International Journal of Nursing Studies 116 (2021) 103524

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/ijns

Symptom perception in heart failure – Interventions and outcomes: A scoping review

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ARTICLE INFO

Article history:
Received 15 July 2019
Received in revised form 12 December 2019
Accepted 2 January 2020

Keywords:
Diagnostic self evaluation
Heart failure
Perception
Scoping review
Signs and symptoms
Symptom perception interventions
Symptom perception outcomes

ABSTRACT

Background: Symptom perception in heart failure has recently been described as essential in the self-care process bridging self-care maintenance and self-care management. Accordingly, symptom perception appears to be critical for improving patient outcomes such as decreased hospital readmission and increased survival.

Objectives: To explore what interventions have been reported on heart failure symptom perception and to describe outcomes responsive to symptom perception.

Design: We conducted a scoping review using PRISMA Extension for Scoping Reviews.

Data sources: Structured searches of Medline, PubMed, Embase, CINAHL, PsychINFO, Web of Science, Cochrane, Joanna Briggs Institute and Grey literature databases.

Review methods: Two authors independently screened references for eligibility. Eligible articles were written in English, French, German, Swedish, Italian or Spanish and concerned symptom perception in adults with heart failure. Data were extracted and charted in tables by three reviewers. Results were narratively summarized.

Results: We identified 99 eligible studies from 3055 references. Seven interventional studies targeted symptom perception as the single intervention component. Mixed results have been found: while some reported decreased symptom frequency, intensity and distress, enhanced health-related quality of life, improved heart failure self-care maintenance and management as well as a greater ability to mention heart failure symptoms, others found more contacts with healthcare providers or no impact on anxiety, heart failure self-care nor a number of diary reported symptoms. Additional interventional studies included symptom perception as one component of a multi-faceted intervention. Outcomes responsive to symptom perception were improved general and physical health, decreased mortality, heart failure decompensation, as hospital/emergency visits, shorter delays in seeking care, more consistent weight monitoring, improved symptom recognition as well as self-care management, decreased hospital length of stay and decreased costs.

Conclusions: While many studies allowed to map a comprehensive overview of interventions supporting symptom perception in heart failure as well as responsiveness to outcomes, only a few single component intervention studies targeting symptom perception have been reported and study designs preclude assessing intervention effectiveness. With regard to multiple component interventions, the specific impact of symptom perception interventions on outcomes remains uncertain to date. Well-designed studies

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https://doi.org/10.1016/j.ijnurstu.2020.103524

are needed to test the effectiveness of symptom perception interventions and to elucidate relationships with outcomes.

What is already known about the topic?

- Symptom perception is a component of heart failure self-care and is requisite for attaining self-care management.
- Symptom perception is challenging for persons living with heart failure.

What this paper adds

- Symptom perception should be a target for improving heart failure self-care.
- Few interventional studies have examined symptom perception as the only intervention component.
- Symptom perception outcomes relate to improved patient health and decreased complications

1. Introduction

Symptom perception has been proposed to have a key role in the self-care process of individuals with heart failure (Riegel et al., 2016) to improve patient and health care system outcomes (Lee et al., 2018). Heart failure self-care comprises maintenance (i.e. treatment adherence, maintaining healthy behaviors), symptom perception and management (i.e. response to symptoms when they occur) (Riegel et al., 2016). Symptom perception concerns body listening and monitoring signs to detect physical sensations enabling the individual to recognize, interpret and label symptoms (Riegel et al., 2016). Activities of symptom detection and interpretation are described as core elements in the self-care process of chronic illness (Riegel et al., 2018). Monitoring signs as well as recognizing and interpreting symptoms has been described as challenging for persons with heart failure (Horowitz et al., 2004, Jurgens et al., 2009). Such difficulties contribute to decreased self-care management and poor patient outcomes (Santos et al., 2019). More specifically, failure to detect and appropriately interpret symptoms can result in inappropriate (Horowitz et al., 2004, Jurgens et al., 2009) or delays in seeking care (Horowitz et al., 2004) as well as prolonged hospitalizations (Sethares et al., 2015). Further, inappropriate symptom management has been found to increase the number of emergency room visits, heart failure hospitalization and all-cause mortality (Lee et al., 2018). Importantly, heart failure self-care remains suboptimal worldwide (Jaarsma et al., 2013) and effective interventions are needed to improve patient outcomes.

Symptom perception is fundamental for effective self-care management (Riegel et al., 2016) and is a target for interventions to improve self-care abilities. The symptom perception literature is embedded in the broader self-care literature. There is a paucity of evidence regarding heart failure symptom perception outcomes and how to effectively support heart failure symptom perception. Recently, the literature on symptom recognition and interpretation have been synthesized identifying that symptom recognition research is largely descriptive in nature (Lam and Smeltzer, 2013). Using a symptom diary improves survival and reduces costs (Lee and Riegel, 2017). Currently, research gaps relate to interventions supporting symptom perception and identifying outcomes related to symptom perception. In this project, we aim to comprehensively review the literature on symptom perception in heart failure. The overall purpose is to identify and synthesize current knowledge on heart failure symptom perception by mapping the current literature on heart failure symptom perception definition, description, factors, instruments, interventions and outcomes. This paper reports the literature review, synthesis of interventions and describes what outcomes have been found to be responsive to symptom perception. It addresses the following three research questions of the study:

1. Which symptom perception interventions have been described, and with which outcomes?
2. Which interventions have measured symptom perception as an outcome?
3. What outcomes are responsive to symptom perception?

2. Methods

2.1. Study design and data sources

We undertook a scoping review according to accepted guidelines using PRISMA Extension for Scoping Reviews (Moher et al., 2009). Data sources comprised Medline OvidSP, PubMed (for references not indexed in Medline), Embase.com, CINAHL, PsychINFO OvidSP, Web of Science Core Collection, Cochrane Library Wiley and Joanna Briggs Institute Database OvidSP bibliographic databases as well as ProQuest (dissertations and theses), BASE, Clinical trials, DART and ICTRP grey literature databases.

2.2. Eligibility criteria

Eligibility criteria were elaborated according to population, concept, and context. We included studies on adults with heart failure reporting on interventions that support symptom perception; interventions measuring symptom perception as an outcome; outcomes responsive to symptom perception. Any study design (including expert opinion) published in English, French, Swedish, German, Italian and Spanish before September 2018 were considered. We excluded studies describing symptom intensity only, symptom severity or symptom distress and studies on symptom perception definition, description, factors related to symptom perception and instruments measuring symptom perception. Studies on remote monitoring or studies on symptoms monitored by healthcare professionals were also excluded.

