

HHS Public Access

Author manuscript JACC Heart Fail. Author manuscript; available in PMC 2019 July 01.

Published in final edited form as:

JACC Heart Fail. 2019 July ; 7(7): 550–557. doi:10.1016/j.jchf.2019.01.010.

Factors Associated with Live Discharge of Heart Failure Patients from Hospice: A Multi-Method Study

David Russell, PhD^{1,2,†}, Dawon Baik, PhD, RN³, Lizeyka Jordan, MPH², Frances Dooley, MSN, RN-BC, ANP-BC, ACHPN, CDE⁴, Scott L. Hummel, MD, MS⁵, Holly G. Prigerson, PhD⁶, Kathryn H. Bowles, PhD, RN, FAAN^{2,7}, and Ruth Masterson Creber, PhD, MSc, RN⁸ ¹Department of Sociology, Appalachian State University

²Center for Home Care Policy & Research, Visiting Nurse Service of New York

³Columbia University, School of Nursing

⁴Hospice and Palliative Care, Visiting Nurse Service of New York

⁵University of Michigan and Ann Arbor Veterans Affairs Health System

⁶Weill Cornell Medicine Center for Research on End-of-Life Care

⁷University of Pennsylvania, School of Nursing

⁸Department of Healthcare Research & Policy, Division of Health Informatics, Weill Cornell Medicine

Abstract

Objective: To identify sociodemographic and clinical factors predicting live discharge among home hospice patients with heart failure, and relate these findings to perspectives among healthcare providers about challenges to caring for these patients.

Background: Hospice patients with heart failure are frequently discharged from hospice prior to death ("live discharge"). However, little is known about the factors and circumstances associated with live discharge among patients with heart failure.

Methods: Quantitative analyses of patient medical records (N=1,498) and qualitative interviews with healthcare providers (N=19) at a not-for-profit hospice agency in New York City.

Results: 30% of home hospice patients with heart failure experienced a live discharge, most frequently due to 911 calls that led to acute hospitalization. The odds of acute hospitalization were greater for younger (Age 18–74: [AOR]=2.10; 95% Confidence Interval [CI]=1.34–3.28), Black (AOR=2.06; CI=1.31–3.24) or Hispanic (AOR=2.99; CI=1.99–4.50), and higher-functioning patients (Palliative Performance Scores of 50–70%: AOR=5.68; CI=3.66–8.79). Qualitative interviews with healthcare providers highlighted the unique characteristics of heart failure (e.g., sudden changes in patients' condition), the importance of patients' understanding of hospice and

[†]<u>Corresponding Author:</u> David Russell, Department of Sociology, Appalachian State University, ASU Box 32115, Boone, NC 28608-2115, russelldj@appstate.edu.

their own prognosis, and the role of socio-cultural and family context in precipitating and potentially preventing live discharge (e.g., absence of social supports in the home).

Conclusions—Live discharge from hospice, especially due to acute hospitalization, is common with heart failure. Greater attention is needed to patients' knowledge of and readiness for hospice care, especially among younger and diverse populations, and to factors related to the social and family context in which hospice care is provided.

Abstract

Objective: To identify factors for live discharge from hospice in heart failure and perspectives among providers about caring for patients.

Methods: Quantitative analyses of patient medical records (N=1,498) and interviews with providers (N=19) at a not-for-profit hospice agency in New York City.

Results: 30% of hospice patients with heart failure experienced live discharge. Odds of live discharge were greater for racial/ethnic minorities, younger and higher-functioning patients. Interviews highlighted the unique characteristics of heart failure, importance of patient understanding and socio-cultural context.

Conclusions: Live discharge from hospice is common with heart failure. Greater attention is needed to assess patients' hospice readiness.

Keywords

Hospice Care; Heart Failure; Live Discharge; Qualitative Research; Multivariate Analysis

BACKGROUND

Advances in cardiovascular disease treatment have increased heart failure survival and palliative interventions have shown significant improvements for patient quality-of-life (1). While heart failure patients represent 15 percent of hospice deaths nationwide, compared with other diagnosis groups such patients are disproportionately likely to be discharged from hospice prior to death (i.e. "live discharge") due to acute hospitalization, elective revocation to resume disease-directed treatment, and loss of eligibility due to extended prognosis (2). Live discharge is problematic for several reasons. First, only a minority of discharged patients re-enroll in hospice, despite that most die within six months (3). Second, many discharges presage burdensome transitions between hospitals and other settings during the last days or weeks of life (4). These transitions are associated with poorer quality care and aggressive interventions (e.g., feeding tubes, intensive care) (5).

