



# Signs and symptoms of patients with heart failure in palliative care: scoping review

*Sinais e sintomas de pacientes com insuficiência cardíaca em cuidados paliativos: revisão de escopo*  
*Señales y síntomas de pacientes con insuficiencia cardíaca en cuidados paliativos: revisión de alcance*

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## ABSTRACT

**Objective:** To map the knowledge production on signs and symptoms of patients with heart failure in palliative care. **Method:** This is a scoping review conducted according to the JBI method. Its writing was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews Checklist. The search was carried out by two independent reviewers in reference databases, information, and gray literature portals mostly using the descriptors “heart failure,” “signs and symptoms,” and “palliative care,” with the Boolean operator “and,” in September 2021 without a time frame. **Results:** Thirty-four articles were included and published between 2001 and 2021 from national and international journals, 21 of which were carried out in the United States of America. These articles made it possible to map 93 signs and symptoms, including pain, dyspnea, fatigue, nausea, and depression — the most frequent ones. **Conclusion and Implications for the practice:** This scoping review produced a scientific production map about the signs and symptoms of heart failure in palliative care. The knowledge of signs and symptoms helps health care professionals develop techniques and technologies to assess the severity of heart failure, plan palliative interventions, and assess their results.

**Keywords:** Palliative Care; Nursing; Heart Failure; Review; Signs and Symptoms.

## RESUMO

**Objetivo:** Mapear a produção de conhecimento acerca dos sinais e sintomas de pacientes com insuficiência cardíaca em cuidados paliativos. **Método:** Revisão de escopo conduzida de acordo com a metodologia JBI e com a redação guiada pelo *Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews Checklist*. A busca foi realizada em setembro de 2021 por dois revisores independentes nas bases de dados referenciais e em portais de informação e de literatura cinzenta, utilizando majoritariamente os descritores “heart failure”, “signs and symptoms” e “palliative care”, com o operador booleano “and”, sem recorte temporal. **Resultados:** Foram incluídos 34 artigos publicados entre 2001 e 2021, provenientes de revistas nacionais e internacionais, sendo 21 publicados nos Estados Unidos da América. Por meio desses artigos, foi possível mapear 93 sinais e sintomas, sendo que os mais frequentes foram dor, dispneia, fadiga, náusea e depressão. **Conclusão Implicações para a prática:** esta revisão de escopo produziu um mapa da produção científica sobre os sinais e sintomas de insuficiência cardíaca em cuidados paliativos. O conhecimento dos sinais e sintomas auxilia os profissionais da saúde no desenvolvimento de técnicas e tecnologias para avaliar a severidade da insuficiência cardíaca, planejar intervenções paliativas e avaliar os seus resultados.

**Palavras-chave:** Cuidados Paliativos; Enfermagem; Insuficiência Cardíaca; Revisão; Sinais e Sintomas.

## RESUMEN

**Objetivo:** Mapear la producción de conocimiento sobre las señales y síntomas de pacientes con insuficiencia cardíaca en cuidados paliativos. **Método:** Revisión de Alcance realizada de acuerdo con la metodología JBI y con la escritura guiada por el *Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews Checklist*. La búsqueda fue realizada por dos revisores independientes, en bases de datos de referencia, portales de información y literatura gris, utilizando majoritariamente las palabras clave “heart failure”, “signs and symptoms” y “palliative care”, con el operador booleano “and”, en septiembre 2021, sin marco de tiempo. **Resultados:** se incluyeron 34 artículos, publicados entre 2001 y 2021, de revistas nacionales e internacionales, 21 de los cuales fueron realizados en los Estados Unidos de América. A través de estos artículos, fue posible mapear 93 señales y síntomas, siendo los más frecuentes el dolor, la disnea, la fatiga, las náuseas y la depresión. **Conclusión e Implicaciones para la práctica:** Esta revisión de alcance produjo un mapa de la producción científica sobre las señales y síntomas de insuficiencia cardíaca en cuidados paliativos. El conocimiento de las señales y síntomas ayuda a los profesionales de la salud en el desarrollo de técnicas y tecnologías para evaluar la gravedad de la insuficiencia cardíaca, planificar intervenciones paliativas y evaluar sus resultados.

