, August 2018<br>Cochrane Central Register of Controlled Trials issue 7 of 12, July 2018<br>Database of abstracts of reviews of effect : issue 2 of 4, April 2015<br>**Joanna Briggs Institute Database OvidSP** | **ProQuest** (dissertations and theses)<br>**BASE** – Bielefeld University Library<br>**Clinicaltrials.gov**<br>**DART** – Europe e-theses portal<br>**ICTRP** – the WHO International Clinical Trials Registry Platform |

were removed. Two reviewers (GCS, ML) independently reviewed titles and abstracts of retrieved references and determined eligibility per inclusion/exclusion criteria without conducting a quality appraisal. Selected references underwent full text review to determine final inclusion. Web-based software (Rayyan),[20] was employed to document and track the study selection process. Both reviewers independently labelled each included reference according to the related research question(s). Data were extracted using structured forms for each research question (see categories used for data extraction in the Supplementary files). Articles were randomly assigned to three independent reviewers (GCS, ML,

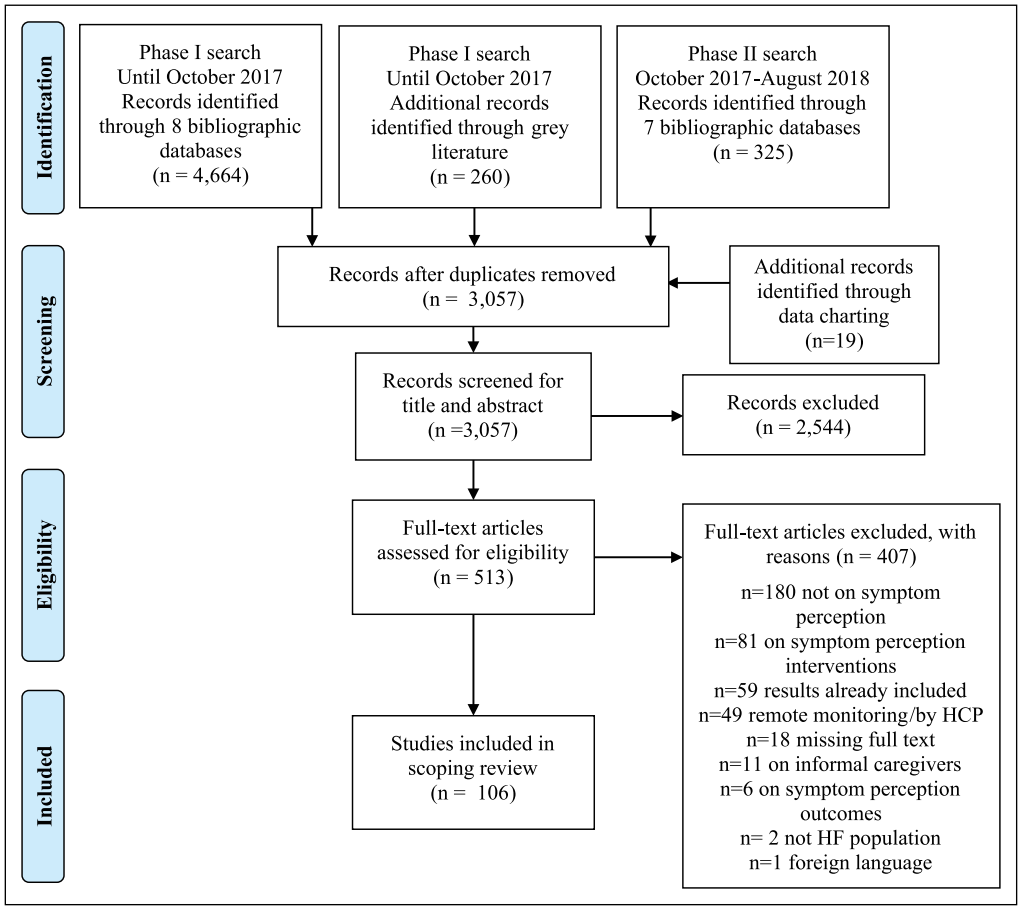


**Figure 1.** Prisma flow diagram[18] of study selection process.

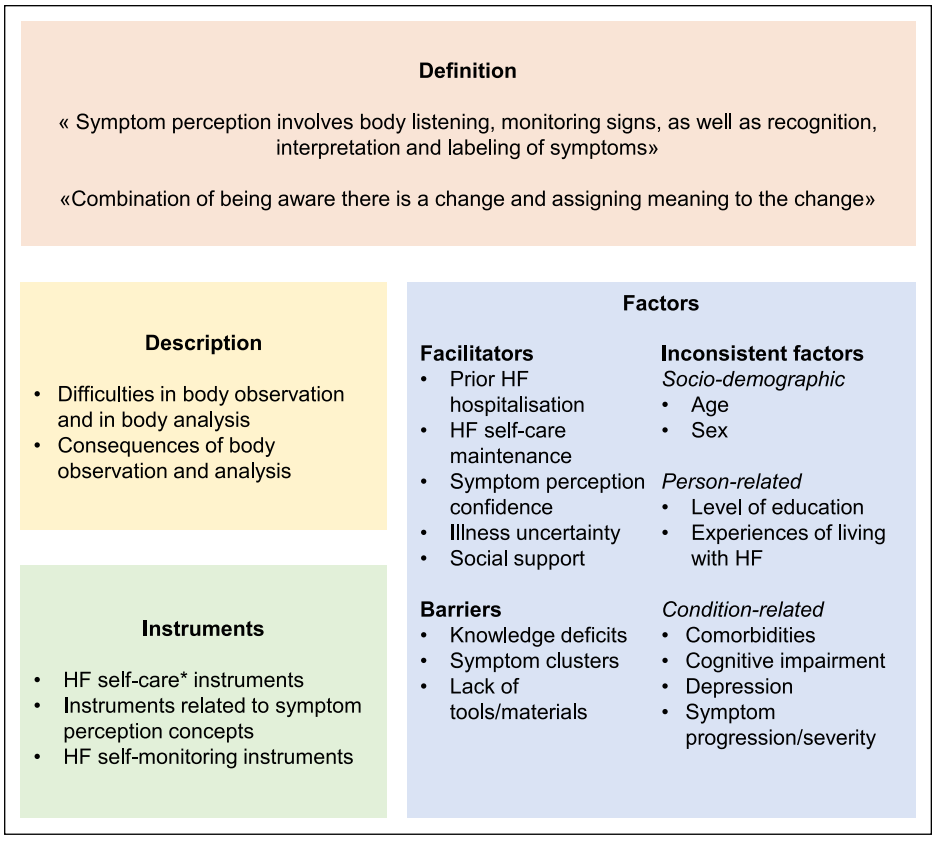


**Figure 2.** Heart failure (HF) symptom perception definition, description, factors and instruments.
The quotes refer to references 1 and 80. *HF self-care is defined as a process that influences maintenance (e.g. treatment adherence, physical exercise), symptom perception (e.g. symptom recognition) and management (e.g. response to symptoms such as contacting a health care professional).[1]

