REVIEW ARTICLE

What Are We Talking About When We Talk About Palliative Care in Heart Failure?

¿De qué hablamos cuando hablamos de cuidados paliativos en insuficiencia cardíaca?

MARIÁNGEL SÁNCHEZ[1], FRANCISCO PROASI[2], LUIS AHUALLI[1], CLAUDIO HIGA[1, MTSAC]

ABSTRACT

Background: Heart failure is a chronic, complex and progressive disease, with high morbidity and mortality, and growing prevalence. Despite advances in therapeutic strategies to improve survival and reduce hospitalizations, heart failure still generates a negative impact on the patients' quality of life, making it necessary to develop health policies based not only on their physical but also on their psychosocial integrity. Palliative care refers to specialized, interdisciplinary care focused on improving the quality of life of patients who suffer a disease with elevated morbidity and mortality. The aim of this review is to assess the impact of the implementation of palliative care in the multidisciplinary treatment of heart failure throughout all the stages of the disease, and to determine the feasibility of its application in clinical practice.

Key words: Heart failure - Palliative care - Prognosis

RESUMEN

La insuficiencia cardíaca (IC) es una enfermedad crónica, compleja y progresiva, con elevada morbimortalidad y creciente prevalencia. Pese al avance en las estrategias terapéuticas, destinadas a mejorar la sobrevida y reducir hospitalizaciones, la IC continúa generando un impacto negativo en la calidad de vida de los pacientes. Surge ante este reto la necesidad de desarrollar políticas de salud basadas no solo en la integridad física, sino también en la integridad psicosocial. Los cuidados paliativos (CP) hacen referencia a un cuidado especializado, interdisciplinario, enfocado en mejorar y mantener la calidad de vida de los pacientes que se enfrentan a una enfermedad con elevada morbimortalidad como lo es la IC. El propósito de la presente revisión es evaluar el impacto de la integración de los CP en el tratamiento multidisciplinario de la IC en todas las fases de la enfermedad y determinar la factibilidad de su aplicación en la práctica clínica.

Palabras clave: Insuficiencia cardíaca - Cuidados paliativos - Pronóstico

INTRODUCTION

Heart failure (HF) is a complex syndrome whose prevalence has increased in the last years as a result of population aging, the presence of multiple comorbidities and the higher survival of cardiovascular diseases. (1-3) Despite the development of therapeutic strategies destined to reduce mortality, HF is associated with elevated morbidity and progressive functional impairment. (4) Moreover, decompensations represent one of the main causes of hospitalization in adults over 65 years of age, with a high rate of rehospitalizations. (5)

Several authors have demonstrated a negative impact on the quality of life of patients with HF due to the limitation in functional class (FC), loss of independence in daily life activities and presence of physical symptoms and mood changes (comparable or greater to those of oncological patients) that are occasionally underdiagnosed and undertreated. (6-8)

The World Health Organization (WHO) acknowledges palliative care (PC) as "an approach to improve the quality of life of patients and their relatives facing problems associated with a potentially mortal disease. It includes the prevention and the relief of suffering through the early identification, assessment and cor-

REV ARGENT CARDIOL 2023;91:273-278. http://dx.doi.org/10.7775/rac.v91.i4.20654

Received: 07/04/2023 – *Accepted:* 07/28/2023

Address for reprints: mariangelsanchez@hospitalaleman.com Avenida Pueyrredón 1640. Ciudad Autónoma de Buenos Aires. Argentina. CPC 1118AAT
tel (+5411) 48277000

https://creativecommons.org/licenses/by-nc-sa/4.0/
©Revista Argentina de Cardiología

---

[1] Division of Cardiology. Department of Internal Medicine. Hospital Alemán. Buenos Aires. Argentina
[2] Division of Palliative Care. Department of Internal Medicine. Hospital Alemán. Buenos Aires. Argentina

rective treatment of pain and other problems, whether physical, psychosocial or spiritual. (9) In oncological patients, the early intervention of PC teams has been shown to improve the quality of life and reduce costs and hospital admissions. It is therefore interesting to evaluate if patients with HF could also benefit from the care provided by the different PC levels.