2.3. Review methods

The scoping review followed a systematic; 4-step process: (1) identifying the research question, (2) identifying and selecting relevant studies, (3) charting the data, (4) collating, summarizing and reporting results (Arksey and O'Malley, 2005). The optional step of consultation (Arksey and O'Malley, 2005), was not conducted. A single study was undertaken to map symptom perception literature and two separate manuscripts resulted, reporting on seven different research questions. Four research questions related to symptom perception description, factors and instruments which has been reported elsewhere (Santos et al., 2019). While all seven research questions are based on the same literature search sources and search strategy, screening references, determining eligibility,

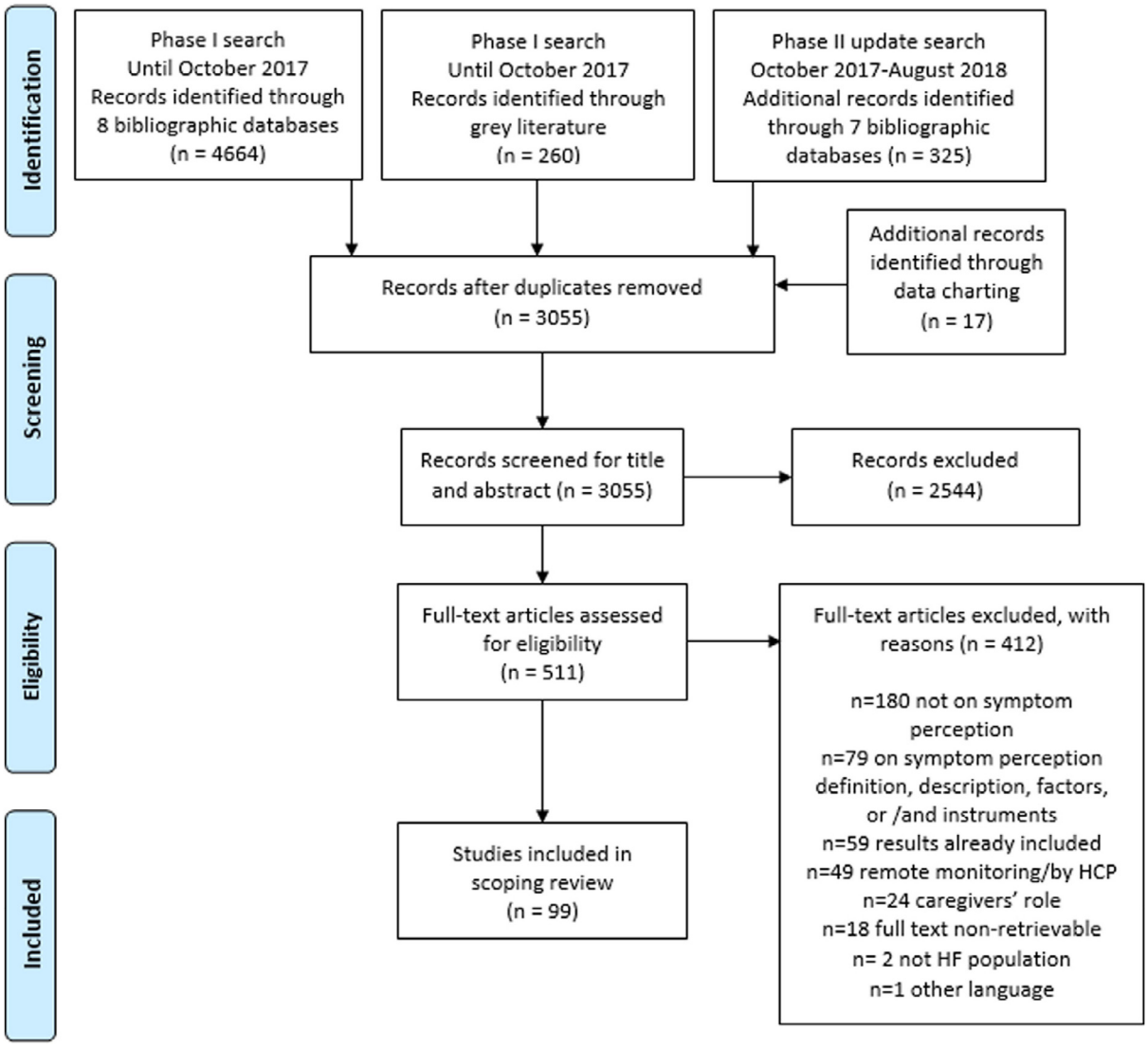

Fig. 1. PRISMA flow diagram (Moher et al., 2009) of the scoping review study selection process. Except identification of references that are identical for all seven research questions, this flow diagram is specific to this manuscript.

included references and results are specific to the research questions - and thus differ between manuscripts.

A medical librarian (CJ) searched in Medline OvidSP with an initial list of identified keywords. The first reviewer (GS) screened relevant articles and discussed articles with the second reviewer (ML). Discussion guided the selection of final keywords and index terms to build the structured search strategy of databases (Supplementary materials). The literature search was actualized on August 21, 2018 in the seven bibliographic databases – yielding the majority of included references. Additional articles were identified from reference lists and were added in the review process. On request, first authors of non-retrievable references provided full-text access for 11 references.

References were imported and duplicates removed using a citation management software (Endnote X7.7.1,Clarivate Analytics). All identified references were independently screened by title and abstract by two reviewers (GS, ML). References meeting inclusion criteria were screened (full text) by both reviewers. Rayyan web-based software (Ouzzani et al., 2016) was used to trace the review and reporting process. Each included reference was first labelled according to the respective research question(s) (GS, ML), then randomly assigned for data charting (GS, ML or JG) and structured data extraction forms were used to chart the data. A 10% sample underwent blinded dual data extraction. Data extracted in duplicate was deemed comparable. GS narratively summarized results and discussed them (ML, JG, PS). Data considered to be unclear were discussed to consensus.

3. Results

After removing duplicates, we identified and screened 3055 references. A total of 2544 references not meeting inclusion criteria were excluded. The remaining 511 references were reviewed by full text yielding 99 references for inclusion (Fig. 1). Included references represent 84 interventional studies (30 randomized controlled trials, 37 quasi-experimental studies, 16 pilot studies, one mixed-methods study), nine observational studies, three literature reviews, one study lacking a description of the study design, one theory and one conceptual framework. Some references were deemed to relate to several research questions: 84 references relate to symptom perception interventions and 21 to symptom perception outcomes (Table 1).

This scoping review mapped the literature on heart failure symptom perception interventions and outcomes (Fig. 2).

Table 1
Included studies, related study designs and research questions, symptom perception intervention components and outcomes. These references are cited in Table 1. (Abdurashidova, 2014, Burke et al., 2016, Varma et al., 1999, Vellone et al., 2019, Wongpiriyayothar et al., 2011, Caramlau et al., 2018, Carroll et al., 2017, Cavusoglu et al., 2017, Cox et al., 2011, de la Porte et al., 2007, DeWalt et al., 2012, Anderson, 1999, Dinh, 2016, Donaho et al., 2015, Dracup et al., 2014, Dunbar et al., 2015, Gee et al., 2010, Hoke, 2002, Holland et al., 2007, Howie-Esquivel et al., 2014, Just et al., 2011, Korajkic et al., 2011, Baker et al., 2011, Lawler et al., 2009, Lee, 2012, Li et al., 2016, Liljeroos and Strömberg, 2017, Lloyd et al., 2017, Ballard-Hernandez, 2010, Lopez-Fernandez et al., 2013, Macabasco-O'Connell et al., 2011, Mack et al., 2009, Miller and Cox, 2005, Mussi et al., 2013, Navidian et al., 2015, Blomqvist et al., 2017, Post et al., 2012, Riegel and Carlson, 2002, 2004, Riegel et al., 2015, 2010, Rosman et al., 2016, Brennan et al., 2010, Shively et al., 2011, Sisk et al., 2006, Song et al., 2017, 2014)