Hospices face challenges in caring for heart failure patients, including multiple comorbidities and extensive disability (6,7). These factors may increase live discharge risk when combined with minimal advance care planning or social support (8). However, little is known about factors for live discharge in heart failure patients. Additionally, few studies have examined challenges faced by hospice providers in keeping these patients supported at home. The aims of this multi-method study were to identify socio-demographic and clinical correlates of live discharge among hospice patients with heart failure, and explore provider perspectives on caring for this population.

METHODS

Design

This study utilized a multi-method approach in which both quantitative data (i.e. medical records) and qualitative data (i.e. interviews with hospice providers) were collected, analyzed, and presented. An underlying assumption of this approach is that our research question can be answered more comprehensively than by using a single method alone (9). Data were obtained from a non-profit hospice agency in New York City with an average daily census of 1,000 patients. The agency Institutional Review Board approved all study procedures.

Quantitative Data

Data on adult home hospice patients admitted and discharged between 2013 and 2017 were obtained by querying medical records. A total of 18,509 patients across all diagnoses were served during this period; the first period of hospice enrollment was examined for patients with multiple episodes. 1,553 patients (8.4%) had a primary diagnosis of heart failure. Approximately 2.7% (n=508) of the total patient population were missing data on one or more variables, including 3.5% (n=55) of heart failure patients. These cases were excluded, resulting in analytic samples of 18,001 patients across all diagnosis groups and 1,498 patients with heart failure. Several measures were identified, including discharge reason, sex, age, race/ethnicity, marital status, primary caregiver, healthcare proxy, and payer. Charlson comorbidity index scores were calculated based on the weights and codes updated by Quan and colleagues (10). Hospice referral source distinguished patients who came to hospice from hospital versus non-hospital settings. The Palliative Performance Scale (PPS) score at hospice enrollment was included as a measure of functional status (11). PPS scores ranged from 10% (bedbound, extensive disease) to 70% (reduced ambulation, significant disease), with higher scores indicating greater functioning (Supplemental Table 1).

Qualitative Data

Nineteen hospice providers were recruited for qualitative interviews between March and May 2018. Purposive sampling was used to select a diverse range of perspectives from hospice providers across region (Manhattan and the Bronx) and discipline (i.e., nursing, social work, medicine). Providers who attended Interdisciplinary Team Meetings on dates when our study team was present were invited to participate in interviews. The researchers explained the study purpose and obtained informed consent from interviewees. A semi-structured interview guide was developed to elicit information about heart failure patient experiences and circumstances that precipitated live discharge (List of Questions in Supplemental Materials). Interviews lasted approximately 30 minutes and were audio-recorded and transcribed verbatim. Interviewees received \$25 gift certificates for their time.

Data Analysis

Quantitative Data—R was used to perform all statistical analyses. Means and percentages were used to describe patient characteristics. A multinomial logistic regression model examined associations of socio-demographic and clinical characteristics with hospice

discharge reason: a discrete variable with five categories (Death, Acute Hospitalization, Elective Revocation, Disqualification, and Transfer). Death in hospice represented the reference category. The model was adjusted for gender, age, race/ethnicity, marital status, primary caregiver, healthcare proxy, payer, referral resource, PPS and Charlson scores at hospice enrollment. Separate analyses were conducted to examine residuals and goodness of fit. There was no evidence of collinearity or lack of model fit. A p-value of 0.05 represented the threshold for determining statistical significance.

Qualitative Data—Conventional content analysis methods were used to identify emerging categories and themes from the qualitative interviews. Four authors reviewed transcripts line-by-line, highlighting key phrases and concepts, and later meeting to compare codes. A final codebook was developed and applied to transcripts using Dedoose, a qualitative and mixed-methods research application (www.dedoose.com) (12). Inter-rater reliability was assessed for six frequently applied codes. Cohen's kappa statistic ranged from 0.77 to 0.88 across three coding pairs, suggesting good agreement.

