

Mapping of current practices of palliative care for patients with heart failure throughout Europe: A scoping review

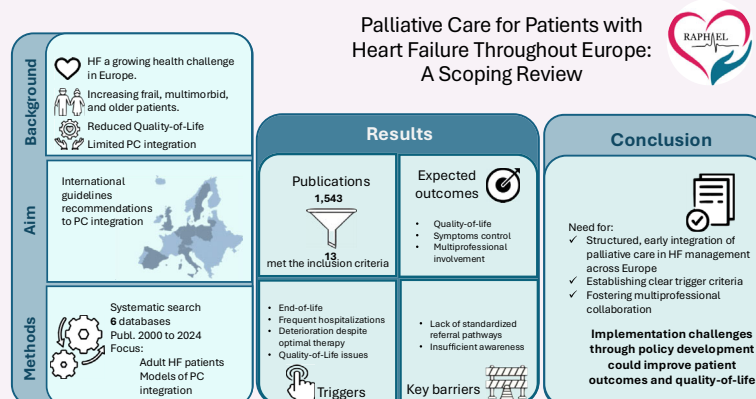
Tania Pastrana¹ , Matthew Grant² , Paula Hidalgo Andrade³ , Daniele Marelli⁴ , Klaus Witte⁵ , Geert-Jan Geersing² , Carla Ripamonti⁴ , Roman Rolke¹ , Marco Metra⁶ , Matteo Pagnesi⁶ , Everlien De Graaf² , Cosimo Chelazzi^{4*}  and on behalf of the RAPHAEL consortium

¹Department of Palliative Medicine, Uniklinik RWTH Aachen, Aachen, Germany; ²Department of General Practice and Nursing Science, Julius Center of Primary Care and Health Sciences, University Medical Center Utrecht, Utrecht, The Netherlands; ³Universidad de Las Américas, Quito, Ecuador; ⁴Palliative Medicine, Department of Medical and Surgical Specialties, Radiological Sciences and Public Health, University of Brescia, Brescia, Italy; ⁵Leeds Institute for Cardiovascular and Metabolic Medicine, University of Leeds, Leeds, UK; and ⁶Cardiology, ASST Spedali Civili. Department of Medical and Surgical Specialties, radiological sciences and Public Health, University of Brescia, Brescia, Italy

Abstract

Heart failure (HF) is a growing health and societal challenge in Europe, due to an increasingly elderly, frail and multimorbid population. Many patients with HF experience a high burden of complex and multidimensional symptoms leading to a reduced quality of life and significant socioeconomic impact. Despite proven benefits, the integration of palliative care into HF management pathways remains inconsistent and underutilized. We aim to map how current national and international guidelines recommend integrating palliative care into HF management across the 10 countries represented by the EU-funded RAPHAEL consortium (Horizon Europe programme, No 101137170): Belgium, Germany, Lithuania, the Netherlands, Spain, Italy, Poland, Sweden, Switzerland and the United Kingdom. A systematic search was conducted across six databases (EMBASE, Global Health, MEDLINE, PsycINFO, The Cochrane Library and Web of Science) for publications from 1 January 2000 to 25 May 2024. Eligible publications focused on adults with HF and models of palliative care integration. Data were synthesized using content analysis. Of 1543 records screened, 13 publications were included. Most studies were guidelines, consensus or position papers; only one was qualitative research. The definition of the population with HF eligible for palliative care was heterogeneous and inconsistently defined, mostly by symptoms (4/13 publications; 31%) and pathophysiology (2/13; 15%). The most frequent triggers for palliative care referral were clinical features and symptoms (8/13; 62%), patients approaching the end of life (8/13; 62%), and symptomatic deterioration despite optimal therapy (7/13; 54%). Additional triggers included multiple (>1) unplanned hospitalizations (6/13; 46%) and spiritual, emotional or social issues (7/13; 54%). Outcomes of palliative care referral for HF patients focused on quality of life (9/13; 69%) and symptom control (9/13; 69%). Multiprofessional involvement was emphasized with cardiologists (12/13; 92%), nurses (10/12; 77%), palliative care specialists (9/13; 69%) and primary care physicians (4/13; 31%). Publications generally noted that despite increased awareness and recommendations, referrals remain low and mostly late stages. This review underscores the need for structured, early integration of palliative care in HF management across Europe with clear triggers for palliative care referral, application of standardized pathways and fostering of multiprofessional collaboration. Developing these, while simultaneously addressing implementation challenges through policy development, could improve patient outcomes and quality of life.

Graphical Abstract



Keywords Cardiology; Europe; Guidelines; Heart failure; Integrated care; Palliative care

Received: 8 April 2025; Revised: 1 September 2025; Accepted: 1 September 2025

*Correspondence to: Cosimo Chelazzi, Palliative Medicine, Department of Medical and Surgical Specialties, Radiological Sciences and Public Health, University of Brescia, Brescia, Italy.

Email: cosimo.chelazzi@unibs.it

Introduction

Heart failure (HF) is a significant healthcare burden due to its high and increasing prevalence, high multidimensional symptom burden, socioeconomic impact, and unpredictable and limited life expectancy.^{1,2} These features contribute to the poor quality of life (QoL) and social isolation suffered by persons living with HF, particularly during the more progressed stages of this condition.

The overall median prevalence of HF in Europe is around 17 per 1000 people, but this ranges widely across countries: ≤ 12 in Greece and Spain, to >30 per 1000 people in Lithuania and Germany, for example.² The prevalence rises considerably with age, affecting 10% of individuals over 70 years and 30% over the age of 85 years.² The growing prevalence of HF is linked to demographic aging, advances in life-saving treatments for ischaemic heart disease (one of the underlying root causes for HF), and increases in the prevalence of obesity and diabetes as growing factors leading to HF (particularly HF with a preserved ejection fraction) and more widespread awareness and diagnostic testing. In addition, effective evidence-based disease-modifying therapies have extended the life expectancy of people with HF, which has also contributed to an increase in prevalence.³ Despite these new therapies, and even in the face of optimal guideline-directed treatment, people with HF continue to experience a high, variable, and unpredictable symptom burden, resulting in significant morbidity and functional limitations, often restricting daily activities and impacting QoL.⁴ Indeed, the 5-year mortality following an HF diagnosis

ranges from 53% to 67%, exemplifying that HF by itself still is a life-limiting condition that essentially is not curable.⁵ These characteristics drive the need for palliative approaches in people with HF.^{5,6} This adverse synergy and the non-linear trajectory of HF add complexity and the need for flexibility to care needs, including attention to non-disease-specific modalities to improve well-being for patients such as palliative care.