Included studies	Related to research question(s)			Symptom perception intervention components						Single component intervention	Symptom perception as an intervention outcome	
	RQ 1	RQ 2	RQ3	Weight monitoring	Weight monitoring with scale provided	Weight monitoring & diary/graph reporting	Heart failure symptom monitoring	Symptom recognition	Symptom interpretation		Weight or symptom monitoring	Symptom recognition and awareness
Interventional studies												
Randomized controlled trials (n=30)												
(Baker et al., 2011)	X			X								
(Cavusoglu et al., 2017)	X				X			X				
(de la Porte et al., 2007)	X					X		X				
(Deek et al., 2017)	X				X						Improved	
(DeWalt et al., 2006)	X				X			X			Improved	
(DeWalt et al., 2012)	X			X			X					
(Dinh, 2016)	X				X	X		X				
(Dracup et al., 2014)	X					X	X					
(Dunbar et al., 2015)	X			X			X					
(Granger et al., 2013)	X							X				Improved
(Hoke, 2002)	X								X			
(Holland et al., 2007)	X						X					
(Jurgens and Riegel, 2011)	X				X	X		X		X		
(Korajkic et al., 2011)	X			X				X				
(Lee, 2012)	X						X					
(Li et al., 2016)	X			X								
(Macabasco-O'Connell et al., 2011)	X			X								
(Meng et al., 2016)		X									Improved	
(Mussi et al., 2013)	X			X				X				
(Park et al., 2017)	X		X		X	X	X	X				
(Riegel and Carlson, 2004)	X							X				
(Riegel et al., 2015)	X						X					
(Shao et al., 2014)	X			X			X				Different	
(Shively et al., 2011)	X			X			X					
(Sisk et al., 2006)	X				X	X	X					
(Song et al., 2017)	X						X					
(Song et al., 2014)	X						X					
(Veroff et al., 2012)	X			X							Improved	
(Wang et al., 2014)	X		X			X					Improved	
(Wongpiriyayothar et al., 2011)	X						X					

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Table 1 (*Continued*).

Quasi-experimental studies (n=37)												
(Abdurashidova, 2014)	X						X					
(Anderson, 1999)	X							X				
(Baker et al., 2005)		X									Improved	
(Ballard-Hernandez, 2010)	X			X				X				
(Blomqvist et al., 2017)	X						X					
(Boehmer et al., 2016)	X		X	X		X	X					
(Brennan et al., 2010)	X						X					
(Carroll et al., 2017)	X						X					
(Cox et al., 2011)	X			X								
(Donaho et al., 2015)	X							X				
(Dorsch et al., 2015)	X						X			X		
(Eastwood et al., 2007)	X		X			X	X					
(Fonarow et al., 1997)	X			X								
(Foster, 2018)	X						X				Improved	Did not improve
(Gee et al., 2010)	X				X			X				
(Gonzalez et al., 2005)	X			X							Improved	Improved
(Hoover et al., 2017)	X							X				Improved
(Just et al., 2011)	X					X						
(Koshy, 2014)	X			X				X			Improved	
(Lawler et al., 2009)	X							X				
(Liljeroos and Strömberg, 2017)	X						X					
(Lopez-Fernandez et al., 2013)	X							X				
(Mack et al., 2009)	X			X								
(Miller and Cox, 2005)	X						X					
(Monteiro Mantovani et al., 2015)	X			X				X			Improved	
(Navidian et al., 2015)	X						X					
(Papasifakis and Vanderveen, 2009)	X						X					Improved
(Pereira Sousa and Santos, 2017)	X							X		X		
(Post et al., 2012)	X			X				X				
(Rauh et al., 1999)	X					X		X				
(Rosman et al., 2016)	X			X				X				
(Staples, 1998)	X			X				X				

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Table 1 (*Continued*).

(Stone, 2012)	X						X					
(Thebaud-Young, 2014)	X		X		X							
(Triggiani et al., 2014)	X							X				
(Wang et al., 2011)	X						X					
(Wright et al., 2003)	X		X			X					Improved	
Pilot studies (n=16)												
(Caldwell et al., 2005)	X			X				X			Improved	
(Caramlau et al., 2018)	X						X					
(Dickson et al., 2014a)	X						X					
(Dickson et al., 2014b)	X						X	X	X		Improved	Improved
(Howie-Esquivel et al., 2014)	X				X	X	X					
(Jurgens et al., 2013)	X			X	X	X	X	X	X			
(Lang et al., 2018)	X						X					
(Lloyd et al., 2017)	X					X						
(Nundy et al., 2013)	X				X			X				Did not improve
(Piamjariyakul et al., 2014)	X						X				Improved	
(Shaw et al., 2014)	X					X	X		X		Improved	
(Tracy, 1999)	X					X		X	X	X		
(Varma et al., 1999)	X						X					
(Wakefield et al., 2016)	X					X	X			X	Improved	
(Weiss et al., 2018)	X							X				
(Wolf et al., 2012)	X					X	X		X	X		
Mixed-methods study (n=1)												
(Sethares and Asselin, 2017)	X					X	X	X	X	X		
Observational studies (n=9)												
(Friedman et al., 1998)			X									
(Jones et al., 2012)			X									
(Jones et al., 2014)			X									
(Lee et al., 2018)			X									
(Lee et al., 2015)			X									
(Riegel et al., 2019)			X									
(Samir and Nour, 2011)			X									
(van der Wal et al., 2010)			X									
(Vellone et al., 2013)			X									

(*Continued on next page*)

Table 1 (*Continued*).

Other study designs												
Literature reviews (n=3)												
(Kent et al., 2011)			X									
(Lam and Smeltzer, 2013)			X									
(Lee and Riegel, 2017)			X									
Study with a non-reported design (n=1)												
(Jurgens et al., 2010)			X									
Theory (n=1)												
(Riegel and Dickson, 2008)			X									
Conceptual framework (n=1)												
(Moser and Watkins, 2008)			X									

RQ: research question. RQ1: "Which symptom perception interventions have been described, and with which outcomes?"; RQ2: "Which interventions have measured symptom perception as an outcome? "; RQ3: "What outcomes are responsive to symptom perception?" Empty cells: not measured/not applicable.