The aim of the present review is to assess the existing evidence on the impact of incorporating PC to the multidisciplinary treatment of HF, the limiting factors in its application and its feasibility in daily clinical practice.

PALLIATIVE CARE

Originally, PC was developed within the frame of care of end-stage oncological patients, with the purpose of achieving symptomatic end-of-life control. (10) The growing prevalence of chronic, non-communicable diseases and the morbidity and mortality they generate has led to a transition from the classical model of care in which PC was administered in end-stage patients, towards a model of integral care which emphasizes the early onset of PC together with the active treatment of the disease. In this last model, as the disease progresses and the needs of the patient increase, PC is intensified to accompany the patient and his/her relatives, even contemplating the care of the family during the mourning process after the patient's death. This organizational model generates a paradigm in the care of the chronic patient, in which both the curative and palliative treatments are similarly rated, allowing a dynamic and integral care that leaves behind the original concept of PC focused on end-of-life treatment (11-13) (Figure 1).

In patients with chronic diseases, PC has shown a consistent benefit in terms of quality-of-life improvement, symptomatic control, reduction of hospitalizations and increase in anticipated measures that prioritize comfort over invasive measures at the end of life, with the consequent reduction in health costs, which avoids futility. (14,15)

Three levels of care are identified in PC. (16,17)

- First level or primary PC: it involves the application of basic PC competencies by first level of care professionals to provide symptomatic control in patients.
- Second level or secondary PC: it consists of interdisciplinary care in which the PC teams are consulted and deliver complementary support. The specific structure of each team varies according to the patient's needs. (11)
- Third level or tertiary PC: care is carried out in healthcare centers with specialized PC teams. It provides care to very complex patients who need hospitalization.

Access to PC has been declared a universal human right. (18) According to WHO, Argentina is among the countries with active growth in PC. (11) However, there is inequity in its access. The National Palliative Care Law was enacted in 2022 to guarantee PC access in all the care settings.

Application of palliative care in heart failure: let´s go to the evidence

In the prospective, randomized and open-label PREFER study, an integral PC home monitoring model together with cardiologists specialized in HF was compared with only the latter monitoring strategy in NYHA FC III-IV HF patients (36 patients per group). The Edmonton symptoms assessment scale (ESAS) and the Kansas City Cardiomyopathy Questionnaire (KVCQ) were used to analyze results. The first refers to a tool evaluating the average intensity of symptoms such as pain, dyspnea, asthenia, nausea, depression, anxiety, welfare, poor appetite and insomnia during a period of time. The second corresponds to a self-administered questionnaire specific for HF, consisting of 23 items that involve 5 self-perceived dimensions regarding the patient's health condition: physical limitation, symptoms (frequency, severity and stability), self-care, quality of life and social limitation. The PC strategy together with HF specialists demonstrated a statistically significant improvement in the quality of life compared with the control group (p=0.05)