JG) for charting the data. Data charting quality was assessed by dual extraction and charting. In total, 10% of manuscripts underwent parallel data extraction by independent reviewers. Examination revealed that data extracted in parallel were comparable for all the references. Data on each research question were summarised narratively by GCS and results were discussed with both reviewers and PSK. Disagreements were resolved through discussion during monthly meetings throughout the review and extraction process.

## Results

Following removal of duplicates, 3057 references were identified and screened by title and abstract. After initial review, 2544 references were excluded per inclusion/exclusion criteria. The remaining 513 references underwent full text review and 106 references were included for data extraction and charting. Reasons for excluding the 407 references are reported in the Prisma flow diagram (Figure 1).[18]

Manuscript types included 46 observational studies,[2, 7, 14, 21–63] 27 qualitative studies,[4, 64–89] 12 literature reviews,[16, 17, 90–99] eight mixed-methods studies,[3, 13, 100–105] six manuscripts without a reported study design,[106–111] two pilot studies,[112, 113] two theories,[1, 8] one quasi-experimental study,[114] one conceptual framework[10] and one case study.[115]

Some of the 106 references related to more than one of the research questions. Twelve included references related to HF symptom perception definition,[1, 8, 17, 27, 34, 43, 54, 75, 80, 100, 102, 106] 68 to description,[2–4, 7, 10, 16, 17, 21–42, 49, 64–74, 76–79, 81–87, 89–98, 100–102, 107, 108, 115] 41 to factors[1, 3, 10, 16, 17, 21, 22, 24, 26–29, 36, 37, 39, 44–48, 50, 66, 73–75, 88, 89, 93, 95, 96, 98, 99, 102–105, 107–111] and 23 to instruments.[3, 13, 14, 32, 39, 44, 50-63, 112–114] An overview of symptom perception definition, description, factors and instruments is shown in Figure 2.

### *HF symptom perception definition*

Several definitions of HF symptom perception are reported in the literature. The situation-specific theory of HF self-care[1] and related publications[17, 102] defined symptom perception as '. . .body listening, monitoring signs, as well as recognition, interpretation, and labeling of symptoms'.[1(p. 227)] This definition was supported by moderate relationships between symptom monitoring and symptom recognition and evaluation ($r$=0.34, $P$<0.01).[43] Another definition of symptom perception was: '. . .a combination of being aware there is a change and assigning meaning to the change'.[80(p. 93)] One may consider HF symptom perception is defined by body observation and body analysis. Body observation includes body listening and monitoring HF signs/symptoms

(i.e. a behavioural process) while body analysis relates to recognising, interpreting and labelling symptoms – as well as assigning meaning (i.e. a cognitive process). Next, we identified several concepts including symptom perception elements. Awareness, interpretation and measurement composed self-care monitoring;[54] body listening and coherence related to symptom recognition;[100] sensitivity to physical sensations and bodily activity secondary to physiological change[27] related to somatic awareness while symptom recognition and interpretation of its severity composed situation awareness.[75]

## *Difficulties in body observation and body analysis and consequences*

Most studies report that body observation is not systematic in patients with HF.[4, 10, 17, 24, 25, 28, 29, 39, 41, 66, 67, 70, 83, 90, 96, 98] Only a minority of patients monitor symptoms regularly[24, 64, 80] and considered symptom monitoring to be important[86] for controlling HF.[64, 74, 78] In a large study, 16 of 22 studies (from 15 countries) reported irregular weight monitoring in more than half of patients.[7] Physical and/or cognitive difficulties were reported in monitoring/recording weight without assistance.[82] Furthermore, adherence to symptom monitoring was difficult[2, 73, 92] and challenges include insufficient knowledge of HF signs/symptoms,[42, 93, 100] poor oedema assessment skills,[17, 39] forgetfulness,[39, 49] worry about HF,[39, 49] lack of time[49] and lack of trust in health professionals' expertise and support.[93] Some patients did not recall having monitored their symptoms during the period preceding a HF exacerbation[80] and most patients experiencing weight gain did not report changes.[22]

Body analysis following body observation is often poor because patients have difficulty recognising signs and symptoms related to chronic HF[4, 21, 31, 33, 36, 66, 67, 74, 81, 83, 93, 98, 101, 107] as well as signs of decompensation.[17, 23, 34–36, 42, 65] Patients have difficulty quantifying subtle changes in dyspnoea[108] and noting changes in symptom status.[10, 26, 32, 97] In fact, objective and subjective reports of thoracic fluid retention (i.e. pleural fluid accumulation measured through intrathoracic impedance-derived fluid index vs. daily reported signs and symptoms) is discordant in 44% of cases.[102] Cumulatively, these factors contribute to inaccurate interpretation of symptoms.[17, 71, 73, 74, 76, 80, 93, 102] Body analysing made patients uncertain,[89] as some patients find it challenging to determine whether a symptom is clinically meaningful[100] – particularly for vague or non-specific symptoms.[87] Patients are often uncertain in situations when symptoms require interpretation[30] when clinical status deteriorates warranting medical attention.[34, 72, 80, 90] Moreover, discrimination of HF symptoms from symptoms related to other comorbidities remains a challenge[66, 79, 92–94, 102] and many patients inaccurately attribute their symptoms to something other than HF[23, 81, 85] such as age,[16, 27, 31, 84, 89, 91, 96, 107] comorbidities,[4, 27, 31, 37, 38, 79, 93] medication,[76, 91, 93] stress,[102] fatigue[38] or the weather.[102]

