Published in final edited form as:

Am J Hosp Palliat Care. 2016 December ; 33(10): 924–928. doi:10.1177/1049909115603689.

Availability of Heart Failure Medications in Hospice Care

Hillary D. Lum, MD, PhD^{1,2}, Carolyn Horney, MD¹, David Koets, MD³, Jean S. Kutner, MD, MSPH¹, and Daniel D. Matlock, MD, MPH^{1,2}

¹University of Colorado School of Medicine, Department of Medicine, Aurora, CO, USA

²Veterans Affairs Eastern Colorado Health Care System, Denver, CO, USA

³The Denver Hospice, Denver, CO, USA

Abstract

Background—Availability of cardiac medications in hospice for acute symptom management of heart failure is unknown. This study explored hospice approaches to cardiac medications for patients with heart failure.

Methods—Descriptive study using a quantitative survey of 46 US hospice agencies and clinician interviews.

Results—Of 31 hospices that provided standard home medication kits for acute symptom management, only 1 provided medication with cardiac indications (oral furosemide). Only 22% of the hospice agencies had a specific cardiac medication kit. Just over half (57%) of the agencies could provide intravenous inotropic therapy, often in multiple hospice settings. Clinicians described an individualized approach to cardiac medications for patients with heart failure.

Conclusion—This study highlights opportunities for practice guidelines that inform medical therapy for hospice patients with heart failure.

Keywords

hospices; terminal care; cardiac failure; medications; inotropes

Introduction

Heart failure (HF) is a common cause of death, and mortality rates are high within 1 year of diagnosis or HF-related hospitalization.^{1–3} The use of hospice by patients with HF is increasing.⁴ At end of life, patients with HF experience a high symptom burden.^{5–7} Traditionally, patients with an HF exacerbation in hospice may receive non-disease-specific medications such as opioids, anxiolytics, antipsychotics, or scopolamine for symptoms such

Reprints and permission: sagepub.com/journalsPermissions.nav

Corresponding Author: Hillary D. Lum, MD, PhD, Division of Geriatric Medicine, Department of Medicine, University of Colorado School of Medicine, 12631 E. 17th Ave B-179, Aurora, CO 80045, USA. hillary.lum@ucdenver.edu

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supplemental Material

The online appendices are available at <http://ajhpm.sagepub.com/supplemental>

as dyspnea, chest pain, or nausea.⁷ These medications are frequently available to patients as part of a “standard home medication kit.” Cardiac medications such as diuretics, angiotensin-converting enzyme (ACE) inhibitors, beta-blockers, nitrates, digoxin, and inotropic medications may provide HF-specific symptom control but are often absent from typical hospice symptom management protocols.^{7–9} The American College of Cardiology (ACC)/American Heart Association (AHA) recommends consideration of intravenous (IV) inotrope treatment for palliation of symptoms, however, hospices face challenges (ie, high cost and lack of expertise) to using IV inotropes.^{10–12} Benefits of intermittent or continuous subcutaneous infusion of furosemide for patients with HF have also been shown.^{9,13,14} Cardiac medications can be beneficial and safe for managing HF exacerbations and improving burdensome symptoms, yet there are no practice guidelines for integrating an HF-specific medication regimen with a hospice care plan.^{10,15}

Although the American College of Cardiology/American Heart Association guidelines recommend the use of cardiac medications to palliate symptoms in HF, it is unknown whether hospices routinely provide cardiac medications. This study explores the availability of medications to assist with acute HF-related symptom management in the hospice setting. We also explored contemporary hospice clinician approaches to medical therapy for patients with HF.

Methods

Design

We conducted quantitative surveys of hospice agencies and qualitative interviews with hospice clinicians to form a contemporary understanding of HF-specific medical therapies, including home medications and inotropic therapies. Using mixed methods, qualitative and quantitative data were collected concurrently, and the results were integrated.¹⁶ The University of Colorado Institutional Review Board approved this study.