RESULTS

Quantitative Data

TABLE 1 describes the hospice patients with heart failure in our study population. Most patients were female (56.7%), 85 years or older (63.4%), and white non-Hispanic (50.1%). However, the agency also served substantial minorities of Hispanics (24.1%), African Americans (18.0%), and Asians or patients with other race/ethnic backgrounds (7.9%). Most patients were not currently married (64.2%) and some patients lacked a primary caregiver (16.4%) or healthcare proxy (16.2%). Medicare Fee-for-Service represented the most frequent payer (61.1%). Most patients were referred to hospice from the hospital (55.1%). The largest group of patients had PPS scores between 10%-30%, indicating extensive disease and near-total care (39.9%).

TABLE 2 compared the distribution of hospice discharge reason among patients with heart failure to other diagnoses. The majority of patients with heart failure died in hospice (69.6%). The share of heart failure patients with live discharge (30.4%) was considerably higher than that for cancer (23.2%), dementia (23.1%), and stroke (17.9%). Perhaps due to similar patterns of prognostic uncertainty and symptom burden, the live discharge rate among patients with pulmonary disease (31.7%) was comparable to heart failure. The most frequent live discharge reason among patients with heart failure included revocations among patients who dialed 911 and were admitted to acute care hospitals (i.e. "Acute Hospitalization," 15.4% of patients). Acute Hospitalization often stemmed from 911 calls due to panic and anxiety associated with sudden uncontrolled symptom exacerbations, including shortness of breath and pain. The second leading reason for live discharge was elective revocations to resume disease-directed treatments without acute hospitalization (i.e. "Elective Revocation," 6.1%). Treatments that prompted Elective Revocation included pacemaker upgrades, insertions of Automatic Implantable Cardioverter Defibrillators or Left Ventricular Assist Devices, implantation of monitoring systems, and trial treatments. Additional reasons for live discharge included a loss of hospice eligibility due to extended

prognosis (*"Disqualification*, "4.8%) and moves out of the service area or to other hospice/ palliative settings (*"Transferred*, "4.1%). A notable trend was observed in live discharge across the study period. The percentage of heart failure patients with live discharge increased from 26.0% in 2013 to 33.6% in 2017. Much of this trend was attributable to an increase in the percentage with *Disqualification*, which rose from 1.9% of all patients in 2013 to 7.2% in 2017.

Associations of sociodemographic and clinical characteristics with live discharge reason were examined among heart failure patients (TABLE 3). The odds of Acute Hospitalization were greater among younger patients, including those ages 18 to 74 (Adjusted Odds Ratio [AOR]=2.10; 95% Confidence Interval [CI]=1.34–3.28) or 75 to 84 (AOR=1.79; CI=1.24– 2.62). Elevated risk of hospitalization was also observed among Hispanic (AOR=2.99; CI=1.99-4.50), African American (AOR=2.06; CI=1.31-3.24), and Asian/other patients (AOR=1.96; CI=1.08–3.57) compared to white patients. Higher PPS scores at hospice enrollment were associated with greater odds of hospitalization (PPS scores of 50-70%: AOR=5.68; CI=3.66-8.79). Risk for *Elective Revocation* was greater among those age 75 to 84 (AOR=1.99; CI=1.18–3.38), patients without a primary caregiver (AOR=2.08; CI=1.25– 3.48), and patients with PPS scores of 50-70% (AOR=3.77; CI=2.14-6.64) or 40% (AOR=1.85; CI=1.06-3.24). Risk for Disqualification was greater among Hispanic patients compared to white patients (AOR=2.32; CI=1.23-4.34), and for patients with PPS scores of 50-70% (AOR=4.90; CI=2.51-9.55) or 40% (AOR=2.57; CI=1.35-4.92). The odds of Transferring were greater among Hispanic (AOR=2.25; CI=1.10-4.62) and Asian/other patients (AOR=2.25; CI=1.04-6.18) compared to white patients. Increased risk for *Transferring* was also observed among those without a primary caregiver (AOR=1.98; CI=1.05-3.71), and for patients with PPS scores of 50-70% (AOR=5.49; CI=2.66-11.34) or 40% (AOR=2.53; CI=1.23-5.23).

Qualitative Data—Interviewees included 17 registered nurses, 1 social worker, and 1 physician. Interviewees were mostly female (78.9%), white (47.4%) or African American (31.6%), English-speaking (52.6%), and had an average age of 48.8 years (SD=12.3). The majority worked in hospice for five years or longer (57.9%; n=11). Three themes were identified: *Unique Characteristics, Understanding and Expectations of Hospice*, and *Socio-Cultural and Family Context*.