Response to body observation and body analysis varies. Some responses are more active in nature and may include resting, relaxing or changing their daily routine.[25, 31, 38, 80, 82] Other responses are more avoidant in nature such as ignoring symptoms[68, 74, 81] or adopting a 'wait and see' strategy[102] in hopes that symptoms will resolve spontaneously.[3, 4, 72, 81] These strategies can delay help-seeking,[38, 97] or patients may only seek medical support if symptoms do not resolve,[82] or symptoms escalate interfering with daily life activities,[27] or become unmanageable,[76, 80] leading to emergency situations[67, 79, 115] and hospitalisation.[107] Only some patients seek medical attention to understand or interpret the significance of symptoms[70] and learned about it when seeking care.[77]

## *Factors impacting symptom perception*

*Facilitators.* Identified facilitators of HF symptom perception include prior HF hospitalisation, HF self-care maintenance, symptom perception confidence, uncertainty about the meaning of illness-related events and social support. Somatic perception improved with the overall number of hospital admissions ($r$=0.42, $P$<0.001) as well as cardiac-related admissions within the past 6 months ($r$=0.36, $P$=0.002).[17] Symptom monitoring and treatment-seeking were poorer in patients without prior HF hospitalisations (sβ=−0.21, $P$=0.02).[29] Self-care maintenance and symptom perception confidence has been shown to help explain variability in symptom perception.[46] The frequency of symptom monitoring predicts symptom monitoring at one month follow-up (odds ratio (OR) 9.18, 95% confidence interval (CI) 2.15–39.3).[24] Furthermore, patients with higher illness uncertainty were shown to pay more attention to somatic changes ($r$=0.36, $P$<0.01).[17, 27] In addition, social support was reported to improve symptom perception as patients living with others are more likely to report dyspnoea[45] and are able to recognise changes in signs and symptoms better compared to patients living alone ($P$=0.014).[17, 36] Informal caregivers may also assist with weight monitoring and symptom recognition.[88]

*Barriers.* Identified barriers of HF symptom perception are knowledge deficits as well as symptom clusters and lack of tools/materials. Insufficient HF knowledge is associated with poor symptom monitoring and treatment-seeking ($P$=0.028).[29] Symptom clusters refers to the experience of several concurrent symptoms,[116] and such clusters may complicate symptom perception.[1] Lack of tools/materials (e.g. patients without scale for weight monitoring)[28] poses additional barriers to symptom perception.

## *Factors with inconsistent impact on HF symptom perception*

Age, sex, level of education, patient experiences of living with HF, comorbidities, cognitive impairment, depression

as well as symptom progression/severity are inconsistently associated with HF symptom perception.

### Sociodemographic factors

Results are inconsistent with regard to the relationship between older age and symptom perception. Several studies have demonstrated that older patients experience more difficulty in symptom perception.[10, 16, 27, 46, 66, 96, 98, 104, 107] Some reported that older patients are challenged to discriminate HF from age-related changes.[89, 95, 98] Furthermore, older persons perceive lower symptom severity,[50] are less likely to detect, interpret[104] or report dyspnoea.[45] However, younger patients appear less able to detect changes in thoracic fluid.[102] Similarly, there is no clear association between age and either somatic awareness,[17] body awareness,[44, 95] monitoring activities[24, 29, 39, 66] or symptom recognition.[36] There is no consensus on age as a determinant of symptom perception.[24, 29, 46]

With regard to the role of sex on symptom perception, one study found better HF symptom interpretation in men compared to women.[105] However, other studies failed to identify sex differences in body awareness,[44, 95] symptom awareness,[110] sign/symptom change recognition,[36] attribution of symptoms,[37, 48] symptom monitoring and treatment-seeking,[29] or in detecting changes in thoracic fluid levels.[102] Furthermore, sex did not predict symptom monitoring.[24]

### Person-related factors

Data on the impact of educational level are inconsistent. One study has found that education did not predict symptom monitoring[24] while others suggest that higher educational levels facilitate symptom recognition.[17, 36]

Patient experiences of living with HF have been proposed to affect symptom perception. Longer disease duration was associated with increased somatic perception,[103] symptom recognition[21] – as experience may facilitate symptom interpretation.[10] Also, prior personal experience with the situation and situation awareness seem to influence mental simulation.[75] Another study failed to identify a relationship between HF duration and thoracic fluid detection.[102]

### Condition-related factors

Comorbidities may reduce patients' ability to identify HF symptoms.[3, 74, 107, 111] Sensory problems (e.g. hearing loss,[99] impaired vision)[10, 99] and disturbed body balance[10] hamper symptom monitoring and recognition. Fatigue and sleepiness, may negatively affect symptom monitoring,[10] recognition and interpretation.[37, 75] Again, one study failed to identify an association between comorbidities and perception of thoracic fluid accumulation.[102]

Regarding cognitive impairment, some studies indicate cognitive impairment results in poor symptom recognition and interpretation.[1, 10, 98, 99, 109–111] In contrast, some studies report no relationship between cognition and either symptom monitoring,[22] thoracic fluid detection[102] or symptom recognition.[26]

Regarding depression, compared to HF patients without depressive symptoms, patients with depression are less likely to monitor body weight ($P$=0.041).[47] Depression also appears to hamper symptom recognition,[75, 111] while mania, alexithymia and psychotic illness may diminish symptom perception.[108] However, other studies have found no relationship between depression and either body awareness[44] or thoracic fluid detection.[102] Moreover, others reported contrasting results, with anxiety and depression associated with even increased symptom perception,[108] likelihood to report dyspnoea[45] and symptom recognition.[110]

For symptom progression/severity, some authors have reported that slowly progressing symptom severity impairs somatic awareness[17] and symptom recognition.[3, 17, 73, 107] Study results based on functional performance data (i.e. New York Heart Association (NYHA) class), however, have been heterogeneous. Several studies report that worse functional ability (higher NYHA class) is associated with increased somatic perception[17] and symptom recognition,[36] yet others report no association with symptom monitoring,[24] decreased symptom recognition[48] and no difference in thoracic fluid detection.[102]

In summary, while a substantial number of factors have been identified in relation to symptom perception (Table 3), the key drivers of symptom perception have yet to be determined.