Participants

Hospice clinicians (eg, physician, nurse practitioner, or nurse) were contacted through the national Population-based Palliative Care Research Network (PoPCRN).¹⁷ From a database of 250 hospice/palliative care organizations, we surveyed 100 hospice agencies with a clinician (physician or nurse) as the primary contact. Hospice clinicians volunteered to be interviewed, and informed consent was obtained. Survey recipients were informed of the study purpose and voluntarily returned the survey, implying consent.

Survey

We created a novel survey instrument based on clinical experience, literature review, consultation with cardiologists and hospice/palliative medicine specialists, and input from staff of The Denver Hospice, a not-for-profit community-academic partner. A brief 17-item survey was created based on feedback from the PoPCRN Scientific Advisory Committee (Supplemental Appendix 1). Survey items focused on (1) “standard home medication kit” and/or “cardiac medication kit,” including medication types; (2) inotropic therapy, including availability, type, estimated number of patients treated, and barriers to inotropic therapy; and

(3) hospice characteristics (eg, type of agency, ownership [not for profit vs for profit vs government], and average daily census). Type of agency included independent hospice, part of a hospital system, part of a home health agency, or part of a nursing home. We used a multistep mailing process based on the Dillman Tailored Design Method, with up to 4 mailings to maximize response rates.¹⁸ Surveys were returned by mail, fax, or e-mail.

Interviews

We conducted in-depth, semistructured interviews using open-ended questions to explore hospice clinicians' perspectives on available cardiac therapies in the hospice setting (Supplemental Appendix 2). Interviewees were selected through purposeful sampling to provide a range of hospice agency type and regional perspectives. Thematic saturation was achieved after 13 interviews.

Data Analysis

Quantitative survey data were analyzed using standard frequency analyses. Interviews were recorded, and quotes were transcribed based on interviewer notes. Data analysis focused on systematic organization of quantitative data and integration of qualitative data related to medication availability and clinical usage.¹⁶ Qualitative data were used to provide a deeper understanding of the quantitative findings. As a team, we reached consensus on identified findings and their meanings. To contextualize the findings, we solicited input on the analysis, interpretation, and potential implications from The Denver Hospice (community partner), an academic palliative medicine group, and the Colorado Cardiovascular Outcomes Research Consortium (cardiologists from multiple institutions).

Results

Participants

Forty-six clinicians from the 100 PoPCRN hospice agencies responded to the survey. Table 1 shows the characteristics of hospice agency. Most hospices were independent (65%) and not for profit (83%). The mean average daily census was 279 patients. Eleven (24%) agencies reported that less than 10% of the daily census had a primary or hospice-qualifying diagnosis of HF, 27 (59%) agencies had between 10% and 20% with an HF diagnosis, and 8 (17%) agencies had more than 20%. Interviews were completed with 13 hospice clinicians, including 6 physicians, 6 nurses, and 1 nurse practitioner, representing the US Midwest, West, South, and East.

Use and Perspectives on Cardiac Medications in Hospice

Respondents described limited routine availability of HF-specific medications in hospice. Sixty-seven percent of the hospice agencies prescribed standard home medication kits to allow patients and families to rapidly address uncontrolled symptoms. Only 1 hospice agency routinely provided furosemide as an oral diuretic in the standard home medication kit. No other medications with cardiac indications were reported to be routinely provided. A "cardiac medication kit" for home management of cardiac-related symptoms was only available from 22% (10 of the 46) of the hospices. Nearly all cardiac medication kits included oral diuretics (90%), nitrates (90%), and aspirin (80%). Sixty percent of the

hospices reported IV diuretics (which may have included option for subcutaneous administration).

There was limited use of inotropic therapy (Table 2). Fifty-seven percent of the hospices provided inotropes. Of those, 80% were independent hospices, that is, not part of a hospital, home health agency, or nursing home. Most hospices (17 of 26) had treated between 1 and 10 patients the prior year. One hospice reported treating more than 20 patients with inotropes. Inotropic therapy was provided by hospices in multiple settings, including home (24 of 26), hospital (25 of 26), hospice facility (15 of 26), and nursing facilities (11 of 26). Cost (69%) and lack of proven efficacy to relieve symptoms (57%) were common barriers to inotropic therapy.