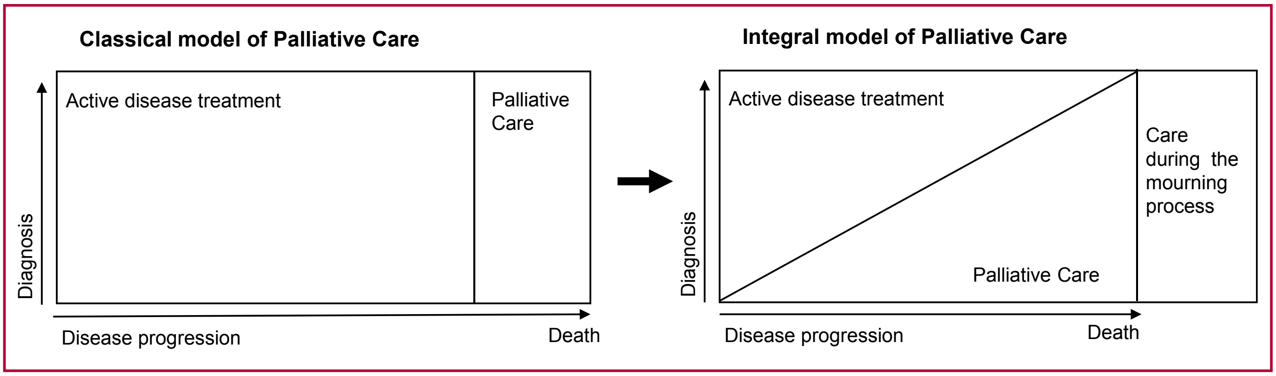

Fig. 1. Transition from the classical model of palliative care towards an integral care model, which emphasizes the early onset of palliative care, together with an active treatment of the disease. Modified from Lynn J, Adamson DM. Living well at the end of life; adapting health care to serious chronic illness in old age. WHO regional office for Europe. 2004.

as well as improved symptom burden (p=0.035). The implementation of integral care evidenced a significant change in FC at 6 months compared with control (39% vs. 10%, p=0.012). Additionally, the intervention group reduced hospitalizations (p=0.009). (19). These findings are consistent with those reported by Wong et al. who showed a reduction in the number of readmissions and symptomatic improvement with a PC strategy in patients discharged after a hospitalization for HF. (20)

In the PAL-HF study, 150 patients with advanced HF (AdHF) were randomly allocated to receive standard medical care, vs. the latter together with PC monitoring. Mean age was 71 years and more than 70% were in NYHA FC III, with an average of 2.2 hospitalizations in the year prior to enrollment. KCCQ scores evidenced poor quality of life, with a high symptom burden. The KCCQ and the Functional Assessment of Chronic Illness Therapy Palliative Care scale (FACIT-Pal) were used to analyze the results. The latter refers to a 46-item self-administered questionnaire evaluating quality of life in the physical, socio-familial, emotional and functional domains and also includes specific PC aspects. A change in favor of patients assigned to the PC interdisciplinary monitoring arm was observed with a KCCQ difference of 9.49 points (95% CI 0.94-18.05; p=0.030) and a difference in the FACIT-Pal scale of 11.77 points (95% CI 0.84-22.71; p=0.035) compared with patients undergoing conventional monitoring at 6 months of follow-up. In addition, a significant benefit was observed in the degree of anxiety (p=0.048) and depression (p=0.020), also in favor of interdisciplinary monitoring. (21)

In a systematic review of randomized controlled clinical trials including 1050 AdHF patients, the implementation of PC plus standard care was compared with standard care alone. The integral PC monitoring combined with standard care was associated with improved quality of life, reduced number of hospitalizations (OR 0.56; 95% CI 0.33-0.94) and decreased symptom burden compared with the usual care. (22)

These findings indicate a consistent benefit in terms of quality of life and symptom burden improvement in patients with AdHF. However, it is necessary to emphasize the difficulty posed by the incorporation and permanence of end-stage patients in research studies, as reflected by the low number of patients they include. Moreover, since most studies evaluate subjective endpoints, the potential risk of bias should be considered when interpreting the results.

Barriers in the implementation of palliative care in patients with heart failure

Heart failure clinical practice guidelines recommend considering the addition of PC to patient care. (23,24) However, one third of the patients are bed-ridden at the time of PC monitoring onset. (25,26) This exposes existing barriers that promote inequity in the access to PC among HF patients.