### HF symptom perception instruments

HF symptom perception instruments intend to measure one or several dimensions of HF symptom perception (Table 4). Several instruments used for HF self-care assessment contain items related to symptom perception dimensions.[13, 14, 51, 53, 59, 60] The 39-item self-care of heart failure index v.7.2 contains the 11-item symptom perception subscale dedicated to HF symptom perception. This subscale aligns with the self-care situation-specific theory definition of symptom perception[51] and covers all dimensions of the HF symptom perception definition. It comprises nine items on monitoring behaviours and two symptom recognition items, and has demonstrated adequate construct validity using a two-factor model (CFI 0.96, RMSEA 0.050, 90% CI 0.039–0.062) and good internal consistency (multidimensional scale global reliability index 0.85).[51]

Other instruments relate to concepts of symptom perception. The HF somatic awareness scale[55] and the HF somatic perception scale[56, 58] measure patient awareness of signs and symptoms and perceived symptom severity. The body awareness questionnaire includes a scale on body attentiveness that has been tested in patients with HF.[44] The revised HF compliance scale includes an item on daily weighing.[39] The self-evaluation of symptoms, signs and compliance to therapy for HF surveillance identifies worsening HF symptoms and discriminates between chronic

**Table 3.** References relating to symptom perception factors.

| Authors, year, country, type of publication | Design, methods, symptom perception metrics | Main aim of the study | Sample size (main characteristics) OR Number of included articles (main characteristics) | Facilitators to symptom perception | Barriers to symptom perception | Neutral factors not reported to be related to, associated to or predictive of symptom perception |
|---|---|---|---|---|---|---|
| **Qualitative studies** | | | | | | |
| Buck et al.,[88] 2017, USA, journal article | Interviews guided by the situation-specific theory of HF self-care, iterative thematic analysis | Qualitatively examine how HF patient and informal caregiver dyads mutually engage in managing the patient's HF at home | *N*=54 persons (27 dyads, mean age patients 76.6±9.6, caregivers 64.12±14.3, 56% male patients, 26% male caregivers) | Caregivers' identification of patient symptoms; alerting patients about symptoms and taking action to respond to symptoms | Not described | |
| Culjis,[66] 2013, USA, dissertation | Interpretive qualitative study, thematic analysis | Describe the lived experiences of older men with HF who are managing symptoms near end-of-life, describe and learn how older men manage symptoms | *N*=30 persons (*n*=15 older men, age range 75–95, veterans with late stage HF receiving palliative care all in NYHA III/IV; *n*=15 caregivers, 93% female) | Not described | Old men (88–95) less vigilant in monitoring activities (weight, diet, symptom recognition) than younger older men (75–82) | |
| Reeder et al.,[73] 2014, USA, conference abstract | Semi-structured interviews | Explore patients' perspectives of scenarios of deteriorating symptoms leading to hospitalisation for acute decompensated HF | *N*=60 hospitalised for acute decompensated HF (main characteristics not described) | Early warning signs or sudden onset impacted symptom recognition | Not described | |
| Riegel et al.,[75] 2013, USA, journal article | Qualitative descriptive approach | Explore the process used by adults with chronic HF to make decisions about their symptoms | *N*=36 (age range 40–98, 50% male, 95% NYHA II/III) | Those who recognised the importance of the situation at hand and that a decision was needed were more likely to simulate options mentally and take action<br>Mental simulation seemed to be based on situation awareness and was influenced by prior personal experience with the situation | Individuals who recognised a symptom but not its importance were unlikely to describe mentally simulating a plan of action.<br>Sleepiness and depression affected decision making by confounding symptom recognition | |
| Riegel and Carlson,[74] 2002, USA, journal article | Structured interview, content analysis | Explore how HF influences patients' lives, assess how they perform self-care, and determine how their life situation facilitates or impedes HF self-care | *N*=26 (mean age 74.4±10.05, 65% male, 73% NYHA II/III) | Not described | Comorbidities: trouble determining if a particular symptom was related to HF, perhaps because of other diagnoses | |
| Winters,[89] 1999, USA, journal article | Qualitative study with interpretive approach, semi-structured interviews | Describe the uncertainty experienced by men and women with HF and to extend the theoretical understanding of uncertainty in chronic illness | *N*=22 (age range 38–88, 68% male, 86% NYHA II/III) | Not described | Thoughts about aging influenced symptoms recognition.<br>Some attributed fatigue and dyspnoea with exertion to the aging process | |
| **Observational studies** | | | | | | |
| Baas et al.,[44] 2004, USA, journal article | Two prospective longitudinal studies, body awareness questionnaire | Describe body awareness in 90 persons with HF or after transplant | *N*=90 (*n*=38 HF persons, HF subsample: mean age 51.8, 50% male, LVEF 27%) | Not described | Not described | No significant differences for age or sex groups.<br>No relationship with positive moods and negative emotional states |
| Carlson et al.,[21] 2001, USA, journal article | The self-management of HF questionnaire | Describe HF self-care abilities and the difficulties that persons with HF experience in practicing self-care and compare those newly diagnosed with HF with those experienced with the diagnosis (>2 months) | *N*=139 patients (mean age 69.27±13, 53% male, 61% NYHA II/III) | Experience in living with HF improved confidence to recognise signs and symptoms if they occurred ($P$=0.04) | Patients newly diagnosed with HF had more difficulty recognising their symptoms as being related to HF ($P$<0.001) | |