The lack of access to palliative care for end-stage HF was first recognized, documented and discussed in 1995,⁷ but only in 2000 did the United Kingdom national service framework for coronary heart disease (CHD) include standards for palliative care in the setting of HF.⁸ Since 2008, the European Society of Cardiology (ESC) HF guidelines also include a section on palliative care, recommending its integration at all stages of heart disease as required.^{9–11}

Integrating palliative care into HF management improves patient-reported outcomes, including reduced symptom burden, improved mental health outcomes and enhanced functional status and QoL, while reducing resource usage and care costs.^{12–14} Nevertheless, palliative care remains underutilized in HF management across Europe. This is largely due to a dominant focus on disease-modifying treatments and a lack of clear evidence regarding the appropriate timing of palliative care provision, and how and what services should be provided.¹⁵ As a result, only around 4% of patients with HF (indeed an incurable condition with persistent and often largely non-modifiable symptoms) are referred to palliative care,¹⁶ and almost always the referral takes place very late in the disease course, usually at the end of life.^{17,18} According

to the European Association for Palliative Care (EAPC) Atlas of Palliative Care, only eight countries report that their cardiology services provide palliative care: the Czech Republic, Denmark, Ireland, Portugal, Spain, Sweden, the Netherlands and the United Kingdom.¹⁹

This scoping review aims to map how the current guidelines describe integrating palliative care into the management of HF in each of the 10 European countries of the integrating a Palliative Care approach for patients with advanced heart failure (RAPHAEL, No 101137170) consortium (Belgium, Germany, Lithuania, the Netherlands, Spain, Italy, Poland, Sweden, Switzerland and the United Kingdom). These countries were selected as part of a European initiative aimed at developing harmonized practices in palliative care for HF. By doing so, we seek to understand better the current recommendations for palliative care provision for people with HF in these countries.

This review explores the integration of palliative care into the care management of patients with HF in consortium countries, and structures the analysis around the following key questions:

- 1 How is palliative care integrated into the guidelines for patients with HF and which models of provision are in place?
- 2 What are the triggers for initiating palliative care in patients with HF?
- 3 What guidance exists for the involvement of different specialties and multidisciplinary care teams for patients with HF?

Methods

Given the expected heterogeneity of information, a scoping review was conducted to systematically assess and synthesize knowledge about the integration of palliative care into the treatment of people with HF. This scoping review followed the six stages described by Arksey and O'Malley,²⁰ expanded by Levac and colleagues,²¹ and the results were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews (PRISMA-ScR) guidelines.²² The protocol was registered with the Open Science Framework on 17 February 2024 (<https://osf.io/4nhgz/>).

Relevant studies were identified using the Participants, Concept, Context (PCC) framework:

Participants/population

The review considered literature covering adults (>18 years) with a diagnosis of HF, including all three HF phenotypes [HF with reduced ejection fraction (HFrEF), HF with preserved ejection fraction (HFpEF) and HF with mildly reduced ejection fraction (HFmrEF)] and all aetiologies. We explicitly did not

restrict our patient population to only patients with progressive symptoms of HF, as our aim was to describe access to palliative care across all stages of HF.

Concept

The review included clinical studies, local guidelines, clinical consensus statements and policy documents that described care pathways for integrating palliative care (through any strategy and setting) into the care management of people with HF. Studies exploring palliative care delivery models in all care settings, including acute hospitals (ambulatory and inpatient services), community-based, home-based and hospice-based care were included.

No single definition of palliative care was imposed. Instead, we included publications that explicitly referred to the integration of palliative care or conceptually related terms such as supportive care or end-of-life care within HF management, regardless of the specific terminology or care model used.

Context

The review focused on 10 European countries: Belgium, Germany, Lithuania, the Netherlands, Spain, Italy, Poland, Sweden, Switzerland and the United Kingdom.

We systematically searched six databases (EMBASE, Global Health, MEDLINE, PsycINFO, The Cochrane Library and Web of Science) on 25 May 2024.

We included publications from 2000 to 2024, written in Dutch, English, Italian, German, Spanish, French, Lithuanian, Polish and Swedish. If an updated guideline was available, only the newest one was included. Papers that did not fit into the above PCC framework of the study were excluded. Abstracts or comments on guidelines were excluded.

Search strategy

The search strategy included terms describing the population (adults with HF) and the concept of interest (palliative care integration for HF). Boolean operators were used to refine search terms for Medline (Ovid SP), and it was adapted for different databases (Data S1). The search strategies were drafted by T.P., M.G., C.C. and P.H.A. and reviewed by an experienced librarian (Dr. Iris Reiman) at the Uniklinik RWTH Aachen.

The final search results were imported into Covidence for deduplication, screening and extraction.²³ The screening process was piloted with small samples to ensure consistency in applying the inclusion criteria. Titles and abstracts were independently screened by two investigators, with any discrepan-

Figure 1 PRISMA flow diagram for the scoping review.