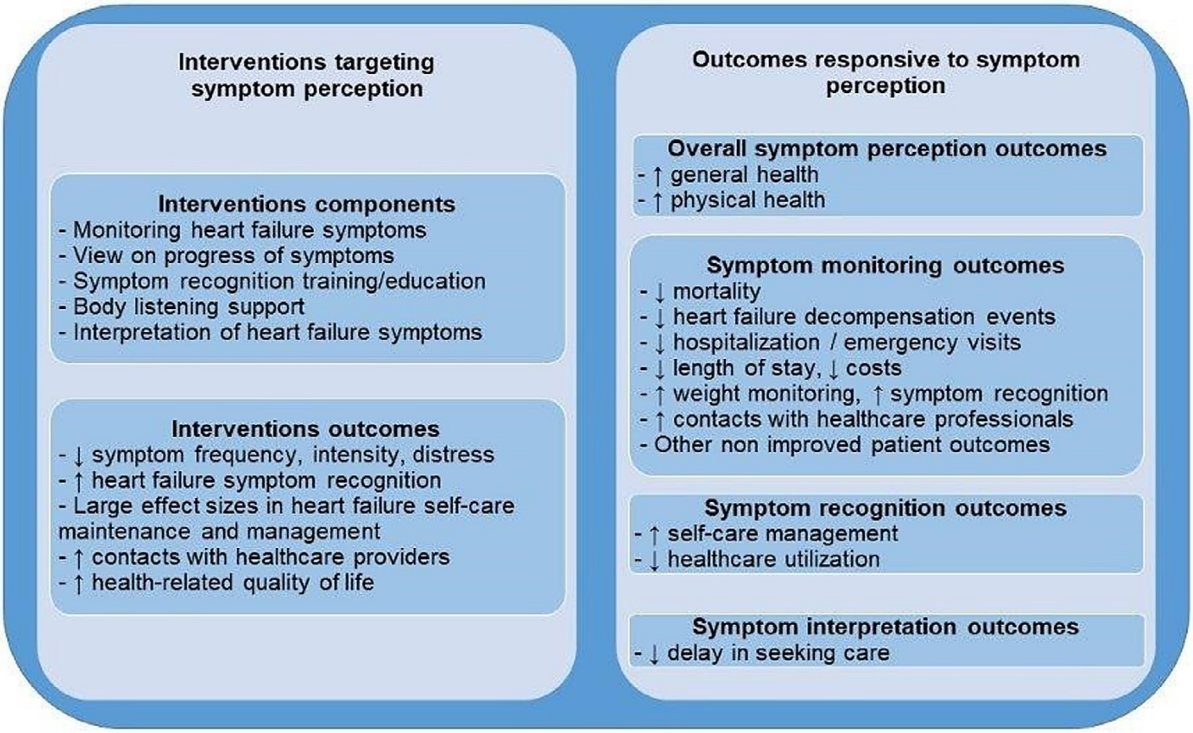

Fig. 2. Overview of scoping review findings on heart failure symptom perception interventions and outcomes responsive to symptom perception.

Table 2a
Interventional studies targeting symptom perception in heart failure as the single intervention component.

Authors (year), country	Design	Sample	Symptom perception intervention description	Outcomes (instrument)
Dorsch et al. (2015). USA	Quasi experimental,[a] one group pre-test–posttest	*N* = 24 persons with systolic HF	Instruction on daily self-monitoring View on progress on web site	• ↓ NYHA classification • ↑ HRQL (MLHFQ)
Jurgens and Riegel (2011). USA	RCT	*N* = 46 persons with HF	Weight scale and self-care booklet Training on symptom recognition and use of a daily symptom graph	• ↓ HF symptom perceived distress (HFSPS) • ↑ contacts with healthcare providers • HF self-care (SCHFI): clinical, no statistical ≠
Pereira Sousa and Santos (2017). Portugal	Quasi experimental,[a] one group pre-test–posttest	*N* = 28 persons admitted with acute HF	Education about symptom recognition and about signs and symptoms	• ↑ of patients mentioning HF symptoms
Sethares and Asselin (2017). USA	Mixed-methods, one group pre-test–posttest	*N* = 10 persons with primary diagnosis of HF	Diary of HF symptoms Reflective questions to explore self-care behaviors, context and meaning of the symptom experience	• ↑ HF self-care maintenance and management (SCHFI, effect sizes)
Tracy (1999). USA	Feasibility study,[a] one group pre-test–posttest	*N* = 7 persons 55–80yrs with symptomatic HF	Health diary Body listening support	• No ≠ in diary reported number of symptoms • No ≠ in anxiety scores (STAI) • ↓ fatigue (Likert scale) • ↓ number of symptoms (MSPQ) • ↑ HRQL (MLHFQ)
Wakefield et al. (2016). USA	Feasibility study,[a] one group pre-test–posttest	*N* = 31 persons with chronic HF	Instruction to use 2 paper-based graphs to monitor weight and dyspnea daily	• No ≠ in HF self-care (SCHFI) • ↑ weight monitoring frequency and ask for a low-salt diet (SCHFI)
Wolf et al. (2012). Sweden	Feasibility study, one group pre-test–posttest	*N* = 4 persons >75yrs with HF	Training to use application for weight, dyspnea, fatigue monitoring. Training to interpret the visual trends of signs and symptoms	• All patients used the application frequently, perceived as useful

HF: heart failure; HFSPS: Heart Failure Somatic Perception Scale, lower score = lower symptom perceived distress; HRQL: health-related quality of life; MLHFQ: Minnesota Living with Heart Failure Questionnaire, lower score = better HRQL; MSPQ: Modified Somatic Perception Questionnaire, lower score = fewer symptoms reported; NYHA: New York Heart Association class; RCT: randomized controlled trial; SCHFI: Self-Care of Heart Failure Index, lower scores = lower self-care; STAI: State-Trait Anxiety Inventory, lower score = lower degree of anxiety; ≠: difference.
[a] Study design qualified by the authors of the scoping review based on information found in the study.

Question 1. Which symptom perception interventions have been described, and with which outcomes?

3.1. Interventions targeting symptom perception

Of the 84 intervention studies, seven tested interventions targeting symptom perception as the single intervention component (Dorsch et al., 2015; Jurgens and Riegel, 2011; Pereira Sousa and Santos, 2017; Sethares and Asselin, 2017; Tracy, 1999; Wakefield et al., 2016; Wolf et al., 2012) (Table 2a).

In a randomized controlled trial, Jurgens and Riegel (2011) tested the effect of an interactive symptom training protocol on self-care, symptom burden and health provider contact in 46 participants (71yrs, 39% female, 78% New York Heart Association class-NYHA III-IV). All persons were provided a weight scale and a self-care booklet. The intervention group was trained on symptom recognition and use of daily symptom graph. After six months, the intervention group showed a lower heart failure symptom perceived distress compared to the control group (10.6 versus 20.4, $p = 0.03$) and more contacts with healthcare providers (10 versus 8 calls, p not reported) – yet clinical difference in self-care scores (Jurgens and Riegel, 2011).

All other studies used a quasi-experimental, single group pre-posttest design. Dorsch et al. (2015) tested the impact of a web application for self-monitoring on heart failure symptoms and health-related quality of life in 24 participants (59yrs, 63% female, 100% NYHA II-III). Similar to the randomized controlled trial of Jurgens and Riegel (2011), patients were instructed to self-monitor heart failure symptoms daily (blood pressure, heart rate, weight) and report results using a web site application providing visualization of progress, prompts for self-care goals and heart failure educational documents. At three months follow-up, the group showed a decreased mean in NYHA classification (2.0 versus 2.5 at baseline; $p = 0.0032$) and increased health-related quality of life (42.6 versus 55.7 at baseline; $p = 0.0078$) (Dorsch et al., 2015). In another pre-post test design study, Pereira Sousa and Santos (2017) tested the effect of symptom recognition education on the ability to mention heart failure symptoms in 28 persons (participants characteristics not described). One week post-discharge, 74% of participants mentioned dyspnea and 15% noted pedal edema. After one month, 61% of participants mentioned dyspnea and 4% pedal edema respectively (Pereira Sousa and Santos, 2017).

Three feasibility studies used a single group pre-posttest design. First, Wakefield et al. (2016) evaluated the feasibility of two patient self-monitoring instruments to facilitate symptom recognition in 31 participants (68yrs, 3% female). Participants used two paper-based graphs to monitor daily weight and dyspnea for three months. After three months, Self-Care of Heart Failure In-

Table 2b
Interventional studies targeting symptom perception in heart failure and self-care management.