For some professionals, PC monitoring together with the active treatment of the disease involves contradictory actions, as they consider that PC is exclusively reserved for end stages of the disease, as a resource when the therapeutic objectives are not met and there are no other alternatives. (27) This reveals the existing conceptual error at the population level regarding the palliative term, as well as the limited training in PC that healthcare professionals have. (28, 29)

On the other hand, several authors agree about the lack of communication between physicians and HF patients. Only 12% of professionals annually discuss the prognosis with their patients (30,31) hampering advanced care planning, as the consultation with the GP in an ambulatory patient constitutes a favorable context to consider anticipated directives. These directives represent a willful declaration that the patient makes in full use of his/her mental faculties, with the aim of their becoming effective when he/she cannot express them. Thus, it ensures that the future healthcare is carried out according to the patient's preferences, guaranteeing the fulfillment of the principle of autonomy and a better quality of end-of-life care. (32,34)

Another important aspect to consider is the difficulty that presents the detection of the right moment for inclusion in PC monitoring. It is frequently found that after an acute decompensation, and following the administration of adequate treatment, the patient can recover and be discharged. However, the patient does not return to his/her previous state. These repeated decompensation episodes with subsequent recovery may cast doubt in the treating physicians, delaying the inclusion in PC programs. A systematic review evaluating the criteria of referral to PC revealed that 50% was carried out due to persistent physical symptoms and mood disorders, 45% for advanced NYHA FC and 37% for frequent hospitalizations. (35) Several scores have been postulated to approach this problem, such as the Heart Failure Survival Score (HFSC) and the Seattle Heart Failure Score (SHFS), (36) as well as the use of the surprise question "would you be surprised if this patient died next year?", to identify HF patients near the end of life and thus promote the consultation with PC. Straw et el. evidenced a statistically significant association between the answer "not surprised" and all-cause death at one year (p=0.046). (37) It is important to emphasize that, unfortunately, these tools expose the idea of referral to PC in advanced stages of the disease. Nevertheless, they could be useful for an objective assessment of the patient's prognosis, guiding advanced care planning.

Palliative care in heart failures: guidelines and recommendations

The European Society of Cardiology HF Association has published several recommendations acknowledging the value of early PC implementation for the multidisciplinary management of HF. (38) The last edition of the Diagnosis and Treatment Guideline establishes that HF patients could benefit from the integration of PC during follow-up, independently of the stage in which they are, even if its incorporation is posed from the moment of diagnosis and its requirements increase as the disease progresses and advances. This organizational model generates a change in the paradigm for the HF patient, categorizing both the curative and palliative treatments, thus allowing a dynamic and integral care that leaves behind the original concept of PC focused on end-of-life treatment. (13) Moreover, it invites healthcare professionals to apply a palliative approach since the first level of care, detecting the patients' needs and enabling the referral to specialized teams for a more specific management when this is necessary (Figure 2).

The early implementation PC model has shown to be beneficial in oncological patients. (15) However, no objective evidence analyzing the impact of PC onset since diagnosis in HF patients has been found, since most studies include patients in advanced stages of the disease. Currently, the randomized, controlled, prospective, open-label, multicenter Early Palliative Care in Heart Failure Trial is being developed, including 200 HF patients with preserved or impaired left ventricular ejection fraction in NYHA FC ≥2. Participants have been randomly assigned to receive standard care by specialized cardiologists or by these physicians associated with PC. The primary outcome will evaluate quality of life at 12 months. (39) The conclusions of this work could provide the necessary impulse to overcome the current challenges related with the limited use of PC and allow a greater application from early stages in patients with HF.

FINAL REFLECTION

Heart failure is a complex and with increasing prevalence disease, which causes progressive functional capacity impairment and elevated associated morbidity and mortality. The existent analogy with oncological patients when evaluating the high symptom burden and the benefits demonstrated by PC carried out since the early stages of the disease invite to consider a paradigmatic change in the care of HF patients.

The progressive implementation of PC since diagnosis and as part of a multidisciplinary management of HF from the first moment has the main purpose of detecting and contributing to the specific needs of each patient, optimizing his/her quality of life, while maintaining an active treatment of the disease. As it progresses and the therapeutic options are exhausted, an adequate and fluid communication is essential to establish a plan of individualized care oriented to the patient and his/her environment preferences, which guarantees autonomy and tries to avoid futile actions that only prolong agony and suffering.

Conflicts of interest

None declared.