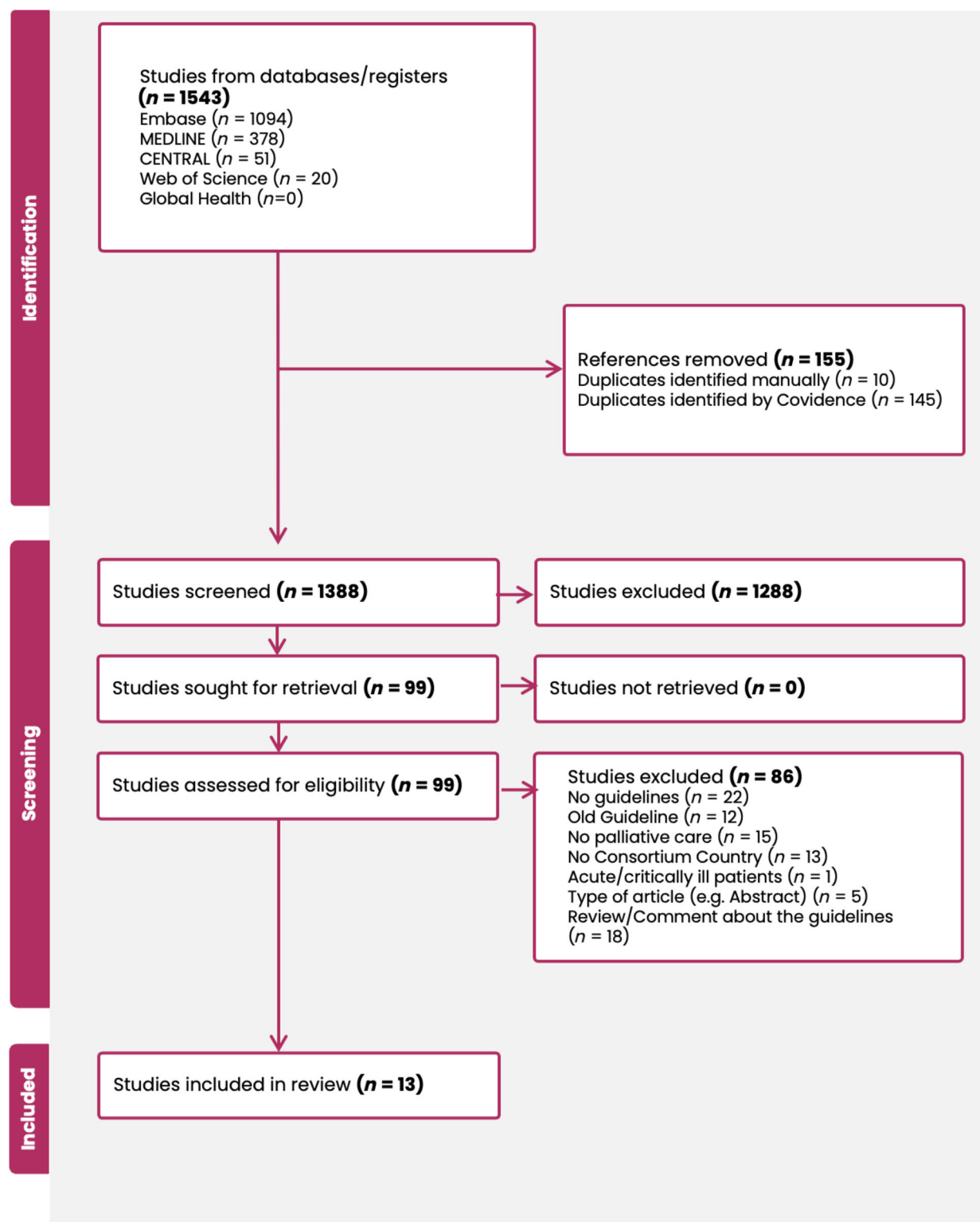


Table 1 Characteristics of the included papers

Study ID	Participating countries	Language	Aim of paperthe paper)	Type of paper
Selman 2007	United Kingdom	English	To describe current provision of specialist palliative care for chronic heart failure (CHF) patients, and explore challenges, referral criteria and recommendations to inform service development.	Qualitative research
Denvir 2015	United Kingdom	English	Review on the introduction of palliative care and Future care planning for patients with HF.	Review
Aspromonte 2016	Italy	Italian	To describe tasks and requirements of the different health system points of contact for HF patients, and to define how diagnosis, management and care processes should be documented and shared among healthcare professionals.	Consensus
Pitcher 2016	United Kingdom	English	To provide guidance for the full range of healthcare professionals who may encounter people with Cardiovascular-implanted electronic devices (CIEDs) and for healthcare managers and commissioners.	Review
Siouta 2016	Belgium, Germany, Italy, Lithuania, Poland, Spain, Sweden, Switzerland, The Netherlands and United Kingdom (and all Europe)	English	To assess guidelines/pathways for integrated palliative care in patients with advanced Chronic Heart Failure and Chronic Obstructive Pulmonary Disease (COPD) in Europe via a systematic literature review.	Review
Crespo-Leiro 2018	Germany, Italy, Poland, Spain, Sweden, Switzerland, The Netherlands, United Kingdom and Others (Turkey, Lebanon, Croatia, USA, Denmark, Greece, Israel, Austria and Serbia)	English	To guide general cardiologists, heart failure cardiologists and other professionals involved in the care of these patients such as internists, primary care physicians, and nurses through transitions in care.	Position paper
Real 2018	United Kingdom	English	To summarize the latest update of the National Institute for Health and Clinical Excellence (NICE) guideline on chronic heart failure in adults.	Summary of National Guideline
Antonione 2019	Italy	Italian	To respond to the increasingly pressing and true need to encourage collaboration between cardiologists and palliative care professionals to guarantee the best and proportionate treatment approach to these patients and their families, through the analysis of current critical issues, the development of assistance strategies and the identification of shareable evaluation and prediction tools, for a correct satisfaction of the complex needs of the phases advanced disease.	Consensus
Hill 2020	Belgium, Germany, Italy, Lithuania, Poland, Spain, Sweden, Switzerland, The Netherlands and United Kingdom (Europe)	English	To synthesize the available evidence and provide clinical guidance on integrating palliative and HF care.	Position paper
Sobanski 2020	Belgium, Germany, Italy, Lithuania, Poland, Spain, Sweden, Switzerland, The Netherlands, United Kingdom and Others	English	To evaluate the existing data and current clinical practices with respect to palliative care for people living with HF.	Position paper
McDonagh 2022	Germany, Italy, Poland, Sweden, Switzerland, The Netherlands, United Kingdom and Others (USA, Greece, France, Romania, Lithuania and Denmark)	English	To help health professionals manage people with HF according to the best available evidence.	Formal Guidelines of the European Society of Cardiology (ESC)
Tomasoni 2022	Italy and Others (Denmark)	English	To describe the medical management of patients with advanced HF, focusing	Review Guideline

(Continues)

Table 1 (continued)

Study ID	Participating countries	Language	Aim of paperthe paper)	Type of paper
Gustafsson 2023	Belgium, Germany, Italy, Lithuania, Poland, Spain, Sweden, Switzerland, The Netherlands and United Kingdom	English	on those with reduced ejection fraction. To provide a review of the literature related to inotropic therapy in patients with advanced chronic HF with reduced ejection fraction and to describe a strategy for inotrope use in the care of this population.	Consensus

cies resolved through discussion during weekly meetings. Full-text articles of selected publications were then independently reviewed by two investigators to confirm final inclusion, and reasons for exclusion were documented, as detailed in the PRISMA-ScR diagram (see *Figure 1*).

Data extraction was conducted using a piloted data collection form in Covidence. Relevant data included population, concept and context information, as well as publication characteristics such as publication year, study setting, participating country/ies, language, type of publication, funding sources and any reported conflicts of interest of the authors. Additionally, we collected information on the definition of HF used in the publications, triggers for initiating palliative care, evaluation methods, recommended instruments and the professionals suggested for providing care. We also noted whether the articles addressed individuals with specific comorbidities or subgroups of HF patients. Key elements such as recommendations, authors' conclusions and the most relevant findings were also systematically extracted. As a scoping review, we did not conduct an appraisal of the evidence. Two investigators extracted the information from each article independently, with discrepancies resolved through consensus. There were no missing articles or information identified in the included articles, and thus it was not necessary to contact authors of any article.

The results were exported to the computer-supported programme MAXQDA,²⁴ where they were synthesized and analysed using content analysis as described by Mayring.²⁵ This approach facilitated the organization, coding and interpretation of data to identify key themes and patterns related to integrating palliative care in HF management.

Consultations were held with five members of the Consortium working with HF patients to review and refine the findings. Their feedback was incorporated into the results. Ethical, cultural and inclusive issues were examined to ensure comprehensive coverage.

Results

A total of 1543 publications were identified through our initial search. After removing 155 duplicates, 1388 remained for title and abstract screening. Based on this screening, 99

full-text articles were assessed for eligibility. Following a full-text review, 13 studies were included in the final analysis. Reasons for the exclusion of publications at the full-text review stage are detailed in *Figure 1*.