Authors (year), country	Design	Sample	Symptom perception intervention description	Self-care management intervention description	Outcomes (instrument)
Caldwell et al. (2005). USA	Pilot RCT	$N = 36$ rural persons with HF	Individualized education and counseling session on symptom recognition, weight diary	Action to take for worsening symptoms, fluid weight management	• ↑ HF knowledge (HF disease knowledge questionnaire) • ↑ self-care behavior(EHFScBS) • No ≠ in BNP
V.V. Dickson et al. (2014b). USA	Pilot study, one group pre-test–post-test	$N = 21$ ethnically diverse multilingual HF persons	Increase knowledge and skill in symptom monitoring, recognition and interpretation	Symptom management	• ↑ self-care maintenance and management (SCHFI) • ↑ HF knowledge (DHFKS) • No ≠ in HRQL (KCCQ)
Jurgens et al. (2013). USA	Pilot RCT	$N = 99$ persons with chronic HF	Weight scale and self-care booklet Most distressing symptoms monitored with graph Training on how to recognize symptoms	Training on how to respond to symptoms	• No ≠ in HF events and survival • No significant ≠ in self-care (SCHFI) but ↑ absolute change in maintenance and confidence in intervention vs control group
Stone (2012). USA	Quasi experimental,[a] one group pre-test–post-test	$N = 19$ persons ≥65yrs with symptomatic HF	HF symptoms daily monitoring	Tool to assist what action to take when assessment of HF symptoms	• ↑ patient awareness about HF, ↑ HF self-management (HF Assessment Questionnaire) • No ≠ in HRQL (MLHFQ) • ↓ physical symptoms (MLHFQ)
Weiss et al. (2018). USA	Feasibility study[a]	$N = 15$ persons with advanced HF	Self-care tool to support HF symptoms recognition	Self-care tool for HF self-management	• Tool easy to understand and helpful in recognizing and reporting HF symptoms

BNP: B-natriuretic peptide; DHFKS: Dutch Heart Failure Knowledge Scale, lower score = lower knowledge; EHFScBS: European Heart Failure Self-Care Behavior Scale abbreviated and adapted form, lower score = lower self-care; HF: heart failure; HRQL: health-related quality of life; KCCQ: Kansas City Cardiomyopathy Questionnaire, lower score = worse health; MLHFQ: Minnesota Living with Heart Failure Questionnaire, lower score = better HRQL; RCT: randomized controlled trial; SCHFI: Self-Care of Heart Failure Index, lower score = lower self-care; vs: versus; ≠: difference.

[a] Study design qualified by the authors of the scoping review based on information found in the study.

dex (SCHFI) maintenance, management and confidence scores were comparable to baseline (pre-post scores: maintenance 71.6 versus 74.6, management 61.3 versus 51.8, confidence 70.2 versus 66.3, all $p>0.05$) while self-care management and confidence decreased over time. Self-care maintenance improved in terms of weight monitoring frequency ($p = 0.002$) and asking for low-salt diet ($p = 0.003$). Mean graph use rate was 79.9% and instruments were perceived to be helpful. Graphic monitoring neither improved self-care management nor self-care confidence and participants may need more intensive intervention to improve outcomes (Wakefield et al., 2016). Second, Tracy (1999) evaluated the feasibility of body listening on symptom recognition/interpretation in seven participants (72yrs, 6/7 female, all NYHA III). Each participant received seven home visits with open-ended questions to support body listening (e.g. "When and how have you thought about your body this past week?", p.158). They completed health diary entries and symptom patterns were discussed. After six weeks, participants could recognize symptoms and had a mean diary completion of 75%. There was no significant change in the number of diary-reported symptoms (p not reported) nor in anxiety scores (40.00 versus 33.86, p not reported). However, fatigue ($p = 0.034$) and number of symptoms on a self-reported instrument (7.43 versus 3.57, $p = 0.014$) decreased. Health-related quality of life increased (54.14 versus 30.00 post-test; $p = 0.046$) (Tracy, 1999), similar to the results of Dorsch et al. (2015). Third, Wolf et al. (2012) investigated the feasibility of a smartphone application for self-monitoring of heart failure signs and symptoms in four older adults (85–95yrs, all NYHA III-IV). Similar to Wakefield et al. (2016), participants were trained to use a smartphone application to record weight, dyspnea and fatigue and to interpret trending signs/symptoms. After three months, all participants used the application frequently and perceived it as useful (Wolf et al., 2012).

Finally, a mixed-methods single group, pre-posttest design evaluated the feasibility of a guided reflective intervention on self-care in 10 persons with heart failure (70yrs, 60% female). Similar to the intervention of Tracy (1999), participants completed a diary of heart failure symptoms and had a one-on-one interview guided by Gibbs reflective cycle questions (e.g. "What sense can you make of the situation?", p.193) to explore self-care behaviors and the meaning of underlying symptom experience. Large effect sizes for heart failure self-care maintenance (79.6 versus 69.9, $d = 1.04$) and management (63.9 versus 47.2, $d = 2.53$) were noted after one month. Eight themes emerged from qualitative data analysis: learning about self, adapting, maintaining vigilance, treating self, recognizing the uncertainty about life, appreciating life, considering family, seeking an accurate diagnosis and acknowledgement of individual symptoms (Sethares and Asselin, 2017).

In summary, the seven interventional studies focused on supporting symptom perception as the single intervention component (with different interventions) by examining symptom monitoring, body listening, recognizing and interpreting symptoms.

3.2. Interventions targeting symptom perception and self-care management

Five studies (Caldwell et al., 2005; Dickson et al., 2014b; Jurgens et al., 2013; Stone, 2012; Weiss et al., 2018) targeted both symptom perception and self-care management together as intervention components (Table 2b).

In a randomized controlled trial, Jurgens et al. (2013) pilot tested the efficacy of a training program on event-free survival and self-care in 99 participants (67yrs, 32% female, 47% NYHA III; intervention group $n = 48$, 67yrs, 33% female, 52% NYHA III; control group $n = 51$, 67yrs, 31% female, 43% NYHA III) – all of whom were provided a scale and self-care booklet. Patients in the intervention group received one-to-one training on recognizing and responding to heart failure symptoms. They also made physical activity to elicit dyspnea and were trained on somatic awareness of heart failure symptoms. Their most distressing symptoms and weight were monitored and graphically reported. After three months, no difference was observed in heart failure events ($p = 0.26$) or survival ($p = 0.216$) between groups and overall event rate was low (27 hospitalizations and four deaths). However, a non-significant trend towards higher event rates in the intervention group was reported (16 versus 11 events) and was explained by increased awareness of symptoms that might have increased visits to healthcare professionals/hospitalization, as participants were also instructed to call provider in case of symptom exacerbation. There was no statistical difference in self-care scores. The intervention group displayed a greater absolute change compared to controls for maintenance (change: 18 versus 12.9) and confidence (change: 10.2 versus 4.8). The authors calculated 228 participants would have been needed to detect a difference in heart failure self-care scores. Daily weighing improved in both groups, and this observation was explained by the fact that weight scales were provided to all participants (Jurgens et al., 2013). In a different pilot randomized controlled trial study, Caldwell et al. (2005) tested the effect of an education program on knowledge, self-care and heart failure severity in 36 rural participants (71yrs, 31% female). The intervention group ($n = 20$, 69yrs, 25% female) received a one-to-one individualized education and counseling session focused on symptom recognition, weight monitoring, managing fluid and seeking help. The control group ($n = 16$, 73yrs, 37% female) received standard health behavior counseling. After three months, the intervention group had higher heart failure knowledge (18.1 versus 14.9, $p = 0.01$) and better self-care behavior (2.9 versus 1.9, $p = 0.03$) compared to controls. However, no difference was noted in B-natriuretic peptide between groups (195 versus 302 pg/ml, $p = 0.21$) (Caldwell et al., 2005).