Unique Characteristics

Healthcare providers were aware that patients in hospice with heart failure are different from other diagnosis groups. Distinguishing features included the disease process itself— described as a "*long road*" with many "*peaks and valleys*." Patients with heart failure typically enrolled in hospice following a series of hospitalizations and emergency room visits. One interviewee described how patients with heart failure "*are so used to getting sick and they get better...sick...better.*" Rapid, sudden, and dramatic changes in patients" conditions were described by providers, including sudden symptom exacerbations (e.g. "*the symptoms could set on...it*'s so sudden") and changes in physical functioning (e.g. "*I could see that he had declined a lot from one time to the next*"). In addition to these distinguishing features, patients with heart failure were also described as having a "*different symptomology*".

and different management of symptoms. "Providers identified several common characteristics among heart failure patients including comorbid conditions (e.g., renal failure, pulmonary disease), medical devices (e.g., pacemakers, defibrillators), and complex medication regimens (e.g., diuretics, inotropes). Patients with heart failure were also described as having certain signs and symptoms that distinguished them from other diagnosis groups like cancer or dementia, and which often represented the focus of hospice providers' care management and educational interventions. These signs and symptoms included weight gain, edema and fluid retention, respiratory distress, weakness, pain, and anxiety (i.e. often as a consequence of distressing symptoms).

Understanding and Expectations of Hospice

Patients arrive to hospice with varying expectations, understanding, and acceptance about their condition. Providers spoke of patients and families who "come into hospice not having any idea what it's about," "don't understand the whole prognosis," are "expecting a miracle," and "use hospice to get the service that they need," without acknowledging that they "are at the end." Limited understanding of "the hospice concept" and "resistance" to educational interventions by hospice nurses were described as barriers to keeping patients continuously enrolled in hospice, especially in cases where patients held perceptions that "if they call 911 and they go to the hospital...they feel that if they hear it from the hospital or doctor there, that's different." Clinicians spoke of educating patients and managing their expectations about what services to expect through hospice. Some patients and families were described as being "pro-hospice" while others were described as harboring views that "hospice is not doing anything." Providers also described needing to manage expectations among patients that nurses and other staff will "be there 24/7 [all the time]."

Providers spoke of identifying patients with greater readiness for home hospice: "*They had the life they had. They are happy...and quite peaceful about it.*" In contrast, patients with less readiness for hospice often lacked advanced directives or had unrealistic expectations about medical interventions at the end-of-life (e.g. cardiopulmonary resuscitation).

Socio-Cultural and Family Context

Hospice providers spoke about the *Socio-Cultural and Family Context* in which patients receive care. Socioeconomic background, culture, religion, social support, language, and family dynamics were all cited as important factors influencing the course and outcomes of hospice. Educational attainment was mentioned as influencing patients' knowledge and readiness for hospice. Financial resources were identified as enabling patients and families to secure needed private care and other assistance; those without such resources were described as "*struggling to put something together.*" Cultural concepts were also highlighted as affecting the patient experience. One concept included the *"hero*," which was invoked to describe patients who *"don't want to die"* and associate aggressive measures, including hospitalization, with *"reassurance"* that they are taking every possible action to prolong life. Language barriers were mentioned as posing obstacles to educational interventions, especially where providers were reliant on interpreters to communicate with patients and caregivers.

A related subtheme was Distress and Panic, which included descriptions of caregivers who expressed anxiety or a "state of panic" towards uncontrolled symptoms, hesitancy to administer treatments perceived as hastening death, and vigilance about providing every opportunity to prolong life. Some providers linked these situations to views among patients and/or caregivers that the hospital is "where you go when you're sick" and is a place that provides them with "every opportunity to live." Distressing circumstances faced by hospice patients often presented dilemmas for caregivers, some of whom were aware of their loved one's preferences to die at home, but nevertheless felt unprepared or uncomfortable keeping patients at home when difficult-to-manage symptoms arose. Panic was described as being dependent on the level of trust between family members and the hospice team, including whether a connection was made with team members that met their needs. Social support was viewed by hospice providers as an important aspect of Socio-Cultural and Family Context that helped to keep patients comfortable at home. Heart failure was viewed by providers as a disease that produces "a lot of emotional and physical distress" for both patients and caregivers. Hospice providers felt that patients who experienced distressing symptoms in the absence of social supports were left with few options other than calling 911 ("Most people that call [911] don't have any support at home. They live alone. Not being able to breathe and live alone, have no one to call...right?'). The presence of nurses, family members, and aides were described as providing emotional support to patients that helped maintain their comfort at home.