(See authors' conflict of interests forms on the web).

Financing

None.

REFERENCES

1. Lippi G, Sanchis-Gomar F. Global epidemiology and future trends of heart failure. AME Med J 2020;5:15-15. https://doi.org/10.21037/amj.2020.03.03

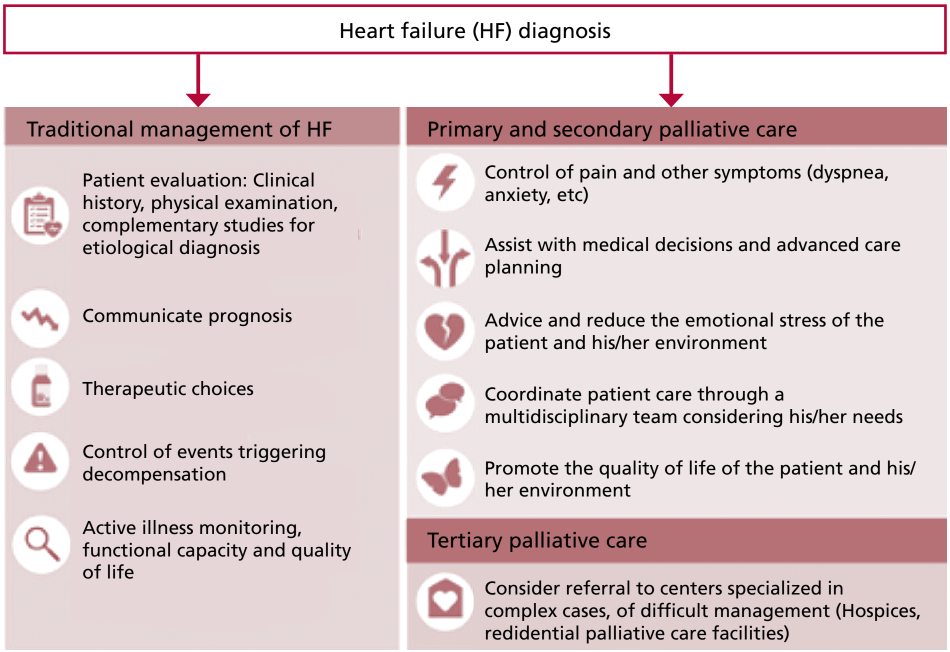

Fig. 2. Integrative care model with the palliative care, at different levels, in the active treatment of heart failure. From the early diagnosis of the disease, a continuum is established between the heart failure specialist with the comfort provided from palliative care specialist, while therapeutic goals are achieved and future planning is done.

2. Virani SS, Alonso A, Aparicio HJ, Benjamin EJ, Bittencourt MS, Callaway CW, et al. Heart disease and stroke statistics-2021 update: A report from the American Heart Association: A report from the American Heart Association. Circulation 2021;143:254-743. https://doi.org/10.1161/CIR.0000000000000950

3. Van Deursen VM, Urso R, Laroche C, Damman K, Dahlström U, Tavazzi L, et al. Co-morbidities in patients with heart failure: an analysis of the European Heart Failure Pilot Survey: Co-morbidities in heart failure. Eur J Heart Fail 2014;16:103-11. https://doi.org/10.1002/ejhf.30

4. Jones NR, Roalfe AK, Adoki I, Hobbs FD, Taylor CJ. Survival of patients with chronic heart failure in the community: a systematic review and meta-analysis. Eur J Heart Fail 2019;21:1306-25. https://doi.org/10.1002/ejhf.1594

5. Roger VL. Epidemiology of heart failure. Circ Res 2013;113:646-59. https://doi.org/10.1161/CIRCRESAHA.113.300268

6. Jaarsma T, Johansson P, Agren S, Strömberg A. Quality of life and symptoms of depression in advanced heart failure patients and their partners. Curr Opin Support Palliat Care 2010;4:233-7. https://doi.org/10.1097/SPC.0b013e328340744d