The region of origin, aims and main findings related to our research question for each of the publications are presented in *Table 1*.

Overview

Seven publications were multinational,^{11,26–31} four originated in the United Kingdom,^{32–35} and two in Italy.^{36,37} All RAPHAEL consortium countries participated in at least four publications. Most publications ($n = 11$) were in English, and two were in Italian. The included publications encompassed reviews,^{29,31–33} consensus,^{27,36,37} position papers^{26,28,30} and guidelines,^{11,35} and there was also one qualitative research manuscript.³⁴ One clinical consensus statement focused only on patients with chronic HF with reduced ejection fraction (HFrEF),²⁷ whereas the other articles were not limited to any specific HF phenotype.

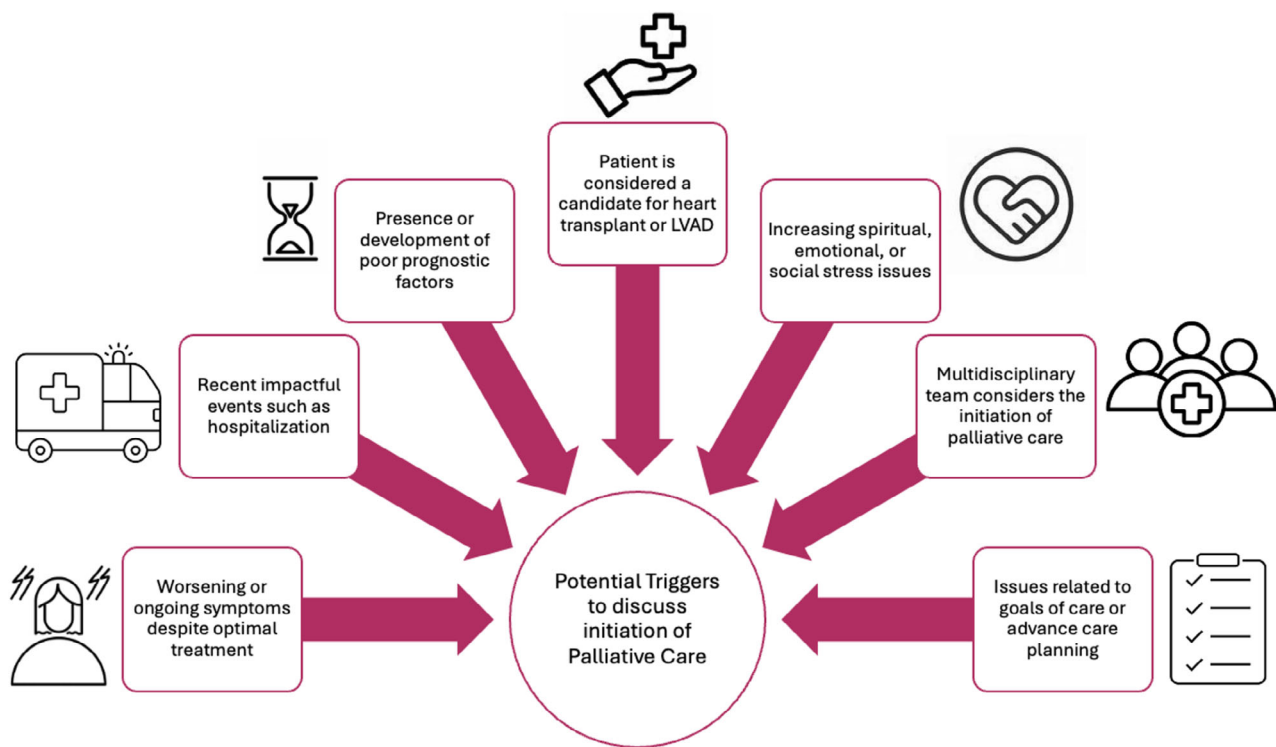
Working definition of HF

The definition of HF was not consistent and included definitions based upon pathophysiology,^{33,37} symptoms^{11,30,33,36} or quality of life.²⁸ Additional perspectives included progressive disease trajectory,^{28,35} poor prognosis,^{32,37} poor response to treatment,^{26,31,37} or the need for palliative³⁵ or end-of-life care.²⁶ Two publications did not define HF.^{29,34}

Triggers for palliative care

The publications identified diverse triggers for initiating palliative care in HF, which were grouped as follows (see *Figure 2*):

- **Clinical features and symptoms:** breathlessness,³⁵ cachexia,^{11,28,30} escalating symptoms,²⁸ limited/declining physical functioning,^{11,28,30,32,34} New York Heart Association (NYHA) Class 4,^{28–30,34} deterioration despite optimal therapy,^{11,26,28,30,32,34,35} and 'end-of-life'.^{11,26,29–34}

Figure 2 Triggers to discuss initiation of palliative care.

- **Event-based:** multiple unplanned hospitalizations or emergency presentations,^{11,28–30,32,34} and the initial diagnosis of HF.^{29,30,34}
- **Prognostic factor based:** poor prognosis/prognostic indicators,^{28,32,36} multimorbidity.^{28,32}
- **Treatment-based:** initiation of inotropic therapy,²⁸ ineligibility for treatments such as transcatheter aortic valve implantation,²⁸ or upon consideration of implantable defibrillator or mechanical cardiac support,^{28,30,31,33} or heart transplantation.^{11,31}
- **Based upon spiritual/emotional/social issues:** poor QoL,^{11,28,31} emotional distress,^{28,30,34} mood disturbances,²⁸ social issues,^{30,32,34,36} care burden,^{30,34} spiritual or existential distress,^{28,32} or fear/worries about treatment.³⁶
- **Team-related:** Patients who require extensive time and attention from the cardiac care team,³⁴ patient and care team agree to the referral to palliative care and understand the role of palliative,³⁴ the confidence of the cardiac team in meeting the needs of the patient was the deciding factor in whether to refer.³⁴
- **Issues related to goals of care or advanced care planning:** request for anticipated death (assisted suicide/euthanasia),²⁸ disagreement between patients and/or informal carers/surrogates on goals of care,²⁸ advanced age.^{28,32}

The most frequently mentioned triggers were approaching the end of life, multiple unplanned hospitalizations and deterioration despite optimal therapy.

Across the included documents, patients were typically considered for palliative care when presenting with a combination of physical, psychosocial and existential factors. However, the specificity and combination of these aspects varied across national contexts and publications.

Outcomes for palliative care integration

The most frequent outcomes discussed were improving QoL^{11,26,28–31,35–37} and reducing symptom burden.^{11,26,28–31,33,35–37}

Siouta et al.²⁹ suggest a ‘comprehensive assessment of physical, psychological, spiritual and social needs’. Several multidimensional, clinical and prognostic tools were reported by many papers, which are reported in the Data S2.

Shared decision-making and planning for deactivation of implantable cardioverter defibrillators in people approaching the end of life was also described, with a failure to do this labelled as ‘bad practice’,³³ underscoring the ethical and clinical responsibility to align care with patient goals and preferences.