DISCUSSION

Findings from this multi-method study highlighted several characteristics and features that shape the experience of hospice patients with heart failure and affect their risk for live discharge. Quantitative analyses revealed that three of every 10 patients with heart failure experience live discharge, most frequently because of 911 calls that precipitate hospitalization. Our study builds upon prior research indicating that hospice patients with heart failure have significantly higher risk of live discharge compared to other diseases such as cancer (2). We also found a greater odds of live discharge due to acute hospitalization among younger compared to older patients, African Americans and Hispanics compared to non-Hispanic whites, and patients with higher versus lower functioning at hospice enrollment. Racial/ethnic disparities in live discharge risk may be driven by several factors. Mistrust of healthcare providers represents a significant barrier to care among African Americans (13). Additionally, research suggests that caregivers of black and Hispanic hospice patients differ from their white counterparts on measures of perceived healthcare quality, including their ratings of emotional and religious support received from hospice providers (14,15). Efforts to improve cultural competency among hospice providers may be key to reducing racial/ethnic disparities in hospitalization and other end-of-life medical interventions such as receipt of cardiopulmonary resuscitation, mechanical ventilation, and intensive care (16).

Qualitative interviews with providers garnered insights into the circumstances and contexts that influence how patients with heart failure experience hospice. Several barriers to caring for these patients were identified, including patient-provider language discordance, limited knowledge of hospice, and cultural preferences for life-sustaining measures and hospital-

based care. Hospice providers spoke frequently of the unique features of heart failure, including rapid changes in patients' conditions, distressing symptoms (e.g., shortness of breath, swelling, and fatigue) that generate panic and anxiety among caregivers, and complex medication regimens. Healthcare providers are tasked with helping patients manage these symptoms as well as cope with lapses in patient-provider communication, limited understanding about their disease, and inaccurate prognostication (17). Hospice providers are often surprised themselves by the sudden declines and distressing symptoms experienced by patients with heart failure—circumstances that provide a limited window of opportunity for intervention to prevent hospitalization. The absence of accurate prognosis estimates also blur the clinical lens through which hospice providers view their intervention efforts among patients with heart failure. Indeed, we observed increases across our study period in the number of patients with heart failure who lost hospice eligibility due to extended prognosis. This increase in disqualification could be reflective of: 1) challenges that cardiologists face in accurately determining patient prognosis and making timely hospice referrals; and 2) improvements in disease management and quality of life associated with hospice services. The PPS may represent a useful tool for estimating hospice survival in heart failure patients (18). Our results suggest that higher-functioning heart failure patients enrolled in hospice with PPS scores of 50-60% have more than five times the odds of acute hospitalization and disqualification. These findings are consistent with research suggesting that PPS scores can be applied to diverse palliative populations for survival prediction (19). One opportunity for further study involves a survival analysis of heart failure patients based on predictions from PPS scores at hospice enrollment.

LIMITATIONS

Patients and providers were studied at a single hospice agency in the northeastern USA. The extent to which our findings generalize to other agencies and palliative settings outside of the USA will require further analysis. Additionally, our dataset did not include measures of patient socioeconomic status (i.e., income/education), language, culture/religion, or perceived social/emotional support. All of these constructs may represent important factors for live discharge among heart failure patients. Future research should clarify their contributions. Further, our qualitative interviews were limited to hospice providers, most of whom were nurses, and thus do not directly represent the views and perspectives of patients or caregivers. Qualitative interviews with patients and caregivers, as well as other healthcare personnel, could provide additional insights into the circumstances underlying live discharge.

CLINICAL PERSPECTIVES

Compared to other conditions, patients with heart failure are more likely to experience live discharge from hospice, most frequently due to 911 calls that lead to hospitalization. Our study identified characteristics of heart failure patients that increased risk for live discharge and described circumstances that introduced challenges for hospice providers. Together, these findings point to several important factors in caring for heart failure patients at end-of-life, including prognostic uncertainty, distressing symptoms, and a lack of understanding and readiness for hospice. Hospice providers are faced with the difficult task of integrating these

elements of the patient's clinical picture into their educational interventions and collaborative goal-setting process.