**Palabras clave:** Cuidados Paliativos; Enfermería; Insuficiencia Cardíaca; Revisión; Señales y Sintomas.

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## INTRODUCTION

Heart failure (HF) is considered a complex, gradual clinical syndrome, an important and challenging public health issue with increasing incidence worldwide. HF is linked with low expectancy and quality of life, frequent hospitalizations, and death.<sup>1,2</sup> From January to October 2021 alone, approximately 130,000 HF hospitalizations and more than 17,000 deaths were recorded in Brazil.<sup>3</sup> Its prevalence has increased in recent years due to population aging and mainly to the improvement of health care and treatment. Due to the adherence to drug treatment and usage of devices such as pacemakers and artificial ventricles, a higher life expectancy has been reached; however, despite all the advances in diagnosing and treating HF, this syndrome is the leading cause of hospitalization in patients over 60 years considering its high range of persistent signs and symptoms.<sup>4</sup>

Dyspnea, fatigue, and swelling are considered HF's characteristic signs and symptoms, although patients commonly report pain, bad moods, and chronic cough. These symptoms significantly impact the quality of their lives. The burden of HF symptoms may be compared to those prominent in patients with advanced cancer or acquired immunodeficiency syndrome.<sup>5</sup> In this context, palliative care aims to ease the suffering of patients and their families, valuing recognizing and managing signs and symptoms to reduce discomfort. Thus, researchers have been concerned with understanding the facts associated with referring patients to palliative care and the best tools for identifying the severity of signs and symptoms of HF patients.

A cross-sectional, multicenter study in 74 Spanish hospitals calculated the prevalence of advanced HF in 3,153 hospitalized patients, described its management, and analyzed the influential factors in referring patients to specialized palliative care. Almost one out of every four patients admitted with HF met the criteria for advanced disease. They were older and had more comorbidities. Palliative care was involved in the minority of patients, especially those highly symptomatic or with cancer.<sup>6</sup> Another study used a database of hospitalized patients to know the usage of palliative care in hospitalizations for acute heart failure in the United States of America. The usage of palliative care was low (4.1%) with a higher frequency in women, Caucasians, the elderly, and patients with comorbidities including diabetes mellitus, liver disease, and acute myocardial infarction.<sup>7</sup>

Managing the symptoms of advanced HF patients in palliative care positively affects their health, satisfaction, documentation of their preferences, and cost reduction. The worsening of physical symptoms, such as dyspnea, is the main reason why HF patients seek care, oftentimes leading to exhausting and costly hospitalizations. The symptoms are the main concerns of both the health team and patients since they are associated with the risk of mortality, therefore strongly affecting the quality of their lives.<sup>8-10</sup> Due to the importance of HF's physical symptoms and considering that this is a high prevalence syndrome in which the intensity of its symptoms interferes with quality of life, it is necessary to know the main signs and symptoms presented by these patients. Through preliminary research in PUBMED

and CINAHL databases, no scoping nor systematic reviews in progress or finalized on the topic of interest were found. Thus, this study aims to map the signs and symptoms of patients with HF in palliative care.

## METHOD

This is a scoping review conducted according to the JBI method. Its writing was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA–ScR) Checklist.<sup>11</sup>

### Protocol and registration

This scoping review was prospectively registered in the Open Science Framework and its final protocol is available at: <https://osf.io/fb7h4/>.

### Eligibility criteria

As inclusion criteria, we elected the studies that considered patients with chronic heart failure in palliative care, without distinction of age group, and that mentioned the signs and symptoms of HF. Studies with no clear method nor required thematic approach were excluded.

This scoping review included descriptive, qualitative or quantitative, methodological, conceptual, and/or reflection studies; randomized controlled clinical trials with experimental or quasi-experimental design; time-series or case-control; and reviews. They were all indexed in databases published in English, Spanish, Portuguese, or French without a time frame.

### Information sources

The search for evidence was performed in September 2021 by two independent reviewers. The databases and portals used were: Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS), Bibliográfico Español em Ciências (IBECs), Base de Dados em Enfermagem (BDENF), Rede de Informação e Conhecimento da Secretaria de Estado da Saúde de São Paulo (SES-SP), Base Internacional de Guias Grade (BIGG) and Base Regional de Informes de Avaliação de Tecnologias em Saúde das Américas (BRISA), USA.gov, Epistemonikos: Database of the best Evidence-Based Health Care, information technologies and a network of experts, and Cochrane Library (Wiley), Elsevier: Embase e Scopus, Clarivate Analytics: Web of Science, Ebsco: Academic Search Premier (ASP), and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search for gray literature through OpenDissertations was also carried out.