Multiprofessional involvement

Professional groups involved in providing care were predominantly cardiologists,^{11,26–30,32–37} ($n = 12$) followed by nurses,^{11,26,28–30,32–35,37} and palliative care specialists^{11,28–30,32–36} ($n = 9$). General practitioners were also frequently mentioned,^{11,30,33,34} along with physicians from various specialties, such as internists,²⁶ psychiatrists,²⁹ cardiac physiologists,³³ and ‘team expert physicians’.³¹

Other professionals noted were psychologists,^{11,29,30,33} social workers,^{30,33} nutritionists,^{29,30} spiritual carers,^{11,33} chaplains,^{29,30} physiotherapists,^{29,30} rehabilitation professionals,³⁵ pharmacists,³⁰ speech therapists³⁰ and occupational therapists.³⁰ The breadth of professionals underscores the need for a comprehensive, multidisciplinary approach to care in these contexts.

Integration models and recommendations

Multiple sources propose that modern HF management should include responsive,³⁰ integrated cardiac and palliative care throughout the HF trajectory, regardless of prognosis, and not solely at the end-of-life stage.^{11,28,30,32} This integrated care model should focus on essential aspects such as symptom management, patient-centred care, shared decision-making and address psychological, social and spiritual needs.³⁰ This scoping review reveals that despite the potential benefits³¹ there is a lack of a systematic approach to integrating palliative care in HF management across Europe.

Key themes that we noted include the following:

Symptom management and quality of life is a primary goal for any palliative approach, which should emphasize frequent holistic assessments^{11,29} to identify needs and alleviate symptoms, such as dyspnoea and pain, as well as psychological, social and spiritual needs resulting from HF and comorbidities.²⁹ The focus of care should focus on optimizing symptom control,^{28,36} improving or maintaining QoL,¹¹ and reducing suffering.²⁹

Multiprofessional, integrated care is essential to address the complex, multidimensional needs of patients with HF.^{30,34} While most patients benefit from a palliative care approach provided by the core team and/or general practitioners, access to specialist palliative care should be ensured for patients with more complex needs and/or transitioning to the end of life.^{30,32} Other health professionals, such as spiritual carers, play an important role¹¹ in addressing often overlooked psychological and spiritual needs of both patients and their close ones.³⁶

Collaborative Team and networking among cardiologists, palliative care specialists and general practitioners is fundamental to improve patients’ outcomes.³² Publications recommend establishing networks linking community-based ser-

vices and hospitals to ensure coordinated, continuous care and access to primary care, specialist palliative care services, and HF support according to each centre’s resources.^{26,34,37} Local community-based PC teams and hospice care should be prioritized, especially for patients in the advanced stages of the disease trajectory and at the end of life.³⁴

Training programmes tailored for cardiologists, nurses and palliative care professionals are essential to address the educational gap in managing complex needs in patients with HF.²⁷ These programmes should also include guidance on deactivating ICDs, along with psychological support for the family.²⁶ Training might focus on improving collaboration and integration of care to ensure consistent and high-quality care,³⁴ and on the delivery of tailored information for patients and carers around palliative care in HF.³⁴

Patient-centred care and communication foster early, open, transparent and compassionate discussions with patients and their families.^{11,32,33} These should focus on best-evidence cardiology treatments, prognosis, changes in goals of care,^{28,29} end-of-life issues,³² preferred place of death and resuscitation decisions.¹¹ Such conversations should be documented and shared across the care team.^{11,33}

Effective communication with patients, families and all members of the healthcare team is crucial to prevent misunderstanding and to support informed decision-making.³³ Emphasis should be placed on providing compassionate care during the final hours of life and offering ongoing support for grieving families.²⁹

Advance and anticipatory care planning in patients with heart disease and poor prognosis represents a critical step toward integrating palliative care into the treatment of all patients with deteriorating health.³² Planning should involve actively involving patients and their families.³⁶ When individuals lack decision-making capacity, choices must be made in their best interests, adhering to legal requirements and involving those with the legal authority to act on their behalf, while also considering the views of close family members.^{11,33}

Device management must not be overlooked. Clearly defined guidelines are essential for deactivating ICDs and reviewing the need for other cardiac devices, ensuring that decisions are made collaboratively through shared decision-making.^{11,27,30,33,35,36} Tomasoni *et al.*³¹ suggest advance care planning at an early phase of the disease, before heart transplantation or left ventricular assist device (LVAD) implantation.

Research and System Improvements are a key area of focus to eventually develop best practices for introducing discussions on advance care planning and implementing optimal processes for information sharing.³² This includes designing effective information-sharing strategies to improve care coordination among all providers.³⁴

Discussion

Our scoping review underscores an increasing recognition of the critical importance of integrating a palliative care approach into the long-term management of individuals with HF.

All consortium countries included in this review participated in at least four publications, with UK authors often taking a primary role. The first proposals and the first guidance around integrative palliative care in HF originated in the United Kingdom,^{7,8} although implementation remains suboptimal.³⁸

Guidelines recommend integrating palliative care in the advanced stage of HF, but there is no consensus on the definition of advanced HF. Rather than clearly distinguishing between 'advanced' and 'end-stage' HF, the reviewed documents often focused on identifying needs as more actionable indicators for initiating palliative care. This suggests that staging terminology alone may be insufficient, and that a shift toward need-based referral criteria may be more relevant in practice.³⁹ Achieving consensus on the specific patient population being addressed would provide clarity and alignment in identifying this population. Disagreements were observed regarding the timing of initiation of palliative care; while publications written from a palliative care perspective advocated for early initiation, even from the time of diagnosis,^{29,30,34} those authored by cardiology experts suggest its implementation only at the end of life.^{11,26,29–34} While people with HF do benefit from palliative care, it is clear that patients with mild symptoms on stable medical therapy are less likely to benefit suggesting that tailored care based upon needs in people with severe or deteriorating HF is likely to be more productive.⁴⁰ Recent therapeutic advances—particularly in patients with HF with reduced ejection fraction (HFrEF)—have extended survival by several years in many patients. As a result, an increasing number of individuals are reaching the advanced stages of heart failure with greater frailty, multimorbidity and psychosocial vulnerability. This demographic shift reinforces the need for proactive integration of palliative care, not only at the end of life but throughout the disease trajectory, tailored to evolving patient needs.

Given the broad spectrum of patients' profiles described in the included publications, no standardized criteria were consistently applied across sources to define palliative care candidacy. This variability reflects real-world complexity but may limit the comparability and implementation of recommendations. The broader integration of validated instruments may support more standardized referral practices and a clearer definition of palliative care needs and intensity across different stages of HF.