Three quasi-experimental, single group, pre/posttest designs tested tools supporting symptom perception and self-care management. First, Stone (2012) tested the impact of a nurse-led telephone intervention on illness awareness, symptom management and quality of life in 19 participants (71yrs, 31% female, 81% NYHA II-III). Patients received a tool using a 'stoplight' to guide actions in response to daily heart failure symptoms. They received six telephone calls supporting heart failure self-care. After six weeks, heart failure awareness and self-management increased (57.06 versus 46, $p < 0.001$), and physical symptoms decreased (26.88 versus 29.5, $p = 0.013$ – yet was health-related quality of life unchanged (32.06 versus 34.88, $p > 0.05$) (Stone, 2012). Second, Dickson et al., (2014a) pilot tested the impact of a visual (language-free) educational materials on self-care, heart failure knowledge and quality of life in an ethnically diverse sample of 21 patients (53yrs, 29% female). Participants received three one-to-one sessions aimed at increasing knowledge and skills in symptom monitoring (weight, edema), symptom recognition, interpretation and management. After one month, participants improved self-care maintenance (70.4 versus 60.4, $p = 0.014$), self-care management (76.4 versus 57.3, $p = 0.046$) and were better at recognizing symptoms ($p < 0.05$) and had higher heart failure knowledge (12.2 versus 9.8, $p < 0.01$) – yet health-related quality of life was unchanged (73.4 versus 70.2, $p = 0.34$) (Dickson et al., 2014b). Finally, Weiss et al. (2018) evaluated the feasibility of a low-literacy tool for heart failure self-management and examined the effect on self-care and quality of life in 15 participants (sample not described). The tool aimed to support heart failure symptom recognition and response. Participants considered it easy to understand and helpful for recognizing and reporting symptoms. Self-care was unchanged at two months, as was health-related quality of life, possibly due to sample size (Weiss et al., 2018).

3.3. Multiple component interventions with one symptom perception component

But for two studies which only measured symptom perception as an outcome (Baker et al., 2005; Meng et al., 2016), the remaining other 70 interventional studies were multiple component interventions including interventions supporting symptom perception and specifically weight monitoring, weight monitoring with scale provided, weight monitoring and diary or graph reporting, heart failure symptom monitoring, symptom recognition, symptom interpretation, and combination of several of these components (Table 1).

Question 2. Which interventions have measured symptom perception as an intervention outcome?

3.4. Symptom perception measured by weight or symptom monitoring

Weight or symptom monitoring were used as an outcome in several multiple component interventional studies. Weight or symptom monitoring improved in all studies ranging from after three days to 12 months (Table 1). Compared to controls, intervention groups were more adherent to weight monitoring ($p < 0.01$) (Wang et al., 2014). Several authors reported that individuals receiving multiple component interventions were significantly more likely to perform daily weight monitoring ($p = 0.002$) (Caldwell et al., 2005), ($p < 0.001$) (Baker et al., 2005), 79% versus 29%, ($p < 0.001$) (DeWalt et al., 2006), 87% versus 29%, ($p < 0.0001$) (Wright et al., 2003) and 44% versus 37% ($p = 0.05$) (Veroff et al., 2012). Compared to controls, the intervention group was more likely to weigh daily ($n = 19$ versus $n = 6$, OR = 3.16, 95% CI = 1.60–6.22, $p \leq 0.0001$), record weight daily ($n = 18$ versus $n = 7$, OR = 2.57, 95% CI = 1.39–4.76, $p \leq 0.0001$) and have a scale at home ($n = 19$ versus $n = 11$, OR = 1.73, 95% CI = 1.15–2.6, $p = 0.004$) (Shaw et al., 2014). More patients in the intervention group recorded weight at follow-up ($n = 93$, 74% versus $n = 57$, 44%, OR = 3.61, 95% CI = 2.13–6.11, $p < 0.01$) (Deek et al., 2017) and daily weight monitoring differed between groups (no statistical result reported) (Shao et al., 2014). Compared to controls, the intervention groups showed superior self-monitoring ($p = 0.039$) (Meng et al., 2016) and a 45% improvement in symptom monitoring (Piamjariyakul et al., 2014).

Between pre- and post-intervention, weight control increased ($p < 0.001$) (Gonzalez et al., 2005), ($p = 0.002$) (Wakefield et al., 2016), and daily weight monitoring improved ($p = 0.0372$) (Koshy, 2014), (+25%, p not reported) (Monteiro Mantovani et al., 2015).

Compared to baseline, daily weight monitoring ($p < 0.01$) and assessing ankle edema ($p < 0.01$) improved (Dickson et al., 2014a). Qualitative data indicate that 9/10 participants felt the heart failure App enhanced self-monitoring (Foster, 2018).

3.5. Symptom perception measured by symptom recognition or awareness

Symptom recognition and awareness were measured as an outcome between two weeks and 12 months in several interventions (Table 1). Compared to controls, symptom recognition scores were increased (1.08 ± 1.91 versus -0.11 ± 1.71, $p = 0.04$) Hoover et al. (2017) and Granger et al. (2013) reported improved symptom recognition (no statistics reported) (Granger et al., 2013). Compared to baseline, symptom recognition improved significantly ($p < 0.05$) (Dickson et al., 2014b), awareness of more than three worsening signs (66.5%–86.6%, $p < 0.001$) (Gonzalez et al., 2005), ability to identify signs and symptoms (+40%) and ability to identify signs and symptoms requiring medical attention (+36%) (Papasifakis and Vanderveen, 2009) all increased. Qualitative data following intervention indicate participants became aware of their symptoms (Tracy, 1999); and nearly all participants correctly described symptoms of worsening heart failure and reported confidence in their ability to recognize symptom patterns in the future (Sethares and Asselin, 2017). Others perceived the tool tested to be helpful in recognizing and reporting heart failure symptoms (Weiss et al., 2018). However, Nundy et al. (2013) reported no differences in symptom recognition scores compared to baseline (mean unstandardized SCHFI score 2.4 versus 4.0, $p = 0.09$) (Nundy et al., 2013). Similarly, Foster (2018) found no differences between pre and post-intervention – yet 60% of the participants reported being more "aware" of their symptoms (Foster, 2018).

Question 3. What outcomes are responsive to symptom perception?

3.6. Overall symptom perception outcomes

We identified outcomes responsive to heart failure symptom perception in our systematic scoping review. Participants (subsample of 89 participants) with SCHFI v7.2 higher symptom perception scores correlated with better general and physical health ($r = -0.31$, $p = 0.003$ and $r = -0.22$, $p = 0.04$, respectively) (Riegel et al., 2019). Other heart failure symptom perception outcomes relate more specifically to the symptom perception activities of symptom monitoring, symptom recognition, and symptom interpretation.