In the absence of specific guidelines for cardiac medications in hospice care for patients with HF, hospice clinicians discussed an individualized approach to cardiac medications, including inotropes (Table 3). They described the importance of education and collaboration with the patient regarding decisions about cardiac medications. Clinicians emphasized using an individualized approach to maintaining, changing, or discontinuing cardiac medications to support patient preferences.

Discussion

This study explored contemporary approaches to cardiac medications for HF-related acute symptom management in hospice. We found that cardiac-specific medications are not commonly available in the standard home medication kits of hospices in this study. Some hospices in this sample tailored care for patients by providing cardiac medication kits and inotropic therapy. Given the absence of evidence-based clinical guidelines, this study reflects challenges that hospice clinicians face in providing symptom management for hospice patients with HF at the end of life.

This preliminary study describes a limited routine provision of cardiac medications in standard home medication kits for uncontrolled symptoms. The limited availability of cardiac medications was first demonstrated in a 2005 survey of 22 New Hampshire hospices that described home medication kits for uncontrolled symptoms.¹⁹ Our study extends those findings by identifying some hospices agencies that provided cardiac-specific medication kits. Similarly, although the challenges of providing inotropic therapy in hospice have been reported previously,^{11,12} this study demonstrates that once a hospice incorporated inotropic therapy into their arsenal of services for patients, these medications were provided in multiple care settings.

Other studies have demonstrated the high prevalence of symptoms among patients with HF in hospice care.^{2,4} There is a need for prospective clinical trials that target symptom management among hospice patients with HF, similar to studies conducted among hospice patients with cancer.^{5,7,20} Future work should also examine cardiac-related medications that were prescribed and provided by hospices for ongoing HF management and symptom control during a patient's hospice enrollment, beyond emergency medication kits and inotropes. One explanation for the very limited finding of cardiac-related medications in

standard home medication kits may be that medications such as diuretics or nitrates were already prescribed and supplied separate from an emergency kit.

This study suggests the need for prospective evidence regarding optimal medication strategies for symptom palliation and appropriate situations to discontinue medications for patients with HF who are receiving hospice care. For instance, it may be appropriate to continue disease-modifying cardiac medications such as ACE inhibitors and beta blockers, however, there are no data to guide clinical practice in the hospice setting. As HF progresses and the patient's primary goals are symptom relief and maximizing quality of life, it may be appropriate to reduce the doses or discontinue cardiac medications. Clinicians must pay close attention to whether cardiac medications are causing adverse effects or contributing to impaired quality of life (eg, due to polypharmacy, falls, fatigue, etc).¹⁵ Our data suggest that hospice clinicians rely on an individualized approach. The creation of guidelines for a cohesive strategy to manage medications for patients with HF would provide additional tools for making therapeutic decisions.

This preliminary study has limitations. First, the findings are based on the knowledge of individual hospice clinicians who completed the survey or who served as key informants through interviews and is not designed to be generalizable. Second, this study focused on the perspectives of hospice clinicians, and although the response rate was low, it is similar to other studies involving clinicians and end-of-life care.²¹ With increasingly complex Medicare hospice regulations for medication availability and coverage, as outlined in the Hospice Wage Index, future studies should assess the prevalence of baseline or chronic cardiac medication usage in hospice care.²² Although this study focused on acute symptom management via home medication kits (including standard or cardiac medication kits) and inotropes, more information is needed about the overall availability and use of cardiac medications to treat HF-related symptoms when HF is the terminal diagnosis or a related condition that contributes to the terminal prognosis and warrants active symptom management to maximize comfort and quality of life. Finally, a larger environmental scan exploring the characteristics of hospice agencies that facilitate better end-of-life care for patients with HF would further inform this discussion.