A broad group of triggers for a palliative care approach was identified. Patients with HF are a heterogeneous population, and they likely have differing (or multiple) reasons that may

vary over time, prompting the engagement of a responsive palliative care programme. More concise triggers or criteria may assist in the identification of patients with palliative care needs, especially in non-specialist settings.⁴¹ Distinguishing between those patients who should be considered for a general palliative care approach and those with specialist palliative care needs can improve care planning and allow patients to access the most appropriate care. Although a wide range of triggers for palliative care was identified, most documents did not clearly distinguish between patient-related clinical conditions, organizational factors and family or caregiver concerns. This lack of clarity may complicate consistent implementation across settings and highlights a broader limitation in existing guidance, which should be addressed in future work.

Developing joint guidelines and fostering more interdisciplinary collaboration between both fields would improve mutual understanding and drive progress in the integrated provision. However, it is apparent that most current guidelines focus on the activities of physicians, with limited representation or guidance for other healthcare professionals. This lack of multidisciplinary representation may limit the comprehensiveness and applicability of current guidelines, especially in community-based or home settings. Greater inclusion of nurses, allied health professionals and spiritual care providers is essential for delivering holistic care across care settings and stages of illness.

In line with this, the available literature also lacks direct input from patients and caregivers. As the sources included were primary clinical guidelines and expert consensus, these voices are rarely incorporated, reflecting a broader structural gap. Future development of integrated care models should actively involve patients and caregivers to ensure person-centredness and alignment with lived experience.

One consensus statement specifically addresses patients with advanced chronic HF with reduced ejection fraction (HFrEF),²⁷ showing no significant deviation from other general recommendations. This suggests that different phenotypes of HF could benefit equally from the integration of palliative care. Nonetheless, it is important to recognize that HFpEF is often associated with a higher burden of comorbidities as well as greater clinical heterogeneity. These characteristics can complicate both standard HF management and the design or delivery of palliative care interventions. As such, tailored approaches that consider HF phenotype and comorbidity profiles may enhance the relevance and feasibility of integrated care models.

Key challenges include the development of more comprehensive evidence-based guidelines, better-defined triggers for referral and improved referral processes, and more collaborative service models. However, the implementation of these guidelines remains a critical issue. Although both European and US Cardiology Associations advocate for palliative care inclusion in the care of patients with HF,⁴² only a small

proportion of patients actually receive it, highlighting the gap in the application of the palliative care approach. The recommendations emphasize stakeholder involvement, advanced care planning and service development to ensure that HF patients receive appropriate palliative care support. The findings of this scoping review will inform future studies and subsequent guidelines and contribute to improving the quality of life for HF patients across Europe.

While there is broad consensus on the potential benefits of palliative care, this review focused on mapping existing practices and guidance. Assessing the comparative effectiveness of different models was beyond its intended scope. Nonetheless, there is a clear need for future research evaluating the impact and effectiveness of integrated palliative care models to support evidence-based implementation.

Based on our findings, we propose several practical recommendations to support the integration of palliative care in HF management. First, structured training programmes for cardiologists, nurses and palliative care professionals are essential to build interdisciplinary competencies and foster collaboration. Second, the establishment of regional or national collaborative care models involving general practitioners, palliative care teams and cardiologists that facilitate coordination between hospital and community-based services. Third, the development of clear care pathways and the use of multidisciplinary teams, including nurses, allied health professionals and spiritual care providers, to ensure that care is holistic, continuous and responsive to patients' needs across disease stages. These measures should be adapted to local health system contexts and informed by further research involving patients, caregivers and healthcare providers. At the policy level, harmonized guidance in Europe could help align national strategies and reduce disparities in access to integrated palliative care.⁴³ Policy incentives such as dedicated funding, performance indicators and integration into chronic disease management frameworks may further support the systematic inclusion of palliative care in HF services.

Strengths and limitations

This review includes diverse sources, including multinational guidelines, position papers and consensus documents from palliative care and cardiologist perspectives, providing a view on the normative aspects of palliative care integration for HF conditions encompassing all consortium countries. We did not, however, explore the multitude of local guidelines across the countries, which would have been prohibitively complex. Although the number of included publications reflects the strict inclusion criteria applied to ensure relevance and quality, this limited sample size may have affected the completeness of the mapped evidence, potentially omitting some local practices or non-indexed guidelines.

Albeit our findings will inform European-based policy makers, a further limitation of our scoping review of the geographic restriction to RAPHAEL consortium countries is the exclusion of potentially relevant publications, particularly from the United States and Australia. This limitation may impact the comprehensiveness of our findings and reduce the generalizability of our conclusions to a broader international context. However, the included countries provide a diverse landscape of health systems and policies, offering a meaningful foundation for comparative insights and potential scalability.

Conclusions

This scoping review highlights deficiencies in the delivery of standardized palliative care to patients with HF that limit the availability of palliative care to people with HF due to challenges with triggers, timing and referral pathways for assessing needs, delivering care and prompting advance care planning. There is also a critical need to develop more explicit guidance regarding the involvement of multi-professional teams to address the multifaceted needs of this patient population. Addressing these aspects through a comprehensive review of palliative care provision across Europe, grounded in clinical evidence and integrating both cardiology and palliative care perspectives, will help develop questions and priority setting for future work aiming in the long term to provide more consistent, equitable and high-quality patient care.

Funding

This work was supported by the European Union's under the grant agreement no. 101137170 (The RAPHAEL Project).

Acknowledgement

The authors thank Dr. Iris Reiman, librarian at the Uniklinik RWTH Aachen, for her support in developing and refining the search strategy.

Open access publishing facilitated by Università degli Studi di Brescia, as part of the Wiley - CRUI-CARE agreement.

Conflict of Interest

None of the Authors declare a conflict of interest.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Data S1. Supporting Information.

Data S2. Supporting Information.