TRANSLATIONAL OUTLOOK

Despite the challenges outlined above, palliative interventions have the potential to improve the end-of-life experience for patients with heart failure (1). Targeted interventions for younger and higher functioning patients could provide consultation prior to admission about hospice goals of care to ensure their readiness for hospice, and develop strategies to help them manage symptoms and crises at home. Tailored services for patients and caregivers, including psychoeducation interventions, could help to improve patient symptom management, promote prognostic communication and understanding, and reduce caregiver stress and anxiety (20–22). Our results also support the development of cardiac-specific training programs for hospice providers geared towards overcoming barriers to palliative care, as well as education programs designed to encourage shared decision making and raise awareness about hospice goals of care. Such interventions may help to keep patients with heart failure comfortable at home and avoid emergency situations that lead to hospitalization. Interventions designed to increase training and support for both informal (i.e., family) and formal caregivers (e.g., Home Health Aides) could help to keep patients with heart failure continuously enrolled in hospice (23,24). Collectively, these findings suggest an opening for the development and testing of programs which meet the unique needs of hospice patients with heart failure, and that provide increased support for caregivers during the end-of-life.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements and Declarations

DR drafted this article, analyzed and interpreted study data. RMC, DB, and LJ contributed to the study design, interpretation of data, and manuscript revisions. FD, SLH, HGP, and KHB revised the article for important intellectual content. Funding for this study was provided by the Eugenie and Joseph Doyle Research Partnership Fund (PI: RMC). Research reported in this publication was also supported by the National Institute of Nursing Research of the National Institutes of Health under Award Number R00NR016275 (PI: RMC). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors have no relevant conflicts of interest to declare.

References

- Rogers JG, Patel CB, Mentz RJ et al. Palliative care in heart failure: the PAL-HF randomized, controlled clinical trial. Journal of the American College of Cardiology 2017;70:331–341. [PubMed: 28705314]
- Russell D, Diamond EL, Lauder B et al. Frequency and risk factors for live discharge from hospice. Journal of the American Geriatrics Society 2017;65:1726–1732. [PubMed: 28295138]
- LeSage K, Borgert AJ, Rhee LS. Time to death and reenrollment after live discharge from hospice: a retrospective look. American Journal of Hospice and Palliative Medicine[®] 2015;32:563–567. [PubMed: 24848665]
- Wang SY, Aldridge MD, Gross CP et al. Transitions between healthcare settings of hospice enrollees at the end of life. Journal of the American Geriatrics Society 2016;64:314–322. [PubMed: 26889841]

- Gozalo P, Teno JM, Mitchell SL et al. End-of-life transitions among nursing home residents with cognitive issues. New England Journal of Medicine 2011;365:1212–1221. [PubMed: 21991894]
- 6. LeMond L, Allen LA. Palliative care and hospice in advanced heart failure. Progress in cardiovascular diseases 2011;54:168–178. [PubMed: 21875515]
- 7. Wong CY, Chaudhry SI, Desai MM, Krumholz HM. Trends in comorbidity, disability, and polypharmacy in heart failure. The American journal of medicine 2011;124:136–143. [PubMed: 21295193]
- 8. Ankuda CK, Fonger E, O'Neil T. Electing Full Code in Hospice: Patient Characteristics and Live Discharge Rates. Journal of palliative medicine 2017.
- 9. Tariq S, Woodman J. Using mixed methods in health research. JRSM short reports 2013;4:2042533313479197. [PubMed: 23885291]
- Quan H, Li B, Couris CM et al. Updating and validating the Charlson comorbidity index and score for risk adjustment in hospital discharge abstracts using data from 6 countries. American journal of epidemiology 2011;173:676–682. [PubMed: 21330339]
- 11. Martell J Palliative Performance Scale (PPSv2). Victoria Hospice Society, 2001.
- 12. Dedoose. 2018.
- Cort MA. Cultural mistrust and use of hospice care: Challenges and remedies. Journal of Palliative Medicine 2004;7:63–71. [PubMed: 15000784]
- Price RA, Parast L, Haas A, Teno JM, Elliott MN. Black and Hispanic patients receive hospice care similar to that of white patients when in the same hospices. Health Affairs 2017;36:1283– 1290. [PubMed: 28679816]
- Luth EA, Prigerson HG. Associations between Race and Dementia Status and the Quality of Endof-Life Care. Journal of palliative medicine 2018.
- 16. Brown CE, Engelberg RA, Sharma R et al. Race/Ethnicity, Socioeconomic Status, and Healthcare Intensity at the End of Life. Journal of palliative medicine 2018.
- Glogowska M, Simmonds R, McLachlan S et al. "Sometimes we can't fix things": a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. BMC palliative care 2016;15:3. [PubMed: 26762266]
- Creber RMM, Russell D, Dooley F et al. Use of the Palliative Performance Scale to Estimate Survival among Home Hospice Heart Failure Patients. Journal of Cardiac Failure 2018;24:S76– S77.
- Baik D, Masterson Creber R, Russell D, Dooley F, Jordan L, Bowles KH. Using the Palliative Performance Scale to Estimate Survival for Patients at the End-of-Life: A Systematic Review of the Literature. Journal of Palliative Medicine 2018.
- 20. Buck HG, Zambroski CH, Garrison C, McMillan SC. "Everything They Were Discussing, We Were Already Doing": Hospice Heart Failure Caregivers Reflect on a Palliative Caregiving Intervention. Journal of hospice and palliative nursing: JHPN: the official journal of the Hospice and Palliative Nurses Association 2013;15:218.
- 21. McMillan SC, Small BJ, Haley WE, Zambroski C, Buck HG. The COPE intervention for caregivers of patients with heart failure: an adapted intervention. Journal of hospice and palliative nursing: JHPN: the official journal of the Hospice and Palliative Nurses Association 2013;15.
- 22. Stocker R, Close H, Hancock H, Hungin APS. Should heart failure be regarded as a terminal illness requiring palliative care? A study of heart failure patients', carers' and clinicians' understanding of heart failure prognosis and its management. BMJ supportive & palliative care 2017:
- Phongtankuel V, Paustian S, Reid MC et al. Events leading to hospital-related disenrollment of home hospice patients: A study of primary caregivers' perspectives. Journal of palliative medicine 2017;20:260–265. [PubMed: 27893951]
- 24. Sterling MR, Silva AF, Leung PB et al. "It's Like They Forget That the Word 'Health'Is in 'Home Health Aide'": Understanding the Perspectives of Home Care Workers Who Care for Adults With Heart Failure. Journal of the American Heart Association 2018;7:e010134. [PubMed: 30571599]