In conclusion, this study describes contemporary hospice practices and challenges faced by hospice clinicians, as they seek to provide patient-centered care to patients with HF. The finding of limited routine availability of cardiac medications for acute symptom management in hospice care, within the hospice agencies surveyed, highlights the opportunities to improve HF-specific, end-of-life care. Further work, including research and quality improvement efforts by hospices, should focus on increasing appropriate usage of cardiac-specific medications for symptomatic relief in HF. Development of multisociety-endorsed guidelines for managing HF at the end of life would promote broader use of appropriate medications for symptom relief.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors would like to thank Dr Margy Nevriy for conducting the semistructured interviews and assisting with the data analysis. They appreciate the expert input and review of study design, data collection tools, data analysis, and interpretation by members of The Denver Hospice/University of Colorado community-academic partnership. They also acknowledge members of the University of Colorado Program in Palliative Care and members of the Colorado Cardiovascular Outcomes Research Consortium for their thoughtful critique of the thematic results. Finally, the authors thank Julia Woodward for research assistance related to survey distribution and data entry.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by a career development award from the National Institutes on Aging (K23AG040696).

References

1. Lloyd-Jones D, Adams R, Carnethon M, et al. Heart disease and stroke statistics—2009 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation*. 2009; 119(3):e21–e181. [PubMed: 19075105]
2. Curtis LH, Whellan DJ, Hammill BG, et al. Incidence and prevalence of heart failure in elderly persons, 1994–2003. *Arch Intern Med*. 2008; 168(4):418–424. [PubMed: 18299498]
3. Curtis LH, Greiner MA, Hammill BG, et al. Early and long-term outcomes of heart failure in elderly persons, 2001–2005. *Arch Intern Med*. 2008; 168(22):2481–2488. [PubMed: 19064833]
4. Unroe KT, Greiner MA, Hernandez AF, et al. Resource use in the last 6 months of life among medicare beneficiaries with heart failure, 2000–2007. *Arch Intern Med*. 2011; 171(3):196–203. [PubMed: 20937916]
5. Wilson J, McMillan S. Symptoms experienced by heart failure patients in hospice care. *J Hosp Palliat Nurs*. 2013; 15(1):13–21. [PubMed: 23853525]
6. Walke LM, Gallo WT, Tinetti ME, Fried TR. The burden of symptoms among community-dwelling older persons with advanced chronic disease. *Arch Intern Med*. 2004; 164(21):2321–2324. [PubMed: 15557410]
7. Zambroski CH, Moser DK, Roser LP, Heo S, Chung ML. Patients with heart failure who die in hospice. *Am Heart J*. 2005; 149(3):558–564. [PubMed: 15864247]
8. Stuart B. Palliative care and hospice in advanced heart failure. *J Palliat Med*. 2007; 10(1):210–228. [PubMed: 17298270]
9. Gadoud A, Jenkins SM, Hogg KJ. Palliative care for people with heart failure: summary of current evidence and future direction. *Palliat Med*. 2013; 27(9):822–828. [PubMed: 23838375]
10. Hunt SA, Abraham WT, Chin MH, et al. ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure): developed in collaboration with the American College of Chest Physicians and the International Society for Heart and Lung Transplantation: endorsed by the Heart Rhythm Society. *Circulation*. 2005; 112(12):e154–e235. [PubMed: 16160202]
11. Goodlin SJ, Kutner JS, Connor SR, Ryndes T, Houser J, Hauptman PJ. Hospice care for heart failure patients. *J Pain Symptom Manage*. 2005; 29(5):525–528. [PubMed: 15904755]
12. Lyons MG, Carey L. Parenteral inotropic therapy in the home: an update for home care and hospice. *Home Healthc Nurs*. 2013; 31(4):190–206.
13. Beattie JM, Johnson MJ. Subcutaneous furosemide in advanced heart failure: has clinical practice run ahead of the evidence base? *BMJ Support Palliat Care*. 2012; 2(1):5–6.
14. Zacharias H, Raw J, Nunn A, Parsons S, Johnson M. Is there a role for subcutaneous furosemide in the community and hospice management of end-stage heart failure? *Palliat Med*. 2011; 25(6):658–663. [PubMed: 21398345]
15. Goodlin SJ, Hauptman PJ, Arnold R, et al. Consensus statement: palliative and supportive care in advanced heart failure. *J Card Fail*. 2004; 10(3):200–209. [PubMed: 15190529]