References

- Rivera FB, Choi S, Carado GP, Adizas AV, Bantayan NRB, Loyola GJP, Cha SW, Aparece JP, Rocha AJB, Placino S, Ansay MFM, Mangubat GFE, Mahilum MLP, Al-Abcha A, Suleman N, Shah N, Suboc TMB, Volgman AS End-of-life care for patients with end-stage heart failure, comparisons of international guidelines. *Am J Hosp Palliat Care* 2024;**41**:87-98. doi:10.1177/10499091231154575
- Savarese G, Becher PM, Lund LH, Seferovic P, Rosano GMC and Coats AJS. Global burden of heart failure: a comprehensive and updated review of epidemiology. *Cardiovasc Res* 2023;**118**: 3272-3287. doi:10.1093/cvr/cvac013.
- Lippi G, Sanchis-Gomar F. Global epidemiology and future trends of heart failure. *AME Med J* 2020;**5**:5.
- Koshy AO, Gallivan ER, McGinlay M, Straw S, Drozd M, Toms AG, Gierula John, Cubbon Richard M., Kearney Mark T., Witte Klaus K. Prioritizing symptom management in the treatment of chronic heart failure. *ESC Heart Fail* 2020;**7**: 2193-2207. doi:10.1002/ehf2.12875
- Rosano GMC, Seferovic P, Savarese G, Spoleitini I, Lopatin V, Gustafsson F, Bayes-Genis A, Jaarsma T, Abdelhamid M, Miqueo AG, Piepoli M, Tocchetti CG, Ristić AD, Jankowska E, Moura B, Hill L, Filippatos G, Metra M, Milicic D, Thum T, Chioncel O, Ben Gal T, Lund LH, Farmakis D, Mullens W, Adamopoulos S, Bohm M, Norhammar A, Bollmann A, Banerjee A, Maggioni AP, Voors A, Solal AC, Coats AJS Impact analysis of heart failure across European countries: an ESC-HFA position paper. *ESC Heart Fail* 2022;**9**:2767-2778. doi:10.1002/ehf2.14076
- Radbruch L, De Lima L, Knaul F, Wenk R, Ali Z, Bhatnagar S, C. Blanchard, E. Bruera, R. Buitrago, C. Burla, M. Callaway, E. C. Munyoro, C. Centeno, J. Cleary, S. Connor, O. Davaasuren, J. Downing, K. Foley, C. Goh, W. Gomez-Garcia, R. Harding, Q. T. Khan, P. Larkin, M. Leng, E. Luyirika, J. Marston, S. Moine, H. Osman, K. Pettus, C. Puchalski, M.R. Rajagopal, D. Spence, O. Spruijt, C. Venkateswaran, B. Wee, R. Woodruff, J. Yong, T. Pastrana Redefining palliative care-a new consensus-based definition. *J Pain Symptom Manage* 2020;**60**:754. doi:10.1016/j.jpainsymman.2020.04.027, 764.
- Jones S. Palliative care in terminal cardiac failure. *BMJ* 1995;**310**:805. doi:10.1136/bmj.310.6982.805
- Department of Health. *National service framework for coronary heart disease*. London: Department of Health; 2000.
- Dickstein, K, Cohen-Solal, A, Filippatos, G, McMurray, JJ, Ponikowski, P, Poole-Wilson, PA, Strömberg A, van Veldhuisen DJ, Atar D, Hoes AW, Keren A, Mebazaa A, Nieminen M, Priori SG, Swedberg K. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the task force for the diagnosis and treatment of acute and chronic heart failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). *Eur J Heart Fail* 2008;**10**:933-989. 20080916. doi:10.1016/j.ejheart.2008.08.005.
- Ponikowski P, Voors AA, Anker SD, Bueno H, Cleland JGF, Coats AJS, Falk Volkmar, González-Juanatey José Ramón, Harjola Veli-Pekka, Jankowska Ewa A., Jessup Mariell, Linde Cecilia, Nihoyannopoulos Petros, Parissis John T., Pieske Burkert, Riley Jillian P., Rosano Giuseppe M. C., Ruilope Luis M., Ruschitzka Frank, Rutten Frans H. van der Meer Peter 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: the task force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 2016;**37**:2129-2200. doi:10.1093/eurheartj/ehw128
- McDonagh, TA, Metra, M, Adamo, M, Gardner, RS, Baumbach, A, Böhm, M, Burri H, Butler J, Čelutkienė J, Chioncel O, Cleland JGF, Coats AJS, Crespo-Leiro MG, Farmakis D, Gilard M, Heymans S, Hoes AW, Jaarsma T, Jankowska EA, Lainscak M, Lam CSP, Lyon AR, McMurray JJV, Mebazaa A, Mindham R, Muneretto C, Francesco Piepoli M, Price S, Rosano GMC, Ruschitzka F, Kathrine Skibellund A. 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: developed by the task force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). *Eur J Heart Fail* 2022;**24**:4-131. doi:10.1002/ehf2.2333.
- Datla S, Verberkt CA, Hoye A, Janssen DJA, Johnson MJ Multi-disciplinary palliative care is effective in people with symptomatic heart failure: a systematic review and narrative synthesis. *Palliat Med* 2019;**33**:1003-1016. doi:10.1177/0269216319859148
- Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM Palliative care interventions for patients with heart failure: a systematic review and meta-analysis. *J Palliat Med* 2017;**20**:84-92. doi:10.1089/jpm.2016.0330
- Sahlollobey N, Lee CKS, Shirin A and Joseph P. The impact of palliative care on clinical and patient-centred outcomes in patients with advanced heart failure: a systematic review of randomized controlled trials. *Eur J Heart Fail* 2020;**22**: 2340-2346. doi:10.1002/ehf2.1783.
- Shah AB, Morrissey RP, Baraghoush A, Bharadwaj P, Phan A, Hamilton M, Kobashigawa J, Schwarz ER Failing the failing heart: a review of palliative care in heart failure. *Rev Cardiovasc Med* 2013;**14**:41-48. doi:10.3909/ricm0635.
- Riley JP, Beattie JM Palliative care in heart failure: facts and numbers. *ESC Heart Fail* 2017;**4**:81-87. doi:10.1002/ehf2.12125
- Fernández-Martínez J, Romero-Correa M, Salamanca-Bautista P, Aramburu-Bodas Ó, Formiga F, Vázquez-Rodríguez P, Conde-Martel Alicia, García-García José Angel, Páez-Rubio Inmaculada, López-Reboiro Manuel, Sánchez-Sánchez Cristina, Arias-Jiménez José Luis Prevalence of advanced heart failure and use of palliative care in admitted patients: findings from the EPICter study. *Int J Cardiol* 2021;**327**:125-131. 20201107. doi:10.1016/j.ijcard.2020.11.002
- Bakitas M, Macmartin M, Trzepkowski K, Robert A, Jackson L, Brown JR, Dionne-Odom JN, Kono A Palliative care consultations for heart failure patients: how many, when, and why?. *J Card Fail* 2013;**19**:193-201. doi:10.1016/j.cardfail.2013.01.011.
- Garralda E, Martínez Sellés M, Díez Villanueva P. Integration of palliative care into cardiology. In Arias-Casas N., Garralda E., Rhee J. Y. et al., eds. *EAPC Atlas of Palliative Care in Europe 2019*. EAPC Press; 2019. p. 85-88.
- Arksey H and O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;**8**:19-32. doi:10.1080/1364557032000119616.