7. Bekelman DB, Rumsfeld JS, Havranek EP, Yamashita TE, Hutt E, Gottlieb SH, et al. Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. J Gen Intern Med 2009;24:592-8. https://doi.org/10.1007/s11606-009-0931-y

8. Evangelista LS, Sackett E, Dracup K. Pain and heart failure: unrecognized and untreated. Eur J Cardiovasc Nurs. 2019;8:169-73. https://doi.org/10.1016/j.ejcnurse.2008.11.003

9. World Health Organization. WHO definition of Palliative Care. 2020. https://www.who.int/es/news-room/fact-sheets/detail/palliative-care

10. Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD, Arnold RM, et al. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation 2012;125:1928-52. https://doi.org/10.1161/CIR.0b013e31824f2173

11. Connor SR, Sepulveda Bermedo MC, Baxter S, Beckwith SK, Clark D, Cleary J, et al. Global Atlas of Palliative Care. Second Edition. 2020.

12. Mounsey L, Ferres M, Eastman P. Palliative care for the patient without cancer. Aust J Gen Pract 2018;47:765-9. https://doi.org/10.31128/AJGP-07-18-4625

13. Lynn J, Admason DM. Living well at the end of life: adapting health care to serious chronic illness in old age. WHO Regional Office for Europe 2004.serious chronic illness in old age. WHO Regional Office for Europe 2004. https://doi.org/10.7249/WP137

14. Kavalieratos D, Corbelli J, Zhang D, Dionne Odom JN, Ernecoff NC, Hanmer J, et al. Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. J Am Med Assoc. 2016;316:2104-14. https://doi.org/10.1001/jama.2016.16840

15. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. Ann Palliat Med 2015;4:99-121.

16. Herrera Molina E, Rocafort Gil J, Cuervo Pinna MA, Redondo Moralod MJ. Primer nivel asistencial en cuidados paliativos: evolución del contenido de la cartera de servicios de atención primaria y criterios de derivación al nivel de soporte. Atencion Primaria. 2016;38:85-92. https://doi.org/10.1157/13094780

17. Von Gunten C.F. Secondary and tertiary palliative care in US hospitals. J Am Med Assoc 2002;287:875-81. https://doi.org/10.1001/jama.287.7.875

18. International Association for Hospice and Palliative Care, Worldwide Palliative Care Alliance: Joint declaration and statement of commitment on palliative care and pain treatment as human rights. J Pain Palliat Care Pharmacother 2008;22:300-2. https://doi.org/10.1080/15360280802537274

19. Brännström M, Boman K. Effects of person-centred and integrated chronic heart failure and palliative home care. PREFER: a randomized controlled study: PREFER: a randomized controlled study. Eur J Heart Fail 2014;16:1142-51. https://doi.org/10.1002/ejhf.151

20. Wong FK, Ng AY, Lee PH, Lam PT, Ng JS, Ng NH, et al. Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. Heart (British Cardiac Society). 2016;102:1100-8. https://doi.org/10.1136/heartjnl-2015-308638

21. Rogers JG, Patel CB, Mentz RJ, Granger BB, Steinhauser KE, Fiuzat M, et al. Palliative care in heart failure. J Am Coll Cardiol 2017;70:331-41. https://doi.org/10.1016/j.jacc.2017.05.030

22. Sahlollbey N, Lee C.K.s, Shirin A, 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;22:2340-6. https://doi.org/10.1002/ejhf.1783

23. McDonagh TA, Metra M, Adamo M, Gardner RS, Baumbach A, Böhm M, et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. Eur Heart J. 2021;42:3599-726. https://doi.org/10.1093/eurheartj/ehab368

24. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey D Jr, Drazner MH, et al. ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. J Am Coll Cardiol. 2013;62:147-239. https://doi.org/10.1016/j.jacc.2013.05.019

25. Warraich HJ, Wolf SP, Mentz RJ, Rogers JG, Samsa G, Kamal AH. Characteristics and trends among patients with cardiovascular disease referred to Palliative Care. JAMA Network Open. 2019;2:192-375. https://doi.org/10.1001/jamanetworkopen.2019.2375