*(Continued)*

**Table 3.** (Continued)

| | | | | | | |
|---|---|---|---|---|---|---|
| Dolansky et al.,[22] 2016, USA, journal article | Daily weighing adherence, weight gain symptom awareness and management behaviour (self-care of HF index v.6.2) | Examine whether cognition is associated with adherence to daily weighing and weight gain incidence and explore self-reported symptom perception and management when a weight increase occurs | *N*=301 patients (mean age 68.7±9.7, 60% male, 85% NYHA II/III) | Not described | Not described | None of the cognitive domains (baseline attention, executive function, memory) predicted adherence to daily weighing |
| Gallagher,[24] 2010, Australia, journal article | Symptom monitoring tool determining frequency of monitoring five key HF symptoms (fatigue, shortness of breath at rest/during activities, weight, swelling) | Determine the level of self-management and frequency of symptom monitoring and factors associated in patients with moderate severity HF living in the community | *N*=63 patients recently admitted or enrolled in treatment for heart failure (mean age 78.38±8.54, 57% male, 57% NYHA II) | The frequency of monitoring at baseline predicted symptom monitoring at one month (OR 9.18, CI 2.15–39.3). The model explained 31% of the variance in symptom monitoring (Cox and Snell $R^2$=0.31) | Not described | Age, gender, education in years, symptom severity, number of comorbid illnesses, self-efficacy for self-management, sense of coherence |
| Harkness et al.,[26] 2014, Canada, journal article | Self-care of HF index v.6.2 | Determine whether mild cognitive impairment is associated with self-care management in a sample of community dwelling older patients with HF | *N*=100 patients (mean age 72.4±9.8, 68% male, 50% NYHA II) | Not described | Not described | No differences in engagement of self-care management behaviours related to symptom recognition relating to mild cognitive impairment |
| Jurgens,[27] 2006, USA, journal article | The HF somatic awareness scale | Explore relationships among somatic awareness, uncertainty, symptom pattern, age, sex, history of HF, and care-seeking delay patterns among patients with acute HF | *N*=201 patients hospitalised for HF symptom management (mean age 70±12, 56% male, 61% NYHA II/III) | Acute symptom duration positively correlated with HF somatic awareness ($r$=0.256, $P$<0.01) Uncertainty correlated with HF somatic awareness ($r$=0.361, $P$<0.01) | Older age negatively correlated with HF somatic awareness ($r$=−0.186, $P$<0.05) | |
| Jurgens et al.,[45] 2016, USA, conference abstract | Secondary analysis of data from two prospective cohort studies, the HF somatic perception scale dyspnoea subscale | Identify clinical and psychosocial factors related to the presence or absence of dyspnoea among patients with chronic HF | *N*=274 patients (mean age 55.4±13.6 62.8% male, 76% NYHA III/IV) | Being married or partnered (OR 2.07; $P$=0.03), having NYHA III/IV versus II class (OR 2.90; $P$<0.01) and anxiety (OR 1.30 per point; $P$<0.01) increased likelihood to report dyspnoea | Older age (OR 0.96 per year; $P$=0.02) decreased likely to report dyspnoea | |
| Jurivich et al.,[28] 2001, USA, conference abstract | Five short questions regarding weight management | Examine barriers to weight management in chronic HF patients | *N*=153 HF cognitively intact frail patients (sample characteristics non described) | Not described | Lack of a home scale | |
| Kato et al.,[29] 2011, Japan, conference abstract | Five items from the modified version (for Japan) of the European heart failure self-care behaviour scale to measure daily weighing, and contacting healthcare professional as HF symptoms increase | Clarify which factors can be related with poor behaviours for symptom monitoring and treatment-seeking among Japanese patients with HF | *N*=135 patients (mean age 62.8±13.7 70% male, mean LVEF 42.3±17.2%) | Not described | Younger age (standard partial regression coefficients (sβ)=−0.22, $P$=0.01), no prior hospitalisation for HF (sβ=−0.21, $P$=0.02), and preserved LVEF (sβ=0.22, $P$=0.01) were independent predictors for poor symptom monitoring and treatment-seeking behaviours. Inadequate knowledge on HF was also associated with the poor behaviours ($P$=0.028). | Gender, aetiology of HF, diabetes mellitus or chronic kidney disease were not related to the behaviours |
| Lee et al.,[50] 2015, Taiwan, journal article | Fluid overload symptoms scale | Develop and test the reliability and validity of a scale about fluid overload symptoms in patients with HF | *N*=56 patients (mean age 71.02±13.61, 60% male, 77% NYHA II/III) | Not described | Older patients tend to have lower perception of symptom severity | |

*(Continued)*

**Table 3.** (Continued)

| | | | | | | |
|---|---|---|---|---|---|---|
| Lee et al.,[46] 2017, USA, conference abstract | The self-care of HF index v.7.1 | Identify determinants of symptom perception in patients with HF | *N*=349 HF community-living adults (mean age 62±13.8, 69% male) | Younger age, longer duration of HF (>1 year), higher HF self-care maintenance, and higher symptom perception confidence were determinants of HF symptom perception. These factors explained 48.3% of symptom perception variance ($P<0.001$) | Older age, newly diagnosed patients with evidence of poor treatment adherence and patients with low self-care self-efficacy are determinants of poor symptom perception | |
| Makaya et al.,[47] 2013, Japan, conference abstract | European heart failure self-care behaviour scale | Evaluate the impact of depressive symptoms on self-care behaviour in HF patients | *N*=187 patients (mean age 66.7±13.9, 64% male) | Not described | Depressed patients had poorer self-monitoring of body weight ($P=0.041$) than those without depression | |
| Samir and Nour,[36] 2011, Egypt, journal article | Self-management of heart failure tool | Describe HF patients' abilities to manage their disease | *N*=120 patients (60% of patients' age ranged 50–60, 67% men, 64% NYHA II/III) | Differences between NYHA class and recognising change with higher recognition in NYHA III ($P=0.037$) and in education with higher recognition in diploma and university graduates ($P=0.05$) | Less recognising change in symptoms for those living alone comparing with those living with others ($P=0.014$) | No statistical difference in recognising change in symptoms regarding sex or age |
| Sethares,[48] 2009, USA, conference abstract | The HF somatic awareness scale, the modified response to symptoms questionnaire | Describe correlations between symptom severity, uncertainty and cognitive and emotional reasons for delay in seeking treatment for symptoms of HF | *N*=123 chronic HF subjects with acute HF decompensation (mean age 75.8±12.3 54% male) | Not described | Symptom severity was correlated with not recognising the importance of symptoms ($r=0.21$, $P=0.05$) | No gender differences in attribution of symptoms |
| Sethares,[37] 2008, USA, conference abstract | The HF somatic awareness scale, the modified response to symptoms questionnaire | Describe symptom severity, attribution and the effect of symptom severity and attribution on delay in seeking treatment for symptoms of HF | *N*=68 chronic HF subjects (mean age 74.3±14.2, 53% male) | Not described | Tiredness might confound proper interpretation of HF symptoms | Men and women did not differ in symptom attribution ($P=0.26$) |
| van der Wal et al.,[39] 2007, The Netherlands, journal article | Revised HF compliance scale | Assess compliance with medication, diet, and daily weighing | *N*=954 patients hospitalised for symptomatic HF (mean age 71±11, 62% male, 96% NYHA II/III) | Not described | Older patients (⩾65 years) forget to weigh more often (30% older vs. 15% younger, $P\leqslant0.01$) | |
| **Mixed-methods studies** | | | | | | |
| Evans,[103] 2016, USA, Dissertation | The HF somatic perception scale | Examine somatic awareness and self-symptom recognition in stage D HF patients, comparing patients newly diagnosed with HF to those with chronic HF | Stage D HF patients newly diagnosed ($n=9$, ⩽2 years) and chronic HF patients ($n=11$, >2 years) (mean age 61±9, 55% male) | Length of time from diagnosis was positively correlated with the HF somatic perception total score ($r=0.53$, $P=0.02$) | Not described | |
| Jurgens et al.,[3] 2009, USA, journal article | The HF somatic perception scale, the modified response to symptoms questionnaire | Describe contextual factors related to symptom recognition and response among elders hospitalised with decompensated HF | *N*=77 (mean age 75.9±7.7, 52% male, 81% NYHA III/IV) | Not described | Comorbid illness such as chronic lung disease and obesity, incorrect symptom attribution, and a gradual progression of symptom severity were factors hampering the identification of the HF symptoms in a subgroup of $n=10$ | |
| Riegel et al.,[104] 2010, USA, journal article | Sample divided at the median to compare younger older patients, Borg measure of perceived exertion and 100 mm VAS for shortness of breath | Assess whether aging is associated with less ability to detect and interpret afferent physiological information | *N*=29 HF persons (mean age 68.7±14.4, 72% male, 59% NYHA II) | Not described | Older patients (⩾73 years) had more difficulty in detecting and interpreting shortness of breath than younger patients | |