16. Zhang W, Creswell J. The use of “mixing” procedure of mixed methods in health services research. *Med Care*. 2013; 51(8):e51–e57. [PubMed: 23860333]
17. Kutner JS, Main DS, Westfall JM, Pace W. The practice-based research network as a model for end-of-life care research: challenges and opportunities. *Cancer Control*. 2005; 12(3):186–195. [PubMed: 16062166]
18. Dillman, D. *Mail and Internet Surveys: The Tailored Design Method*. 2. Hoboken, NJ: John Wiley & Sons; 2007.
19. Bishop MF, Stephens L, Goodrich M, Byock I. Medication kits for managing symptomatic emergencies in the home: a survey of common hospice practice. *J Palliat Med*. 2009; 12(1):37–44. [PubMed: 19284261]
20. Bruera E, Hui D, Dalal S, et al. Parenteral hydration in patients with advanced cancer: a multicenter, double-blind, placebo-controlled randomized trial. *J Clin Oncol*. 2013; 31(1):111–118. [PubMed: 23169523]
21. Goldstein N, Carlson M, Livote E, Kutner JS. Brief communication: management of implantable cardioverter-defibrillators in hospice: a nationwide survey. *Ann Intern Med*. 2010; 152(5):296–299. [PubMed: 20194235]
22. Hospice—Centers for Medicare & Medicaid Services. [Accessed March 1, 2015] Web site. <http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/index.html>

Table 1**Hospice Agency Characteristics.**

Characteristic (n = 46)	N (%)
Hospice agency type	
Independent hospice	30 (65)
Part of a hospital system	8 (17)
Part of a home health agency	4 (9)
Part of a nursing home	1 (2)
Unknown	3 (7)
Ownership type	
Not for profit	38 (83)
For profit	6 (13)
Government	1 (2)
Unknown	1 (2)
Average daily census, patients	
100	18 (39)
101–200	6 (13)
201–300	7 (15)
301–400	4 (9)
401–500	3 (6)
501–1000	4 (9)
>1000	3 (6)
Unknown	1 (2)
Estimated percentage of census with heart failure as the hospice-qualifying diagnosis	
<10%	11 (24)
10%–20%	27 (59)
21%–30%	6 (13)
>30%	2 (4)

Table 2

Availability of Cardiac Medications.

	N (%)
Emergency medication kit available ^a (n = 46)	
Yes	31 (67)
Cardiac medication kit available ^a (n = 31)	
Yes	10 (22)
Medication included in the cardiac medication kit (n = 10)	
Oral diuretics	9 (90)
Intravenous diuretics	6 (60)
Nitrates	9 (90)
Aspirin	8 (80)
Beta blockers	2 (20)
Ability to provide inotropic therapy, n (%) ^b	
Any inotrope	26 (57)
Dobutamine	23 (50)
Milrinone	17 (37)
Patients treated with inotropic therapy in the past 1 year (n = 26)	
None	4 (15)
1–10 patients	16 (62)
11–20 patients	2 (8)
>20 patients	1 (4)
Unknown	3 (11)
Barriers to inotropic therapy ^c	
Cost	32 (69)
Lack of or difficulty with intravenous access	21 (45)
Lack of clinician knowledge	19 (41)
Lack of family caregiver support	22 (48)
Lack of proven efficacy to relieve symptoms	26 (57)

^aIn the home hospice setting.

^bIn any hospice setting.

^cResponse to the question, “To what extent is each of the following factors a barrier to the use of inotropic therapy by your hospice?” Includes “Extreme” and “Somewhat”; excludes “Minimally” and “Not at all.”

Table 3**Individualized and Careful Approach to Cardiac Medications.**

Patient-centered decision making	Sometimes with these very hopeful patients, having the medications is the only control they have left. So, we will work with that. We do not routinely stop medications without a lot of conversation. Until [patients self-discontinue medications], we do not have a situation in our program where someone comes in and says, "Okay you can't take any of your heart medications."
Education and collaboration	[Patients] are on such a regimen of drugs. It is hard to get them to give those up. To our estimation, we feel that they are not getting much benefit from them. To them, they have had a lot of really good clinicians who have entrenched in taking them. It is probably hardest to convince them that [the medications] have probably already done all they are going to do.
Support for inotropes	We will basically do anything in the arsenal . . . up through milrinone, your diuretics, your beta blockers—whatever a cardiologist believes to maintain quality of life.