### Search

The search intends to answer the following question: What are the signs and symptoms of patients with heart failure in palliative care?

It is presented in the mnemonic **P** (population), **C** (concept), and **C** (Context), where **P** – Heart Failure, **C** – Signs and symptoms, and **C** – Palliative care. From these elements, we identified the following controlled vocabularies: Descritores em Ciências da

Saúde (DECS), Medical Subject Heading (MESH), Embase Subject Headings (Emtree), the standardized search terms and their synonyms in English, Portuguese, and Spanish. In the preliminary search, other terms identified in the titles, abstracts, and descriptors/MESH of the articles were included. For relating the terms of each PCC element, we used the Boolean operator OR – it allows the grouping/sum of the synonyms. For relating the sets in the databases, we used the operator AND – it intersects the terms. Chart 1.

In this study, the PCC terms were defined as search strategies, and there was no determination of period and languages.

### Selection of studies

Search results were imported into the Endnote references manager to identify duplicates. Subsequently, they were exported into the Rayyan application of the Qatar Computing Research Institute (QCRI), where the selection process through title and abstract analysis was carried out. The Rayyan system was developed to assist researchers in the process of systematic review selection. It enables the research team to implement blind selections, which are performed individually and simultaneously by enabling the blinding options on the Blind On or Blind Off buttons.

The system identifies and generates a pie chart containing included and excluded registers, as well as doubts. It allows the visualization of conflicts (when the Blind Off option is enabled and controls the minutes and sessions of each researcher.

Departing from the title and abstract selection of two independent reviewers, the exclusion and inclusion process of the full texts was controlled in an Excel spreadsheet generated by Rayyan. The issues related to the inclusion or exclusion of articles were solved through discussions and subsequent consensus among the researchers. Studies that met the criteria were fully read and assessed in detail regarding the inclusion criteria, while the ones that did not satisfy the requirements were excluded.

### Data extraction

After the papers that met the criteria were chosen, the full texts were downloaded and inspected in depth. In each paper, all the relevant data were identified and extracted, including authors,

year of publication, country of inception, type of study, population, central themes, scales used, and the signs and symptoms.

### Data mapping process

All the data were presented in tables, charts, flowcharts, images, and narrative discussion considering the objective of this scoping review. A narrative summary follows the mapped results to describe how they related to the research objective and question. The flowchart herein was based on the PRISMA flow diagram.

### Data items

The extracted data were the signs and symptoms of patients with heart failure in palliative care mentioned in the articles found.

### Critical assessment of individual sources of evidence

In this scoping review, the assessment of the quality of included pieces of evidence was not performed, since the aim was to widely identify the theme but not the quality of the studies.

### Summary of the results

The results of the extracted data were presented in two sections, the first describing the selection process and the PRISMA flowchart. The second section included the results concerning reviewing.

## RESULTS

The search strategy enabled us to retrieve 4,482 articles, of which 2,176 were excluded because they were duplicated in the databases. In the following stage, 2,305 articles were analyzed by two independent reviewers. As for the inclusion and exclusion criteria, 2,191 papers were excluded after reading their titles and abstracts since they did not meet the criteria; it resulted in a total of 114 studies that were selected for a full reading. Among these, 80 were excluded for not answering the research question and 34 were included in the review. The totality of bibliographic

**Chart 1.** Search strategy used on the PUBMED database. Niterói, RJ, Brazil, 2022.

Database	Search strategy
PUBMED	((“Heart Failure”[mh] OR Heart Failure[tiab] OR Cardiac Failure[tiab] OR Heart Decompensation[tiab] OR Myocardial Failure[tiab] OR cardiac backward failure[tiab] OR cardiac decompensation[tiab] OR cardiac incompetence[tiab] OR cardiac insufficiency[tiab] OR cardiac stand still[tiab] OR cardial decompensation[tiab] OR cardial insufficiency[tiab] OR heart insufficiency[tiab] OR decompensatio cordis[tiab] OR heart backward failure[tiab] OR heart decompensation[tiab] OR heart incompetence[tiab] OR insuffientia cordis[tiab] OR myocardial insufficiency[tiab]) AND (“Signs and Symptoms”[mh] OR “Signs and Symptoms”[tiab] OR “Symptoms and Signs”[tiab] OR Symptom*[tiab] OR Sign[tiab] OR SignS[tiab] OR “defining characteristic” [tiab] OR “defining characteristics” [tiab])) AND (“Palliative Care” [mh] OR “Palliative Care” [tiab] OR Palliative Treatment[tiab] OR “Palliative Therapy” [tiab] OR “Palliative Supportive Care” [tiab] OR “Palliative Surgery” [tiab] OR palliation[tiab] OR “palliative consultation” [tiab] OR “palliative medicine” [tiab] OR “symptomatic treatment” [tiab])

Source: Prepared by the authors.