3.7. Symptom monitoring outcomes

Symptom monitoring outcomes included reduced mortality (Jurgens et al., 2010; Park et al., 2017; van der Wal et al., 2010; Wright et al., 2003), fewer heart failure decompensation events (Boehmer et al., 2016), decreased hospitalization/emergency visits (Jones et al., 2012; Jones et al., 2014; Wright et al., 2003), decreased length of stay/costs (Eastwood et al., 2007) as well as better weight monitoring (Kent et al., 2011) and better symptom recognition (Lee et al., 2015) that were observed with symptom diary use (Boehmer et al., 2016; Eastwood et al., 2007; Jones et al., 2014; Jurgens et al., 2010; Kent et al., 2011; Lee and Riegel, 2017; Park et al., 2017; Wright et al., 2003), weight monitoring (Jones et al., 2012; van der Wal et al., 2010; Wright et al., 2003) and symptom monitoring (Lee et al., 2015). Compared with diary non-users ($n = 129$), high ($n = 135$) and very high diary users ($n = 62$) were less likely to experience all-cause mortality ($p = 0.02$ and $p = 0.01$, respectively) (Park et al., 2017). Diary users ($n = 76$) compared to non-diary users ($n = 24$) had lower mortality at 12 months (11% versus 46%, $p < 0.0001$) and more days alive outside of hospital (334 versus 217 days, $p < 0.0001$) (Wright et al., 2003). Individuals consistently recording weight ($n = 310$) compared to those who did not ($n = 146$) and symptom diary questions ($n = 246$) compared to those who did not ($n = 170$) had fewer heart failure decompensation events ($p = 0.023$ and $p = 0.0003$, respectively) (Boehmer et al., 2016). Average length of stay hospital admissions for diary users ($n = 70$) decreased by 58% ($p < 0.002$) and average costs were decreased by 56% ($p < 0.011$) (Eastwood et al., 2007). Less frequent daily weighing ($\leq$1X/week) compared to three or more times per week was associated with increased mortality ($N = 830$, hazard ratio 1.57, 95% CI = 1.08–2.27; $p = 0.02$) (van der Wal et al., 2010). Weight monitoring adherence (weighing >5X/week) was associated with lower adjusted odds of a heart failure-related emergency department visits/hospitalization ($n = 876$ time periods, OR 0.42, 95% CI = 0.23–0.76) (Jones et al., 2012). More persons with heart failure weighing regularly ($n = 51$) compared to those weighing irregularly ($n = 25$) had no hospital admission (71% versus 44%, $p = 0.04$) (Wright et al., 2003). Those participants who completed the equivalent of 80% or more weight diary entries ($n = 107$) had an incidence rate ratio of heart failure-related hospitalizations (0.37, 95% CI = 0.18–0.75) compared to those who completed less than 80% of weight diaries ($n = 109$) (Jones et al., 2014). Providing a diary increased rates of daily weighing ($N = 222$, OR 7.75, 95% CI = 4.16–14.43) (Kent et al., 2011). Further, no participant who regularly monitored their weight and edema ($n = 47$) failed to recognize symptoms, while approximately 1/5 non-adherent patient ($n = 90$ monitoring weight and edema irregularly and $n = 174$ not monitoring weight and edema) did not recognize symptom changes (Lee et al., 2015). In addition, when testing the relationships between the situation-specific theory of heart failure self-care components in 417 participants, symptom monitoring correlated with treatment implementation ($r = 0.38$, $p < 0.01$) and treatment evaluation ($r = 0.25$, $p < 0.01$) (Vellone et al., 2013).

However, several studies reported different outcomes with no difference or worse outcomes in relation to symptom monitoring. Two studies (Eastwood et al., 2007; Wright et al., 2003) reported more visits to healthcare professionals. Diary use, and diary users ($n = 70$) had 35% more telephone contacts with healthcare professionals and 47% more with heart failure clinics compared with diary non-users ($n = 54$) (Eastwood et al., 2007). Similarly, Wright et al. (2003) found patients completing diary entries ($n = 76$) compared to diary non-users ($n = 24$) had more heart failure clinic visits ($p < 0.0001$), more telephone calls ($p = 0.0002$) and more general practitioner visits ($p = 0.008$) (Wright et al., 2003). However, there were no differences in heart failure readmission between patients who regularly weighed versus those who did not ($n = 26$ versus 6, $p = 0.62$) (Wang et al., 2014) and hospital readmission was faster when scales were provided ($n = 25$) compared to no scale providing ($n = 25$) (mean days to readmission 7.48 ± 13.187 versus 10.12 ± 6.585, $p = 0.003$) (Thebaud-Young, 2014). Individuals who weighed themselves regularly ($n = 51$) or irregularly ($n = 25$) did not differ in terms of mortality (3 versus 5 deceased, $p = 0.6$) (Wright et al., 2003). Self-reported recall of daily weight monitoring was not associated with fewer heart failure hospitalizations (incidence rate ratio 1.34, $N = 216$, 95% CI = 0.24–7.32) (Jones et al., 2014).

3.8. Symptom recognition outcomes

Several studies identified symptom recognition outcomes were related to better self-care management and less healthcare utilization. In summary, individuals who recognized their symptoms were more likely to self-treat them (Moser and Watkins, 2008, Riegel and Dickson, 2008). An adequate response to symptoms pre-

dicted better survival in a cohort of 459 heart failure patients (Lee et al., 2018). More specifically, treatment initiation scores were significantly higher in those patients who rapidly recognized symptoms ($n = 35$) compared to those who were slower to identify changes in status ($n = 59$) (1.66 ± 0.94 versus 1.19 ± 0.54, respectively; $F = 9.6$, DF=1.92, $p = 0.003$) (Riegel and Dickson, 2008). Notably, patients exhibiting adequate symptom recognition and response behaviors ($n = 112$), compared to those with poor symptom response behaviors ($n = 151$), were less likely to require emergency care, hospitalization or to die (hazard ratio 0.66, 0.46–0.96, $p = 0.03$) (Lee et al., 2018). Thus, recognizing and responding to heart failure symptoms appears to predict patient outcomes (Lee et al., 2018). Vellone et al. (2013) found positive correlations between components of the situation-specific theory of heart failure self-care in 417 participants. Symptom recognition and evaluation correlated with treatment implementation ($r = 0.23$, $p < 0.01$) and treatment evaluation ($r = 0.28$, $p < 0.01$) (Vellone et al., 2013). A separate study of 120 participants found that patients recognizing a change in signs/symptoms correlates with implementing ($r = 0.291$, $p = 0.001$) and evaluating treatment ($r = 0.471$, $p < 0.01$) (Samir and Nour, 2011).

3.9. Symptom interpretation outcomes

A central goal of symptom perception is to enable patients to seek care in a timely manner to avoid decompensation and hospitalization. Indeed, symptom interpretation appears to decrease delays in seeking care (Friedman et al., 1998; Lam and Smeltzer, 2013). Patients who accurately attribute their symptoms to heart failure ($n = 16$) spend less time at home with symptoms compared to patients attributing their symptoms to other causes ($n = 109$) (6 versus 17 days, p not reported) (Friedman et al., 1998). Similarly, other investigators have found delayed care-seeking in patients who do not accurately attribute their symptoms to heart failure (Lam and Smeltzer, 2013).