26. Bakitas M, MacMartin M, Trzepkowski K, Robert A, Jackson L, Brown J.R, et al. Palliative care consultations for heart failure patients: How many, when, and why? J Cardiac Fail. 2013;19:193-201. https://doi.org/10.1016/j.cardfail.2013.01.011

27. Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, et al. Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. J Am Heart Assoc 2014;3: e000544. https://doi.org/10.1161/JAHA.113.000544

28. Zimmermann C, Wong JL, Swami N, Pope A, Cheng Y, Mathews J, et al. Public knowledge and attitudes concerning palliative care. BMJ Support Palliat Care. 2021;0:1-11. https://doi.org/10.2139/ssrn.3802496

29. Pieters J, Dolmans DH, Verstegen DM, Warmenhoven FC, Courtens AM, Van den Beuken Van Everdingen MH. Palliative care education in the undergraduate medical curricula: students' views on the importance of, their confidence in, and knowledge of palliative care. BMC Support Palliat Care 2019;18:72. https://doi.org/10.1186/s12904-019-0458-x

30. Dunlay SM, Foxen JL, Cole T, Feely MA, Loth AR, Strand JJ, et al . A survey of clinician attitudes and self-reported practices regarding end-of-life care in heart failure. Palliat Med 2015;29:260-7. https://doi.org/10.1177/0269216314556565

31. Schallmo MK, Dudley Brown S, Davidson PM. Healthcare providers' perceived communication barriers to offering palliative care to patients with heart failure: An integrative review: An integrative review. J Cardiovasc Nurs 2019;34:9-18. https://doi.org/10.1097/JCN.0000000000000556

32. Seymour J, Gott M, Bellamy G, Ahmedzai SH, Clark D. Planning for the end of life. Soc Sci Med.2005;59:57-68. https://doi.org/10.1016/j.socscimed.2003.10.005

33. Belli LF. El debate en torno a la validez de las directivas anticipadas en salud. Persona y Bioetica 2014;18:213-25. https://doi.org/10.5294/pebi.2014.18.2.10

34. Chen JL, Sosnov J, Lessard D, Goldberg RJ. Impact of do-not-resuscitation orders on quality of care performance measures in patients hospitalized with acute heart failure. Am Heart J. 2008;156:78-84. https://doi.org/10.1016/j.ahj.2008.01.030

35. Chang YK, Kaplan H, Geng Y, Mo L, Philip J, Collins A, et al. Referral criteria to palliative care for patients with heart failure: A systematic review: A systematic review. Circulation. Heart Fail. 2020;13:e006881. https://doi.org/10.1161/CIRCHEARTFAILURE.120.006881

36. Goda A, Williams P, Mancini D, Lund LH. Selecting patients for heart transplantation: comparison of the Heart Failure Survival Score (HFSS) and the Seattle heart failure model (SHFM). J Heart Lung Transplant 2011;30:1236-43. https://doi.org/10.1016/j.healun.2011.05.012

37. Straw S, Byrom R, Gierula J, Paton MF, Koshy A, Cubbon R, et al. Predicting one-year mortality in heart failure using the "Surprise Question": a prospective pilot study. Eur J Heart Fail

2019;21:227-34. https://doi.org/10.1002/ejhf.1353
38. Hill L, Prager Geller T, Baruah R, Beattie JM, Boyne J, De Stoutz N, et al. Integration of a palliative approach into heart failure care: a European Society of Cardiology Heart Failure Association position paper. Eur J Heart Fail. 2020;22:2327-39. https://doi.org/10.1002/ejhf.1994
39. Becher MU, Balata M, Hesse M, Draht F, Zachoval C, Weltermann B, et al. Rationale and design of the EPCHF trial: the early palliative care in heart failure trial (EPCHF). Clin Res Cardiol 2021;9:1-9. https://doi.org/10.1007/s00392-021-01903-1