Chart 2. Synthesis of the included studies' characteristics. Niterói, RJ, Brazil, 2022.

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
1	Abshire et al. <sup>12</sup> USA/2015	To consider how the fear and experience of symptoms are perceived in patients with HF at the end of life.	Convergent mixed-methods	Fifty-five patients with HF at the end of life.	HF; end of life; symptoms	McGill Quality of Life Questionnaire	Dyspnea, pain, fatigue, swelling, psychological symptoms
2	Agustia Nova <sup>13</sup> Indonesia/2018	To inspect the perceptions of patients with HF about the necessity of palliative care.	Qualitative study	Five patients with NYHA III or IV HF.	HF; palliative care; symptoms	Not applicable.	Dyspnea, fatigue, cough, insomnia, swelling, and nausea
3	Albert et al. <sup>14</sup> USA/2002	To assess and describe the approach used in managing the heart failure program in The Cleveland Clinic Foundation.	Review	Not applicable.	HF; palliative care; symptoms	Not applicable.	Dyspnea, pain, abdominal fullness, nausea, feeding satiety, palpitations, fast heart rate, fatigue, weakened legs, inability to perform daily activities, persistent cough, weight loss, sleep disorders, memory problems, mental obtundation, swelling
4	Alpert et al. <sup>15</sup> USA/2017	Not described.	Review	Not applicable.	HF; palliative care; symptoms	Not applicable.	Pain, dyspnea, depression, nausea, constipation, anorexia, fatigue
5	Anderson et al. <sup>16</sup> USA/2001	To determine the main concerns of patients with terminal illness identified by palliative care teams that work in Manchester and patients were treated in a heart failure clinic.	Prospective study	Two hundred thirteen patients in palliative care (mainly with cancer) and 66 patients with HF.	Terminal illness; HF; symptoms	A questionnaire prepared by the authors	Pain/angina, independence loss, difficulty walking, anxiety or depression, tiredness, shortness of breath, constipation, nausea, vomiting, difficulty sleeping

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
6	Araújo et al. <sup>17</sup> Portugal/2017	To group the main symptoms according to the basis of pathology, as well as the therapeutic possibilities	Review	Not applicable.	Palliative care; symptoms	Not applicable.	Pain, dyspnea, anorexia, swelling and ascites, nausea and vomiting
7	Årestedt et al. <sup>18</sup> Sweden/2018	To describe the main aspects of palliative care during the last week of the life of patients with HF according to health professionals	National register study	Three thousand, nine hundred eighty-one patients were diagnosed with HF as the basic cause of death.	End of life care; hf; palliative care; symptoms	Visual scale, analogic, numerical classification scale and <i>abbey pain scale</i>	Pain, shortness of breath, anxiety, nausea, rales, confusion
8	Årestedt et al. <sup>19</sup> Sweden/2021	To describe the prevalence of symptoms such as pain, shortness of breath, anxiety, and nausea, identifying the factors associated with symptoms' ease in patients with HF during their last week of life.	National register study	Four thousand, two hundred fifteen patients with HF diagnosed as the basic cause of death.	Death; end of life; hf; palliative care; symptoms	Visual scale, analogic, numerical classification scale and <i>Abbey Pain Scale</i>	Pain, anxiety, shortness of breath, nausea