*(Continued)*

**Table 3.** (Continued)

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|---|---|---|---|---|---|---|
| Riegel et al.,[105] 2010, USA, journal article | The self-care of HF index v.4 | Describe HF self-care in men and women and to identify gender-specific barriers and facilitators influencing HF self-care | *N*=27 (mean age 68.7±14.7, 70% male, 59% NYHA II) | The men were better than the women at interpreting their symptoms as being related to HF and in initiating treatment | Not described | |
| Riegel et al.,[102] 2018, USA, journal article | The HF somatic perception scale, thoracic fluid accumulation measured with an implantable cardioverter defibrillator (OptiVol) | Explore symptom perception in patients with chronic HF: to evaluate the accuracy of HF patients' abilities to detect changes in fluid retention, to explore factors associated with inaccurate detection | *N*=36 HF outpatients, *n*=18 with OptiVol data available for analysis (mean age 64±15.2, 67% male, 57% NYHA III) | Not described | Those with a mismatch were younger (53.9±15.2 vs. 72.5±7.9 years, *P*=0.004) | No differences between the groups in sex, depression, Charlson comorbidity index scores, cognition scores, Iowa gambling task decision-making scores, symptoms or symptom variability, duration of HF, and weight monitoring frequency |
| **Reviews, conceptual framework and theory** | | | | | | |
| Evans,[95] 2016, USA, journal article | Integrative review | Understand how symptom recognition impacts healthcare utilization in adult patients with HF | *N*=26 articles, 10 reported as descriptive or qualitative studies, 13 reported as observational designs, 1 RCT, 2 systematic reviews | Not described | Older adults have difficulty differentiating symptoms of HF from age-related changes | Sex not associated with any significant differences in symptom recognition. No difference in body awareness when examined for age, sex and treatment |
| Falk et al.,[96] 2013, Sweden, journal article | Integrative review | Explore and summarise the current literature examining self-reported symptoms, illness experience, and self-care management in older patients with HF | *N*=23 articles, 5 qualitative designs, 18 cross-sectional or pre-post test designs | Not described | Limited HF knowledge undermined the importance of regular symptom monitoring. Older patients have more difficulty in detecting and interpreting symptoms of dyspnoea | |
| Herber et al.,[93] 2017, Germany, journal article | Qualitative meta-summary | Integrate the findings of qualitative studies pertaining to barriers and facilitators to self-care | *N*=31 articles, 23 qualitative, 8 mixed-methods | Worsening symptoms acted as a facilitator in some patients and led to an increase in vigilance. Men were better than women at interpreting their symptoms as being related to HF | Not described | |
| Lam and Smeltzer,[16] 2013, USA, journal article | Integrative review | Examine research to date on self-reported patterns of symptom recognition and treatment-seeking behaviors in HF patients | *N*=14 descriptive studies, 7 retrospective, 7 prospective | Not described | Older age groups were less likely to recognise symptoms | |
| Lee and Riegel,[17] 2017, USA, journal article | Integrative review | Describe the research conducted on HF symptom perception to further understanding of this new concept | *N*=21 studies, 9 descriptive studies, 7 two-group randomised studies, 3 mixed-methods, 2 qualitative studies | Those living with others recognised changes in signs and symptoms better than those who lived alone (*P*=0.014). Those with college education recognised symptoms better. NYHA (*r*=0.35, *P*=0.002), number of hospital admissions (*r*=0.42, *P*<0.001) and cardiac-related admissions within a 6-month period (*r*=0.36, *P*=0.002) positively correlated with somatic perception. Higher uncertainty positively correlated with awareness of somatic changes (*r*=0.36, *P*<0.001) Smaller symptom duration (less than 72 hours) more likely to be aware of somatic changes (*r*=0.26, *P*=0.001) | Age negatively correlated with somatic awareness (*r*=−0.19, *P*=0.015) Gradual symptom progression as a barrier to symptom detection | |

*(Continued)*

**Table 3.** (Continued)

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|---|---|---|---|---|---|
| Moser and Watkins,[10] 2008, USA, journal article | Conceptual framework | Addressing the complex set of factors that influence decisions among patients with HF | | Experience is necessary for patients to interpret their symptoms correctly | Cognitive impairment may contribute to failed symptom perception, recognition and interpretation. Daily weighing is difficult for those with impaired vision and balance. Elderly individuals might perceive symptoms less intensely than younger people. Increased daytime sleepiness interferes with ability to monitor symptoms. Chronic lung disease, depression, neuropathy make symptom interpretation difficult |
| Riegel et al.,[1] 2016, USA, journal article | Situation-specific theory | Describe the revised, updated situation-specific theory of HF self-care | 85 Articles | Not described | Older patients have issues with sensing and interpreting early symptoms. Age-related impairment in interoception has been suggested as one mechanism for poor symptom perception. The sheer volume of symptoms experienced complicates symptom perception. Persons with mild cognitive impairment have difficulty in recognizing symptoms of an exacerbation |
| Woods et al.,[98] 2016, Australia, Journal article | Narrative literature review | Identify and analyse the literature on HF patients' experiences of non-pharmacological self-care | *N*=18 papers, 14 primary articles (6 quantitative studies, 5 qualitative, 3 mixed-methods studies) and 4 literature reviews | Not described | Poor self-care monitoring in persons aged >75, elderly have problems with sensing and attributing worsening HF symptoms to their condition. Relating to cognition, some patients were deemed to be unaware of their worsening symptoms |
| Zavertnik,[99] 2014, USA, journal article | Integrative review | Examine the evidence specific to self-care in older adults, 65 years or older, with HF and to indicate best nursing practice interventions for use in this population | *N*=9 articles, 3 RCT, 2 non-RCT trials, 4 qualitative studies | Not described | Hearing and vision loss and decreased cognition impact older patients' ability to attend to internal physical symptoms and may result in poor early symptom detection |
| **Non-reported study designs** | | | | | |
| Dickson et al.,[109] 2007, USA, journal article | | Explore cognitive deficits known to exist in persons with HF | | Not described | Deficits in memory, attention, and executive function may impair the perception and interpretation of early symptoms |
| Jurgens et al.,[107] 2010, USA, journal article | | Discuss the relationship between self-care and HF symptom management and to provide nursing strategies for assessment and promotion of self-care in older adults with HF | | Not described | Sedentary lifestyles may limit the experience or perception of dyspnea or fatigue. An insidious increase in chronic symptoms may also make a change in severity difficult to detect. Comorbid illness complicates determining the source and meaning of symptoms |