Page 11

TABLE 1.

Characteristics of Home Hospice Patients with Heart Failure

	Study Population
Independent Variables	% (N) or M (SD)
Total Sample	100.0% (1,498)
Gender	
Male	43.3% (648)
Female	56.7% (850)
Age	86.1 (10.7)
18 to 74 Years	14.0% (210)
75 to 84 Years	22.6% (339)
85 Years or Older	63.4% (949)
Race/Ethnicity	
White Non-Hispanic	50.1% (750)
Hispanic	24.1% (361)
African American	18.0% (269)
Asian or Other	7.9% (118)
Marital Status	
Currently Married	35.8% (537)
Not Currently Married	64.2% (961)
Primary Caregiver	
Has Primary Caregiver	83.6% (1,252)
No Primary Caregiver	16.4% (246)
Advanced Directives	
Has Health Care Proxy	83.8% (1,255)
Does Not Have Health Care Proxy	16.2% (243)
Primary Payer Source	
Medicare Fee-for-Service	61.2% (917)
Other Insurance Source	38.8% (581)
Palliative Performance Score at Admissio	n
10-30%	39.9% (597)
40%	36.3% (544)
50-70%	23.8% (357)
Charlson Comorbidity Score	2.5 (1.3)
Referral Source	
Hospital	55.1% (826)
Other	44.9% (672)

Discharge Reason by Primary Diagnosis Category among Home Hospice Patients

	Heart Failure	Cancer	Dementia	Stroke	Pulmonary	Other Diagnosis
	(N) %	(N) %	(N) %	% (N)	(N) %	% (N)
Total Sample	100.0% (1,498)	100.0% (9,295)	100.0% (1,498) 100.0% (9,295) 100.0% (2,520) 100.0% (777) 100.0% (679) 100.0% (3,232)	100.0% (777)	100.0% (679)	100.0% (3,232)
Hospice Discharge Reason						
Death	69.6% (1,042)	76.8% (7,140)	76.9% (1,937)	82.1% (638)	68.3% (464)	76.4% (2,470)
Live Discharge	30.4% (456) ***	23.2% (2,155)	23.1% (583)	17.9% (139)	31.7% (215)	23.6% (762)
Live Discharge Reason						
Acute Hospitalization	15.4% (230) ***	11.3% (1,047)	7.7% (194)	5.1% (40)	16.3% (111)	10.0% (324)
Elective Revocation	6.1% (92)	4.1% (385)	3.6% (90)	3.2% (25)	4.6% (31)	4.8% (156)
Disqualification	4.8% (72)	1.1% (103)	10.1% (255)	7.5% (58)	7.5% (51)	5.3% (171)
Transferred	4.1% (62)	6.7% (620)	1.7% (44)	2.1% (16)	3.2% (22)	3.4% (111)