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
9	Bekelman et al. <sup>20</sup> USA/2007	To describe the prevalence of anguish caused by symptoms in patients in ambulatory care with HF.	Cross-sectional study	Sixty patients with HF	Quality of life; depression; symptoms; hf; palliative care	Physical symptoms on the Memorial Symptom Assessment Scale-Short Form; Geriatric Depression Scale-Short Form; Kansas City Cardiomyopathy Questionnaire	Shortness of breath, lack of energy, pain, drowsiness, dry mouth, numbness/tingling of hands and feet, difficulty sleeping, cough, difficulty focusing, urinary issues, dizziness, sexual issues, swelling of the hands or feet, constipation, changes in skin, itching, swelling feeling, sweats, change in taste, nausea, "I don't look like myself," lack of appetite, weight loss, diarrhea, hair loss, difficulty swallowing, vomiting, mouth sores
10	Bekelman et al. <sup>21</sup> USA/2011	To describe the attended patients and the questions approached in an ambulatory program of palliative care for patients with HF.	Number of cases	Fifty patients were treated in an ambulatory program of palliative care in HF.	HF; Palliative care; Symptoms	Kansas City Cardiomyopathy Questionnaire (KCCQ); Patient Health Questionnaire-9 (PHQ-9); Generalized Anxiety Disorder-7 (GAD-7); Memorial Symptom Assessment Scale-Short Form (MSAS-SF)	Depression, anxiety, pain, fatigue, shortness of breath, and sleep disorders

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
11	Bekelman et al. <sup>22</sup> USA/2009	To inspect the necessity related to palliative care in both conditions, comparing the burden symptom and psychological and spiritual well-being in patients with heart failure and cancer.	Cross-sectional study	Sixty ambulatory patients with HF symptoms and 30 ambulatory patients with advanced lung disease or pancreatic cancer.	HF; quality of life; palliative care; symptoms; spirituality; depression	Memorial Symptom Assessment Scale-Short Form; Geriatric Depression Scale-Short Form; Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale	Shortness of breath, lack of energy, pain, feeling drowsy, dry mouth
12	Blinderman et al. <sup>23</sup> USA/2008	To explore the relation between symptoms and quality of life of patients with advanced HF.	Prospective study	One hundred three patients with terminal HF or chronic lung disease.	HF; quality of life; symptoms	Charlson Comorbidity Index (CCI); Short Portable Mental Status Questionnaire (SPMSQ); Memorial Symptom Assessment Scale (MSAS); Mental Health Inventory-5 (MHI-5); Sickness Impact Profile (SIP); Multidimensional Index of Life Quality (MILQ); Functional Assessment of Chronic Illness Therapy Spirituality Scale (FACT-Spirituality)	Lack of energy, dry mouth, shortness of breath, drowsiness, numbness or tingling in the hands and feet, difficulty sleeping, feeling worried, itching, difficulty focusing, feeling irritated, arm and leg swelling, lack of appetite, pain or pressure in the chest, feeling swelled, dizziness, urinary issues, issues with sexual intercourse or the interest in it, constipation, “I don’t look like myself,” headaches, sweats, weight loss, changes in skin, wheezing, feeling afraid, change in taste, nausea, difficulty swallowing, mouth sores, hair loss, diarrhea, vomiting.

Source: Data from the review.



Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
13	Dobbie et al. <sup>24</sup> USA/2017	To characterize the patients described by the ambulatory, palliative cardiology service, including the stage of their HF, symptoms, comorbidities, topics approached in the clinic, prescribed palliative treatments, advanced guidelines, status, and mortality.	Retrospective study	Eighty patients with HF from the palliative care services of <i>Cleveland Clinic</i> .	HF; Palliative care; Symptoms	Edmonton Symptom Assessment Scale (ESAS);  Palliative Prognostic Index (PPI)	Tiredness, pain, dyspnea, drowsiness, anxiety, depression, loss of appetite, nausea
14	Flint et al. <sup>25</sup> USA/2019	To assess if the specific health status of heart failure was associated with the QV domains and identify a scoring rate that grants a deeper evaluation of the QV domains deficit.	Randomized clinical test	Three hundred fourteen patients with heart failure with bad health status.	HF; Symptoms; Depression; Anxiety; Spiritual well-being	Memorial Symptom Assessment Scale-Short Form (MSAS-SF); Kansas City Cardiomyopathy Questionnaire (KCCQ); Patient Health Questionnaire-9 (PHQ-9); Generalized Anxiety Disorder-7 (GAD-7)	Pain, nausea, difficulty sleeping, constipation, dry mouth, numbness/tingling, issues with interest in sex, drowsiness, depression, spiritual well-being
15	Flowers <sup>26</sup> USA/2003	To provide a brief and general view of common symptoms and suggestions on HF administration.	Review	Not applicable.	Palliative care; HF	Not applicable.	Fatigue, worsening of renal functions, bad mood and anxiety, sleep disorders, loss of appetite, constipation, urinary issues, swelling, changes in skin