4. Discussion

4.1. Symptom perception interventions

Many interventional studies included an intervention component relating to heart failure symptom perception. However, most interventions included symptom perception as one aspect of a multi-component intervention – thus limiting our ability to dissect the relative contribution of symptom perception on outcomes. Few studies target heart failure symptom perception as the single intervention component. Disparate interventions, study designs, variables measure/instruments, as well as limited sample size provide preliminary insights into feasibility and preliminary impact - yet preclude conclusions about intervention effectiveness. Importantly, decreased symptom frequency, intensity and distress, enhanced health-related quality of life and large effect sizes in heart failure self-care post-intervention suggest interventions supporting symptom monitoring combined with symptom recognition and interpretation (rather than interventions supporting symptom monitoring alone). Several studies describe interventions supporting body listening (Tracy, 1999), somatic awareness (Jurgens et al., 2013) and reflection on symptom experience (Sethares and Asselin, 2017). Such studies provide promising results for decreasing intensity and number of symptoms (Tracy, 1999), clinical improvement in heart failure self-care (Jurgens et al., 2013; Sethares and Asselin, 2017) and better health-related quality of life (Tracy, 1999). Several interventions combining symptom perception support and self-care management (Caldwell et al., 2005; Dickson et al., 2014a; Jurgens et al., 2013; Stone, 2012) assist patients in recognizing, responding and managing symptoms - which is crucial for effective heart failure self-care (Lee et al., 2018). Reported clinical improvement (Jurgens et al., 2013) and statistically significant changes in heart failure self-care (Caldwell et al., 2005; Dickson et al., 2014b) as well as better heart failure knowledge (Dickson et al., 2014a, 2014b; Jurgens et al., 2013) have been noted. However, increased healthcare utilization has been reported (Jurgens and Riegel, 2011; Jurgens et al., 2013) and research is needed to test the impact of symptom perception interventions on survival and costs. This would inform if more contacts with healthcare professionals could avoid hospitalization and thus decrease costs, as well as reducing mortality.

Further, in our review we identified studies including caregivers in the intervention - thereby contributing to symptom perception. Data from several multiple component intervention studies suggest that caregivers play a key role in heart failure symptom perception (Deek et al., 2017; Fonarow et al., 1997; Lang et al., 2018; Piamjariyakul et al., 2014; Rauh et al., 1999; Staples, 1998; Triggiani et al., 2014; Wang et al., 2011). Caregivers can also contribute to increased self-care maintenance and confidence in the patients (Deek et al., 2017; Lang et al., 2018). Indeed, there appears to be growing interest in including caregivers in heart failure symptom perception interventions, and further exploration of their role in symptom perception support seems warranted.

This synthesis of the current state of the science on symptom perception interventions may be useful to inform development and testing of interventions supporting symptom perception in adults living with heart failure. The present results could also inform approaches to support symptom perception in other chronic illnesses. Indeed, the individual's symptom experience is central to supporting self-care (O'Neill and Morrow, 2001) and is a key element for self-management of chronic illness (Leventhal et al., 2016).

4.2. Symptom perception outcomes

Our results are consistent with previous reviews (Lam and Smeltzer, 2013; Lee and Riegel, 2017) noting few interventional studies focusing on symptom perception. Symptom diary use has been associated with improved patient outcomes (i.e. decreased heart failure decompensation, hospitalization and mortality) as well as health system outcomes (i.e. decreased length of stay and costs) (Lee and Riegel, 2017). Our results provide additional information supporting that symptom diary use is associated with improved weight monitoring and symptom recognition. It appears that weight or symptom monitoring are related to better symptom recognition, decreased hospitalization and reduced mortality - independent of diary use. We expand on prior reviews by reporting potential negative outcomes of symptom monitoring including increased contact with healthcare professionals, service utilization and hospital readmissions (Eastwood et al., 2007; Thebaud-Young, 2014; Wright, 2003). It is possible that providing a scale for daily weighing, educating patients on diary use and daily symptom monitoring may sensitize patients to heart failure signs/symptoms thereby triggering care-seeking behavior and increased healthcare utilization (Jurgens et al., 2013). Increased healthcare utilization could be perceived as a negative outcome. Conversely, seeking care could also be a positive outcome – as earlier attention may head off decompensation and prolonged hospitalization (Sethares et al., 2015). Thus, increased healthcare utilization may actually contribute to decreased overall healthcare costs via shorter length of stay and/or more contact with healthcare professionals resulting in decreased hospitalization. Importantly, this scoping review provides a comprehensive overview on outcomes responsive to symptom perception. The symptom perception outcomes identified in this review converge with self-care outcomes for other chronic conditions, i.e. stability of illness, symptom burden, quality of life and mortality (Riegel et al., 2018).

4.3. Clinical implications

In the light of the current absence of definitive evidence regarding effective symptom perception interventions, recommendations for clinical practice warrant caution. However, symptom perception is a requisite for attaining self-care management and there is a relationship between symptom perception outcomes and improved patient health as well as decreased complications. Clinicians should be aware of the crucial role of symptom perception in heart failure self-care and its impact on patient health. Evidence suggest that clinicians should consider symptom perception as a specific intervention component for supporting heart failure self-care. Interventions that may be useful include teaching patients to monitor heart failure symptoms and progression, symptom recognition training, body listening support and/or interpretation of heart failure symptoms (see Fig. 2). Additionally, clinicians should be aware, that symptom perception is challenging for persons living with heart failure and caregivers may be included as part of ongoing patient support. While the precise role of caregivers in symptom perception is beyond the scope of this paper, we believe it merits further examination.

4.4. Limitations and strengths

A limitation of this scoping review is that a quality appraisal of included articles was not conducted – yet this is widely accepted for scoping reviews (Arksey and O'Malley, 2005). We initially launched a single study with seven predefined research questions to map the symptom perception literature. However, given the vast number of references retrieved using a structured search process we opted to report the findings in two separate manuscripts to synthesize the literature in a digestible format with sufficient detail. This paper reports findings on three research questions while the remaining four research questions (relating to conceptualization and operationalization of symptom perception i.e. definition, description, factors and measurements) are reported in a separate publication (Santos et al., 2019). Thus, there are no overlapping findings to threaten the internal validity of the reports. Together, these complementary publications offer a comprehensive overview on the state of the science on symptom perception in heart failure. In the present work, a total of 18 full texts were not retrieved – as they were study protocols related to ongoing studies without any available result. It is worthwhile to note that the ongoing studies are multi-component interventions. Thus, we feel confident that the inclusion of these studies would not directly alter our findings focusing exclusively on symptom perception. Finally, consultation exercises were not conducted and stakeholder perspectives are not included in the results. Overall, we consider the systematic process used in the scoping review to be a strength and supporting internal validity of our findings, and the inclusion of many articles published in six languages strengthen the external validity of this study.

5. Conclusions

This article provides a comprehensive overview of the current state-of-science in heart failure symptom perception interventions and outcomes. Given the importance of symptom perception on both patient and health system outcomes, symptom perception is a relevant and important component of self-care support interventions. Further work is needed to test symptom perception intervention components and to evaluate the effectiveness of interventions for improving symptom perception and improving heart failure outcomes. Interventional studies with strong experimental designs testing the effect of interventions supporting symptom perception are needed. The availability of strong evidence from definitive trials will help delineate implications for clinical practice.

Importantly, symptoms can motivate people to seek care and use healthcare resources (Riegel et al., 2018). Thus, there appears to be a delicate balance between supporting symptom perception and minimizing healthcare expenditures due to unplanned emergency visits and hospitalizations.

Declaration of Competing Interest

None.

CRediT authorship contribution statement

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Acknowledgments

We appreciate the critical input from senior researchers during several research seminars. We thank the clinical nurses who provided important input and helped validate the findings from a clinical perspective. We also wish to recognize the administrative support of Dr. François Mooser during this process. Finally, we thank SAGE Publishing and the European Journal of Cardiovascular Nursing for permission to re-publish the search strategies from Santos et al. (2019) Symptom perception in heart failure: a scoping review on definition, factors and instruments (Santos et al., 2019).

Funding

This work (ML) was supported in part by Centre for Clinical Research Sörmland, Uppsala University, Eskilstuna, Sweden.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnurstu.2020.103524.

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