*(Continued)*

**Table 3.** (Continued)

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|---|---|---|---|---|
| Riegel et al.,[110] 2011, USA, journal article | Review what is known about HF self-care in terms of predictors and outcomes, and to discuss their implications on clinical practice, public health and policy | Anxiety and depression have been suggested to increase somatic awareness. Individuals with high negative affectivity are thought to be internally focused and more likely to notice somatic and visceral changes including early HF symptoms | Comorbidities and neural deficits may affect symptom monitoring and interpretation | No detection of difference of awareness of HF symptoms between men and women |
| Rushton et al.,[111] 2011, UK, journal article | Explore challenges of comorbidity by taking a look at the care of HF patients | Not described | Comorbidity impacts symptom recognition and makes difficult to distinguish what symptom relates to which condition. Depression can delay symptom recognition | |
| Skotzko,[108] 2009, USA, journal article | Non described | Depressive disorders, anxiety disorders, personality disorders (histrionic, borderline, dependent) may be associated with amplification of perception of HF symptoms | Mania, alexithymia, chronic psychotic illness may be associated with diminished perception of chronic HF symptoms | |

Table 3 provides a summary of the study characteristics of all articles included reporting on factors related to symptom perception.
HF: heart failure; LVEF: left ventricular ejection fraction; NYHA: New York Heart Association classification; OR: odds ratio; RCT: randomised controlled trial; v: version.

**Table 4.** HF symptom perception instruments and related symptom perception dimensions.

| Instrument | Body observation | | Body analysis | | |
|---|---|---|---|---|---|
| | Body listening | Monitoring signs | Recognising symptoms | Interpreting symptoms | Labelling symptoms[1] |
| | Being aware there is a change | | | Assigning meaning to the change[80] | |
| **Heart failure self-care instruments** | | | | | |
| Self-care of heart failure index v. 6.2[13] | | × | × | × | |
| European heart failure self-care behaviour scale[14] | | × | | | |
| Self-care of heart failure index v. 7.2[51] | × | × | × | × | × |
| Caregiver contribution to heart failure self-care[53] | × | × | | | |
| Self-management of heart failure tool[59] | | | × | × | × |
| Caregiver contribution to self-care of heart failure index[60] | | × | × | × | |
| **Instruments related to symptom perception concepts** | | | | | |
| Heart failure somatic awareness scale[55] | × | × | | | |
| Heart failure somatic perception scale[56, 58] | × | × | | | |
| Body awareness questionnaire[44] | × | | | | |
| Revised heart failure compliance scale[39] | | × | | | |
| Self-evaluation of symptoms, signs and compliance to therapy for heart failure surveillance[32] | × | × | | | |
| Modified response to symptoms questionnaire[3] | | | × | × | |
| Dyspnoea visual analogue scale[63] | | × | | | |
| **Heart failure self-monitoring instruments** | | | | | |
| Fluid overload symptoms scale[50] | × | × | | | |
| HeartMapp[52] | | × | | | |
| Evaluation scale for self-monitoring by patients with chronic heart failure[54] | × | × | × | × | |
| Heart failure symptom tracker (HFaST)[57] | × | × | | | |
| Weight management scale[61] | | × | | | |
| Heart failure symptom-tracker mobile application[62] | × | × | | | |
| Heart failure monitoring instruments[112] | | × | | | |
| Application for self–monitoring and interpreting HF signs and symptoms[113] | × | × | × | × | |
| Heart health diary[114] | × | × | | | |

and acute volume overload.[32] The modified response to symptoms questionnaire contains items related to the cognitive response to symptoms.[3] The dyspnoea visual analogue scale uses a 100 mm visual analogue scale to quantify perceived dyspnoea severity. In the latter, meaningful changes (i.e. a little less or a little more difficulty) correspond to 21.1 mm (95% CI 12.3–29.9 mm).[63]

Nine HF self-monitoring instruments were found.[50, 52, 54, 57, 61, 62, 112–114] The evaluation scale for self-monitoring by patients with chronic HF measures self-monitoring.[54] The heart health diary was developed to monitor common signs and symptoms of HF (i.e. weight, blood pressure, pulse, blood sugar, fatigue, shortness of breath, cough, oedema and chest pain).[114] We identified several mobile health applications:[52, 62, 113] HeartMapp can be used to monitor weight and vital signs,[52] the HF symptom-tracker mobile application was designed to monitor weight and symptoms and was tested for acceptability in patients older than 60 years of age,[62] another smartphone application for self-monitoring and interpreting HF signs and symptoms has acceptable usability scored in 75-year-old and older adults with HF.[113] Other instruments focusing on specific HF signs and symptoms are the fluid overload symptoms scale,[50] weight management scale[61] and HF monitoring instruments[112] to facilitate HF symptom recognition and reporting of dyspnoea and weight gain to providers. The HF symptom tracker (HFaST) supports ongoing evaluation of symptom changes over the previous 24 hours compared to usual patient experiences.[57]

## Discussion

This scoping review maps the literature on HF symptom perception to report on definition, description, related factors and instruments, and updates the state of the science provided in previous reviews. Importantly, HF symptoms

often undetected by patients lead to negative health sequelae.[16]

In line with previous reviews, this scoping review highlights facilitators of HF symptom perception including more prior HF hospitalisation, higher levels of illness uncertainty and living with others.[17] We report further that both self-care maintenance and symptom perception confidence facilitate symptom perception, while symptom clusters represent a barrier to accurate symptom perception. Importantly, this scoping review identified sociodemographic, person-related and condition-related factors with inconsistent findings across studies with regard to their impact on symptom perception. Younger age,[46] higher education,[17] longer duration of HF,[46] shorter symptom duration,[17] worse functional class[17] were previously reported as facilitators; aging,[17] comorbid conditions,[17] gradual symptom progression[17] were previously reported as barriers. The greater number of references included in this scoping review and the different dimensions of HF symptom perception considered may have allowed these findings.