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
16	Hoyt Zambroski <sup>27</sup> USA/2006	To discuss the current status of palliative care for patients with advanced heart failure; To explain the basic pathophysiology and the signs and symptoms resulting from advanced heart failure.	Review	Not applicable.	HF; palliative care; symptoms	Not applicable.	Dyspnea, nocturnal paroxysmal dyspnea, cough and orthopnea, swelling, pain in the chest, sleep disorders, nausea, and swelling
17	Johnson <sup>28</sup> USA/2010	Not described.	Text	Not applicable.	HF; palliative care; symptoms	Not applicable.	Shortness of breath, fatigue, loss of appetite, nausea, constipation, dry skin, depression, anxiety
18	Jorgenson et al. <sup>29</sup> USA/2016	To describe the palliative actions on patients with HF in the interventional group and examine actions for the subset of patients from the interventional group with the highest symptom load.	Retrospective study	Two hundred thirty-two patients with HF that engaged in an RCT: 116 = GI 116 = GC	HF; palliative care;	Edmonton Symptom Assessment System (ESAS);  Patient Health Questionnaire 9 (PHQ-9)	Pain, shortness of breath, swelling, tiredness, drowsiness, nausea, lack of appetite, anxiety, depression
19	Kurogi et al. <sup>30</sup> Brazil/2020	To assess the prevalence of symptoms in patients with heart failure and to inspect the relation between symptoms, functional capacity, and performance.	Cross-sectional study	One hundred seventy patients with HF that were hospitalized in inpatient units (IU) or intensive care units (ICU).	HF; Signs and symptoms	Edmonton Symptom Assessment System (ESAS);  Karnofsky Performance Status (KPS)	Dyspnea, fatigue, tiredness, swelling, weakness, pain, nausea, inappetence, dizziness, cough, tachycardia, anxiety, depression, sleep alteration, sadness

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
20	Lowey <sup>31</sup> USA/2018	This article will focus exclusively on the administration of patients with advanced clinical status or stage D, heart failure, and the usage of palliative or interventional care in their overall treatment plan.	Review	Not applicable.	Advanced care planning; HF; end of life care; palliative care; symptoms control	Not applicable.	Anorexia, confusion, cough, dyspnea, swelling, fatigue, insomnia, pain, anxiety, and depression
21	Lum et al. <sup>32</sup> USA/2016	To identify the potentially changeable factors related to patients that foretell the specific health status of the HF throughout one year	Prospective study	Three hundred eighty-four patients with HF.	HF; health status; symptoms; spirituality; depression	Kansas City Cardiomyopathy Questionnaire (KCCQ); Patient Health Questionnaire-9 (PHQ-9)	Pain in the chest, Dizziness, Numbness/tingling, Dry mouth, Pain, Nausea, Cough, Constipation, Depressive symptoms, Low spiritual well-being
22	Nordgren and Sörensen <sup>33</sup> Sweden/2003	To reach a deeper understanding of patients with end-stage HF and describe the symptoms of these patients throughout their last six months of life by examining documentation in medical records.	Retrospective study	Eight patients with HF that were hospitalized at least once in the last six months of life.	HF; symptoms; palliative care	Not applicable.	Shortness of breath, pain, fatigue, anxiety, physical activity limitations, nausea, ankle swelling, constipation, loss of appetite, insomnia, persistent cough, confusion, dizziness, urinary incontinence, orthopnea, diarrhea, persistent itching, depression or bad mood, persistent thirst, palpitations, nocturia

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
23	Opasich and Gualco <sup>34</sup> Italy/2007	To explore the load of symptoms and control and to examine some of the instruments used to assess and monitor the suffering of patients with heart failure.	Review	Not applicable.	HF; palliative care; symptoms	Not applicable.	Dyspnea, tiredness, depression, gastrointestinal symptoms, pain, itchiness
24	Oriani et al. <sup>35</sup> England/2019	To determine if the POS and IPOS capture the main symptoms and concerns reported by patients with advanced HF.	Secondary analysis	One hundred two patients with HF.	HF; Palliative care;	The Palliative care Outcome Scale (POS);  Integrated Palliative care Outcome Scale (IPOS)	Poor mobility, shortness of breath, pain, feeling anxious, low quality of life, liquid retention or swelling, lack of appetite, loneliness, lack of focus/insufficient memory, concerns with self-esteem, concerns related to the bowel, drowsiness, itching, cough, depression, not sleeping well
25	Puckett and Goodlin <sup>36</sup> Canada/2020	To review the available publications that explore the integration of palliative care in HF treatment and propose an ambulatory model that assesses the necessities and symptoms, in addition to direct HF specialists or palliative care according to this assessment.	Review	Not applicable.	HF; Palliative care;	Not applicable.	Dyspnea, anxiety, pain, depression, sleep disorders, anemia