21. Levac D, Colquhoun H, O'Brien KK Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69. doi:10.1186/1748-5908-5-69
22. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garritty C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö, Straus SE PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018; **169**:467-473. doi:10.7326/m18-0850
23. Veritas Health Innovation. *Covidence systematic review software*. Melbourne, Australia: Veritas Health Innovation; 2019.
24. VERBI Software. *MAXQDA 2020*. Berlin: VERBI Software; 2021.
25. Mayring P. *Qualitative Inhaltsanalyse. Grundlagen und Techniken*, 9th ed. Weinheim Basel: Beltz UTB; 2007.
26. Crespo-Leiro MG, Metra M, Lund LH, Milicic D, Costanzo MR, Filippatos G, Gustafsson F, Tsui S, Barge-Caballero E, de Jonge N, Frigerio M, Hamdan R, Hasin T, Hülsmann M, Nalbantgil S, Potena L, Bauersachs J, Gkousziouta A, Ruhparwar A, Ristic AD, Straburzynska-Migaj E, McDonagh T, Seferovic P, Ruschitzka F Advanced heart failure: a position statement of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2018; **20**:1505-1535. doi:10.1002/ehf.1236
27. Gustafsson F, Damman K, Nalbantgil S, Van Laake LW, Tops LF, Thum T, Adamopoulos S, Bonios M, Coats AJ, Crespo-Leiro MG, Mehra MR, Filippatos G, Hill L, Metra M, Jankowska E, de Jonge N, Kaye D, Masetti M, Parissis J, Milicic D, Seferovic P, Rosano G, Ben Gal T Inotropic therapy in patients with advanced heart failure. A clinical consensus statement from the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2023; **25**:457-468. doi:10.1002/ehf.2814
28. Hill L, Geller TP, Baruah R, Beattie JM, Boyne J de Stoutz N, Prager Geller Tal, Di Stolfo Giuseppe, Lambrinou Ekaterini, Skibelund Anne K., Uchmanowicz Izabella, Rutten Frans H., Čelutkienė Jelena, Piepoli Massimo Francesco, Jankowska Ewa A., Chioncel Ovidiu, Ben Gal Tuvia, Seferovic Petar M., Ruschitzka Frank, Coats Andrew J. S., Strömberg Anna, Jaarsma Tiny Integration of a palliative approach into heart failure care: a European Society of Cardiology Heart Failure Association. *Eur J Heart Fail* 2020; **22**:2327-2339. doi:10.1002/ehf.1994
29. Siouta N, van Beek K, Preston N, Hasselaar J, Hughes S, Payne S, Garralda E, Centeno C, van der Eerden M, Groot M, Hodiament F, Radbruch L, Busa C, Csikos A, Menten J Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliat Care* 2016; **15**:18. doi:10.1186/s12904-016-0089-4
30. Sobanski PZ, Alt-Epping B, Currow DC, Goodlin SJ, Grodzicki T, Hogg K, Janssen DJA, Johnson MJ, Krajnik M, Leget C, Martínez-Sellés M, Moroni M, Mueller PS, Ryder M, Simon ST, Stowe E, Larkin PJ Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement. *Cardiovasc Res* 2020; **116**:12-27. doi:10.1093/cvr/cvz200
31. Tomasoni D, Vishram-Nielsen JKK, Pagnesi M, Adamo M, Lombardi CM, Gustafsson F, Metra M Advanced heart failure: guideline-directed medical therapy, diuretics, inotropes, and palliative care 2022; **9**:1507-1523. doi:10.1002/ehf2.13859 *ESC Heart Fail*
32. Denvir MA, Murray SA and Boyd KJ. Future care planning: a first step to palliative care for all patients with advanced heart disease. *Heart* 2015; **101**:1002-1007. doi:10.1136/heartjnl-2014-306724
33. Pitcher D, Soar J, Hogg K, Linker N, Chapman S, Beattie JM, Jones S, George R, McComb J, Glancy J, Patterson G, Turner S, Hampshire S, Lockey A, Baker T, Mitchell S, CIED Working Group Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the resuscitation council (UK), British Cardiovascular Society and National Council for Palliative Care. *Heart (British Cardiac Society)* 2016; **102**:A1-A17. doi:10.1136/heartjnl-2016-309721
34. Selman L, Harding R, Beynon T, Hodson F, Coady E, Hazeldine C, Walton M, Gibbs L, Higginson IJ Improving end-of-life care for patients with chronic heart failure: 'let's hope it'll get better, when I know in my heart of hearts it won't'. *Heart* 2007; **93**:963-967. doi:10.1136/hrt.2006.106518
35. Real J, Cowles E, Wierzbicki AS Chronic heart failure in adults: summary of updated NICE guidance. *BMJ* 2018; **362**:k3646. doi:10.1136/bmj.k3646
36. Antonione, R, Sinagra, G, Moroni, M, Corrales, M, Redaelli, D, Scrutinio, D, Malinverni E, Nodari S, Calabrò R, Penco I, Mercurio G. Palliative care in the cardiac setting: a consensus document of the Italian Society of Cardiology/Italian Society of Palliative Care (SIC/SICP). *G Ital Cardiol* (2019) **20**:46-61. doi:10.1714/3079.30720
37. Aspromonte N, Gulizia MM, Di Lenarda A, Mortara A, Battistoni I, De Maria R, Gabriele M, Iacoviello M, Navazio A, Pini D, Di Tano G, Marini M, Ricci RP, Alunni G, Radini D, Metra M, Romeo F [ANMCO/SIC consensus document: the heart failure network: organization of outpatient care]. *G Ital Cardiol* (2006) **20**:570-593. doi:10.1714/2330.25052
38. Oduwale A, Allotey J, Romer E, Younsi T, Shahid M, Waheed M, Hall R, Herbert M Integrated palliative care in the management of advanced heart failure. *Future Healthc J* 2022; **9**:95-96. doi:10.7861/fhj.9-2-s95
39. Janssen DJA, Johnson MJ and Spruit MA. Palliative care needs assessment in chronic heart failure. *Curr Opin Support Palliat Care* 2018; **12**:25-31. doi:10.1097/spc.0000000000000317
40. Balata M, Radbruch L, Hesse M, Westenfeld R, Neukirchen M, Pfister R, Batzler YN, Öztürk C, Kavsar R, Tiyerili V, Weltermann B, Pölsler R, Standl T, Nickenig G, Becher MU Early integration of palliative care versus standard cardiac care for patients with heart failure (EPCHF): a multicentre, parallel, two-arm, open-label, randomised controlled trial. *Lancet Healthy Longev* 2024; **5**:100637. doi:10.1016/j.lanhl.2024.08.006
41. Hui D, Mori M, Watanabe SM, Caraceni A, Strasser F, Saarto T, Cherny N, Glare P, Kaasa S, Bruera E Referral criteria for outpatient specialty palliative cancer care: an international consensus. *Lancet Oncol* 2016; **17**:e552-e559. doi:10.1016/s1470-2045(16)30577-0
42. Blum M, Goldstein NE, Jaarsma T, Allen LA, Gelfman LP. Palliative care in heart failure guidelines: a comparison of the 2021 ESC and the 2022 AHA/ACC/HFSA guidelines on heart failure. *Eur J Heart Fail* 2023; **25**:1849-1855. doi:10.1002/ehf.2981
43. Allcroft, P., De Pasquale, C. G., Lim, D., Amgarth-Duff, I., and Agar, M.R. (2025) Elements of effective palliative care interventions in advanced heart failure: a narrative review. *ESC Heart Failure*, **12**:1759-1775. doi:10.1002/ehf2.15243