This review reports on several studies that did not identify a relationship between sociodemographic factors (i.e. age and sex) and HF symptom perception.[36, 44] Several studies on the relationship between age and symptom perception are reported with conflicting results. Concerning sex, only one study reported men to be better than women in symptom interpretation,[105] while five studies[24, 29, 36, 44, 48] – all with larger sample sizes – report no relationship between sex and symptom perception. Also, person-related factors such as education were not found to be related to symptom perception.[24] Patient experiences of living with HF seem to facilitate symptom perception,[21, 46, 103] but one study found no relationship between HF duration and thoracic fluid detection.[102] Yet we know that congestion is not readily detected by patients.[117] Similarly, condition-related factors such as comorbidities and cognition were not reported to be associated with patients' detection of thoracic fluid accumulation.[102] With regard to comorbidities, sensory problems and fatigue/sleepiness that are plausible barriers to symptom perception negatively affect symptom perception.[10, 75] None of the primary studies included in our scoping review[22, 26, 102] found any relationship between cognitive impairment and symptom perception. Further research should elucidate the role of depression as well as symptom progression/severity in symptom perception. Overall, further research is needed regarding the impact of sociodemographic, person-related and condition-related factors on symptom perception to determine a patient risk profile.

Several facilitators and barriers of HF symptom perception converge with the broader literature on HF self-care[9] as well as factors relating to self-care in chronic conditions.[118] In line with findings of this scoping review, confidence and social support have been reported to facilitate HF self-care[9] and self-care in other chronic conditions.[118] Habits integrated into daily routines are important for self-care[118] – that may relate to HF self-care maintenance thereby facilitating symptom perception (e.g. weighing oneself regularly). Experience and skills, as well as functional and cognitive abilities, influence HF self-care[9] and self-care in chronic illness more broadly.[118] In the present review, prior HF hospitalisation facilitates symptom perception. Furthermore, greater experience of living with HF, as well as cognitive impairment, are inconsistent factors of symptom perception – which contrasts with the broader literature.[118] Nevertheless, disparate results across studies on symptom perception factors neither provide insight into experience nor cognitive abilities as a potential facilitator of symptom perception.

Overall, we identified one instrument[51] measuring all dimensions of HF symptom perception, yet further psychometric testing in other HF patient samples and additional languages seem warranted.

For other chronic conditions, these results may contribute to address current research gaps related to self-care monitoring,[119] describing symptom perception challenges and related behaviours. As in other chronic conditions,[120] HF symptom perception is related to emotional distress which may guide symptom response.[80] Symptom response is challenging in other chronic conditions such as atrial fibrillation[121] and stroke.[122] Some have postulated that difficulty interpreting non-specific symptoms results in delays in seeking care.[121, 122] Definitions of HF symptom perception converge on the concepts of detecting and interpreting symptoms in chronic conditions.[119]

Limitations of this scoping review include the lack of a structured quality appraisal of included articles, which is appropriate for scoping reviews.[19] A quality appraisal could be useful for supporting interpretation of data in further reviews. Also, we did not consider studies reporting on symptom intensity, severity or descriptions of distress relevant to be included as they do not directly relate to symptom perception within the HF self-care process.

Relative strengths of this review include the systematic searching process that included unpublished (grey) literature thus minimising publication bias. Including grey literature as well as conference abstracts allowed us to identify articles not yet published in August 2018 which we tracked for inclusion in this report. In particular, the first author (GCS) reran the search in August 2019 in the three major bibliographic databases (i.e. Medline, Embase, Web of Science) yielding the majority of the references included in the initial search. After screening the new references published in 2018 and 2019, five additional references[123–127] were identified. Importantly, the five additional references were not deemed to alter significantly the overall synthesis findings of the scoping review and are not included in this review as the screening deviated slightly from the structured systematic search process. Furthermore, references in multiple languages were included providing a comprehensive, broad and

culturally inclusive perspective. References were screened and selected by independent reviewers and data charting as well as results reporting followed a structured, systematic way – helping to ensured internal validity.

Symptom perception in HF is established, has been described and well defined. Several symptom perception factors are known, and further work is needed to dissect the relative effect of factors and elucidate inconsistent results related to the facilitators and barriers to HF symptom perception. This will be important to determining patient risk profiles related to poor symptom perception. In addition, further work is needed on symptom perception measurement in HF for both research and clinical use. Deepening our understanding of symptom perception, its factors and measurement will be important for strengthening person-centered self-care support in HF and reducing negative health sequelae resulting from unravelled limitations to symptom perception.

## Implications for practice

- Heart failure symptom monitoring, recognising and interpreting is challenging for persons.
- Persons' characteristics can be detected to identify those at risk for poor heart failure symptom perception.
- The self-care of heart failure index v.7.2 and its symptom perception subscale can be used to measure self-care and symptom perception in heart failure.

## Acknowledgements

The authors would like to acknowledge Dr François Mooser for his support with administrative issues along the study and related to the submission of this work. GCS is grateful for expert feedback received during presentations of this work during doctoral seminars at the Institute of Higher Education and Research in Healthcare (IUFRS), University of Lausanne and during Swiss PhD in nursing science education (SPINE) doctoral days as well as during research seminars at the University of Applied Sciences and Arts Western Switzerland (HES-SO) School of Health Sciences, Fribourg.

## Declaration of conflicting interests

The authors declare that there is no conflict of interest.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: this work was supported by the School of Health Sciences Fribourg, HES-SO University of Applied Sciences and Arts Western Switzerland (to GCS, PSK, JG) and county council Sörmland Sweden (to ML) to dedicate a part of their positions' time to the scoping review.

## Supplementary material

Supplementary material for this article is available online.

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