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
26	Riley and Beattie <sup>37</sup> England/2017	Not described.	Editorial	Not applicable.	HF; Palliative care;	Not applicable.	Shortness of breath, feeling drowsiness/tiredness, pain, "I don't look like myself," weight loss, lack of energy, arms/legs swelling, difficulty sleeping, hand/feet tingling, change in taste, difficulty focusing, issues with interest in sexual intercourse, cough, nausea, dizziness, feeling swelled, dry mouth, issues urinating, itching, constipation, vomiting, sweats, diarrhea, worrying, feeling irritated, feeling sadness, feeling nervousness.
27	Shah et al. <sup>38</sup> USA/2013	To assess, through the Edmonton Symptom Assessment System (ESAS), the pain and other symptoms experienced by the patients with HF during acute decompensation that requires hospitalization.	Cross-sectional study	One hundred patients with HF history.	HF; Symptoms; pain	Edmonton Symptom Assessment System (ESAS)	Pain, decreased well-being, tiredness, shortness of breath
28	Steinberg et al. <sup>39</sup> Canada/2017	To circumscribe the management of symptoms, in addition to offering a home-based protocol for patients with advanced heart failure (HF)	Review	Not applicable.	HF; Palliative care;	Not applicable.	Pain, fatigue, insomnia, nausea, anorexia, constipation, depression, anxiety

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
29	Stewart and McPherson <sup>40</sup> USA/2017	To review the most common and distressing symptoms of heart failure, analyze pieces of evidence or the lack of them for the pharmacological management of the symptoms, and provide prescribing considerations according to the side effect, profiles, and comorbidities.	Review	Not applicable.	HF; Symptoms	Not applicable.	Dyspnea, swelling, pain, cachexia, depression, fatigue
30	Texier et al. <sup>41</sup> France/2014	To assess the access to palliative care in cardiologic care during the six months prior to the death and, more particularly, during the last hospitalization.	Retrospective study	Twenty-nine patients died from HF.	HF; Symptoms; Palliative care	Not applicable.	Pain, dyspnea, fatigue, anorexia, nausea, vomiting, constipation, pressure ulcer, unconsciousness
31	Udeoiji et al. <sup>42</sup> USA/2012	To assess the prevalence and severity of pain in patients with chronic, stable heart failure (HF) in an ambulatory clinic environment.	Cross-sectional study	Sixty-two patients with HF.	HF; symptoms; palliative care	Edmonton Symptom Assessment System (ESAS)	Tiredness, decreased well-being, shortness of breath, drowsiness, pain

Source: Data from the review.

Chart 2. Continued...

S	Author/country/year	Objective	Type of study	Population	Central themes	Scales	Signs or symptoms
32	Yu et al. <sup>43</sup> China/2016	To identify symptoms groups among patients with advanced heart failure (HF) and the independent relations with quality of life (QoL)	Cross-sectional study	One hundred nineteen patients with advanced HF.	HF; Palliative care; quality of life	Edmonton Symptom Assessment Scale (ESAS, Chinese version); McGill Quality of Life Questionnaire (MQoL; Chinese version)	Shortness of breath, depression, anxiety, fatigue, nausea, drowsiness, reduced appetite, pain, overall discomfort
33	Zambroski and Bekelman <sup>44</sup> USA/2008	To review assessment and management strategies for patients with heart failure that remain symptomatic, despite the treatment for heart failure indicated by the guidelines.	Review	Not applicable.	HF; Symptoms; palliative care	Not applicable.	Dyspnea, fatigue, difficulty sleeping, depression, anxiety
34	Zambroski et al. <sup>45</sup> USA/2005	To describe the characteristics of patients that received palliative care, identify the most commonly related symptoms by the patients with HF at the psychiatric hospital during their last seven days of life, and identify interventions used by nurses from the psychiatric hospital to control the symptoms.	Retrospective study	Ninety patients with HF that died when receiving palliative care.	HF; Symptoms; palliative care	Charlson Comorbidity Index (CCI);  Palliative Performance Scale (PPS)	Pain, shortness of breath, swelling, urinary incontinence, diarrhea

Source: Data from the review.