,498)
(N=1)
Characteristics
Patient
Dutcome on
Discharge (
Hospice
of Home
Regression o
ogistic
Multinomial L

	Acute Hospitalization ¹	Elective Revocation ²	3 Disqualification	Transferred ⁴
Independent Variables	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)
Gender				
Female	1.02 (0.72, 1.44)	$0.70\ (0.43,\ 1.13)$	1.01 (0.58, 1.76)	0.77 (0.42, 1.39)
Age				
18 to 74	$2.10\left(1.34, 3.28 ight)^{**}$	1.83 (0.93, 3.59)	$0.86\ (0.38,\ 1.95)$	1.82 (0.84, 3.97)
75 to 84	$1.79~(1.24, 2.62)^{**}$	$1.99\left(1.18, 3.38 ight)^{*}$	0.77 (0.39, 1.50)	1.67 (0.88, 3.20)
85 or older	I	-	I	I
Race/Ethnicity				
White Non-Hispanic	I	I	I	I
Hispanic	$2.99 (1.99, 4.50)^{***}$	1.70 (0.94, 3.08)	2.32 (1.23, 4.34) **	$2.25 \ (1.10, 4.62)^{*}$
African American	$2.06\left(1.31, 3.24 ight)^{**}$	1.39 (0.73, 2.64)	1.45 (0.69, 3.06)	1.64 (0.74, 3.64)
Asian or Other	$1.96\left(1.08,3.57 ight)^{*}$	1.49 (0.65, 3.41)	1.07 (0.36, 3.18)	2.25 (1.04, 6.18)*
Marital Status				
Not Currently Married	$1.37\ (0.95,1.960$	1.33 (0.80, 2.18)	1.34 (0.74, 2.43)	1.33 (0.46, 1.49)
Primary Caregiver				
No Primary Caregiver	0.97 (0.63, 1.50)	2.08 (1.25, 3.48) **	$0.84\ (0.40,1.74)$	$1.98\ (1.05,\ 3.71)^{*}$
Health Care Proxy				
No Health Care Proxy	0.81 (0.52, 1.25)	1.14 (0.64, 2.04)	0.82 (0.39, 1.72)	1.02 (0.49, 2.13)
Primary Payer Source				
Medicare (FFS)	$0.82\ (0.59,1.13)$	0.89 (0.56, 1.42)	0.88 (0.51, 1.49)	0.77 (0.44, 1.36)
Other Insurance Source	I	I	I	I
Hospice Referral Source				
Other than Hospital	$0.95\ (0.68,1.33)$	1.43 (0.89, 2.29)	1.31 (0.78, 2.20)	$1.94\ (1.09,\ 3.44)^{*}$
Palliative Performance				
10–30%	I	I	I	I
40%	$4.00\ (2.66,\ 6.03)^{***}$	$1.85\ (1.06,\ 3.24)^{*}$	2.57 (1.35, 4.92) ^{**}	$2.53 \left(1.23, 5.23 ight)^{*}$
50-70%	5.68 (3.66, 8.79) ^{***}	3.77 (2.14, 6.64)	4.90 (2.51, 9.55) ***	5.49 (2.66, 11.34)

Author Manuscript

	Acute Hospitalization ^I	I Elective Revocation ²	Disqualification ³	Transferred ⁴
Independent Variables	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)	AOR (95% CI)
Charlson Score	0.99 (0.88, 1.11)	$0.90\ (0.75,1.08)$	1.07 (0.89, 1.29)	0.98 (0.79, 1.20)

NOTES: Home Hospice patients with a primary diagnosis of heart failure admitted and discharged during the period between 2013 and 2017. Hospice discharge reason was represented by a discrete variable with five categories: Death (n=1,042),

I Acute Hospitalization (n=230);

 2 Elective Revocation (n=92),

 \mathcal{J} Disqualification (n=72),

⁴Transfer (n=62).

Death in hospice represented the reference group; The regression model is adjusted for all independent variables listed in the table;

* *p*<0.05, p<0.01, p<0.01, s**