the disease or disorder, and its evolution without intervening or modifying any aspect they are studying. Observational studies greatly contribute to understanding various diseases and other interesting events, as is the case of this very paper, as well as identifying signs and symptoms observed in the target population.<sup>46</sup>

Concerning the signs and symptoms in patients with HF in palliative care, the pain was prevalent, dyspnea, fatigue, nausea, depression, sleep disorders, anxiety, swelling, and a high range of less frequent symptoms. Corroborating the findings of this review, a study published in January of 2022 detected that the 10 main symptoms of elderly people with chronic HF, in descending order, are: shortness of breath, leg and arm swelling, dizziness, cough, palpitations, lack of energy, insomnia, difficulty breathing at bedtime, dry mouth, and lack of appetite.<sup>47</sup> One study evidenced that the most frequent symptoms reported by patients with HF in palliative care were lack of energy, dry mouth, shortness of breath, and drowsiness. The least commonly reported ones include numbness or tingling in the hands and feet, insomnia, cough, and anorexia. Patients also described various psychological symptoms, such as worry, sadness, nervousness, difficulty focusing, and irritation.<sup>37</sup>

A cross-sectional study carried out through an analysis of secondary data of 173 patients with HF concluded that pain, fatigue, and depression were associated with decreased functional performance in HF, highlighting the necessity of interventions in managing HF symptoms.<sup>48</sup> The approach to HF as a complex and evolving clinical syndrome, classified in stages by the New York Heart Association (NYHA), favored the possibility of HF prevention and treatment through the importance of recognizing the signs and symptoms of the disease. Four assessment classes are proposed: Class I - the symptoms, especially dyspnea, are absent during activities; Class II - daily activities trigger the main symptoms; Class III - the symptoms are triggered by small efforts or in less intense activities than the daily ones; Class IV - the symptoms are present at rest.<sup>49</sup>

Bolstering the importance of this classification, the Brazilian, European, and American Heart Failure Guidelines indicate that this form of assessment allows an evolutionary understanding of the disease and serves as a basis for identifying patients with signs of decompensation. It provides support for the health professional to assess at which moment of the disease the patient, their quality-of-life level, the prognosis, and identify priorities and the proper therapeutic approach. However, in isolation, the signs and symptoms have limitations of sensitivity and/or specificity for the diagnosis of HF.<sup>2,4,50</sup>

The signs and symptoms of patients with HF in palliative care impact their functionality, limiting their capacity for executing daily and self-care activities, which implies a decreased quality of life. Thus, it is fundamental that health professionals manage the physical and psychological signs and symptoms of these patients, one of the main conducts of the palliative team, must be involved in the line of care of patients with HF early on to improve quality of life and prevent unnecessary hospitalizations.<sup>51</sup>

Nonetheless, dealing with the distressing signs and symptoms disclosed by patients with advanced HF and promoting quality palliative care mainly depends on trained and qualified health professionals. Poor knowledge may affect treatment adherence, which is one of the major causes of HF decompensation. In this regard, the non-pharmacological approach uses the strategies of education, monitoring, lifestyle changes, and palliative care. Hence, the results of this scoping review may direct vocational training and continuing education actions, therefore contemplating this topic of great relevance.<sup>52</sup>

With respect to this study's limitations, one can highlight, especially as a limitation of scoping reviews — unlike systematic reviews — the non-incorporation of an assessment of the studies' quality before their inclusion. In this case, the studies included in this review were not assessed by their scientific rigor since, as mentioned herein, scoping reviews usually do not encompass critical analyses of the methods employed in their studies. Another possible drawback is that, despite trying to develop an extensive search strategy, we potentially missed other relevant studies. Studies and research not published in academic journals included in the databases consulted in this review, such as government documents or annals of scientific events, were not inspected but could have provided some additional information.

## CONCLUSION AND IMPLICATIONS FOR PRACTICE

This review mapped the signs and symptoms of patients with HF in palliative care. The study has implications for the practice because it presents these phenomena in a clear and summarized manner, easing their early recognition, especially regarding pain, dyspnea, fatigue, nausea, and swelling — common in palliative care. It also contributes to teaching practices since, through the evidence summarized herein, an update on the theme and an emphasis on the importance of palliative care in patients with heart failure are emphasized. As of this study, the accomplishment of new research and the development of technological products and processes for patients with HF in palliative care will be possible, contributing to the progression of knowledge in nursing and health.

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