

UCSF

UC San Francisco Previously Published Works

Title

Barriers of Acceptance to Hospice Care: a Randomized Vignette-Based Experiment.

Permalink

<https://escholarship.org/uc/item/3sj3s2wx>

Journal

Journal of General Internal Medicine, 38(2)

Authors

Trandel, Elizabeth

Lowers, Jane

Bannon, Megan

et al.

Publication Date

2023-02-01

DOI

10.1007/s11606-022-07468-7

Peer reviewed

ORIGINAL RESEARCH

Barriers of Acceptance to Hospice Care: a Randomized Vignette-Based Experiment



Elizabeth T. Trandel, MD¹, Jane Lowers, PhD, MPA¹, Megan E. Bannon, MD², Laura T. Moreines, APRN, FNP-BC, ACHPN³, Elisabeth P. Dellon, MD, MPH⁴, Patrick White, MD⁵, Sarah H. Cross, PhD, MSW, MPH¹, Tammie E. Quest, MD¹, Keith Lagnese, MD⁶, Tamar Krishnamurti, PhD⁶, Robert M. Arnold, MD⁶, Krista L. Harrison, PhD⁷, Rachel E. Patzer, PhD MPH¹, Li Wang, MS⁶, Ali John Zarrabi, MD¹, and Dio Kavalieratos, PhD¹

¹Emory University, Atlanta, GA, USA; ²Northwestern University, Chicago, USA; ³New York University, New York, USA; ⁴University of North Carolina, Chapel Hill, USA; ⁵Washington University in St. Louis, St. Louis, USA; ⁶University of Pittsburgh, Pittsburgh, USA; ⁷University of California, San Francisco, San Francisco, USA.

BACKGROUND: The *per diem* financial structure of hospice care may lead agencies to consider patient-level factors when weighing admissions.

OBJECTIVE: To investigate if treatment cost, disease complexity, and diagnosis are associated with hospice willingness to accept patients.

DESIGN: In this 2019 online survey study, individuals involved in hospice admissions decisions were randomized to view one of six hypothetical patient vignettes: “high-cost, high-complexity,” “low-cost, high-complexity,” and “low-cost, low-complexity” within two diseases: heart failure and cystic fibrosis. Vignettes included demographics, prognoses, goals, and medications with costs. Respondents indicated their perceived likelihood of acceptance to their hospice; if likelihood was <100%, respondents were asked the barriers to acceptance. We used bivariate tests to examine associations between demographic, clinical, and organizational factors and likelihood of acceptance.

PARTICIPANTS: Individuals involved in hospice admissions decisions

MAIN MEASURES: Likelihood of acceptance to hospice care

KEY RESULTS: N=495 (76% female, 53% age 45–64). Likelihoods of acceptance in cystic fibrosis were 79.8% (high-cost, high-complexity), 92.4% (low-cost, high-complexity), and 91.5% (low-cost, low-complexity), and in heart failure were 65.9% (high-cost, high-complexity), 87.3% (low-cost, high-complexity), and 96.6% (low-cost, low-complexity). For both heart failure and cystic fibrosis, respondents were less likely to accept the high-cost, high-complexity patient than the low-cost, high-complexity patient (65.9% vs. 87.3%, 79.8% vs. 92.4%, both $p < 0.001$). For heart failure, respondents were less likely to accept the low-cost, high-complexity patient than the low-cost, low-complexity patient (87.3% vs. 96.6%, $p = 0.004$). Treatment cost was the most common barrier for 5 of 6 vignettes.

CONCLUSIONS: This study suggests that patients receiving expensive and/or complex treatments for palliation may have difficulty accessing hospice.

J Gen Intern Med 38(2):277–84

DOI: 10.1007/s11606-022-07468-7

© The Author(s) under exclusive licence to Society of General Internal Medicine 2022

INTRODUCTION

Hospice provides symptom-focused care and psychosocial, spiritual, and practical support to over 1.5 million Americans each year who are expected to live less than 6 months and are willing to forgo life-prolonging treatments.¹ Enrolling in hospice has many demonstrated benefits, including improved patient satisfaction, improved pain and symptom control, and increased likelihood of goal-concordant care including at-home death.^{2–6} However, fundamental inequities in access to hospice care by race, citizenship status, or need for resource-intensive services are prevalent.^{7–11}

In 1982, the US Congress created the Medicare hospice benefit, developed largely around the needs of terminally ill patients with cancer. The original benefit used a *per diem* rate for hospice care, with a secondary objective of cost-containment.¹² Today, the *per diem* is \$199.25 for routine home hospice care, subject to geographic modification,¹³ but the palliative treatments available for both cancer and non-cancer illnesses have increased exponentially, outpacing the financial structure of the Medicare hospice benefit. Hospice organizations must closely monitor costs by evaluating patient mix and frequency and length of visits; optimizing personnel; and training families to provide hands-on care.¹² Additionally, because this *per diem* rate does not adjust for patient-specific factors, many hospice organizations have formal or informal enrollment practices that may limit acceptance of patients with complex or rare illnesses that may have less predictable prognoses.^{7, 10} Such practices, while necessary for hospices to

Prior presentations: This work was presented, in draft form, at Emory University’s 7th Annual Health Services Research Day (May 5, 2021).

Received December 21, 2021

Accepted February 15, 2022

Published online March 22, 2022

remain viable, may contribute to systemic inequities in end-of-life care and outcomes.

Two such chronic, life-limiting diseases with less predictable trajectories at the end of life are heart failure and cystic fibrosis.^{14–18} Both present similar barriers to hospice access, including difficult prognostication and symptom management using intensive disease-directed therapies.^{14, 19–21} Prognostication may affect both the hospice's assessment of 6-month eligibility and perceived risk of ongoing high costs, as *per diem* reimbursement decreases 60 days after enrollment.²²

Although there is evidence that organization-level practices do influence patient acceptance to hospice care, there is no literature about how hospices make individual decisions about patient acceptance.⁷ Understanding these decision-making factors is essential to intervening upon potential sources of inequitable hospice access. We thus designed a survey using patient vignettes to investigate how different patient factors—medication cost, disease complexity, and/or disease rarity (heart failure vs. cystic fibrosis)—are associated with hospice willingness to accept patients who meet criteria for referral.

METHODS

With stakeholder input (e.g., hospice and palliative care clinicians and researchers, heart failure clinicians, cystic fibrosis clinicians, and decision-making experts), we developed an internet-based survey investigating the likelihood of hospice organizations to accept patients with different diagnoses, associated costs, and complexity of disease management. Survey respondents were clinicians and administrators who self-identified as being involved in hospice admissions decisions.

Patient Vignette Development and Design

We developed six hypothetical patient vignettes with varying complexity, cost, and disease. Each vignette included patient age, gender, medical history, insurance, support at home, prognosis, goals for hospice care, and medications with weekly costs (see Table 1 for a summary of our experimental

design, and Appendix Tables 1–6 for complete patient vignettes).

We estimated weekly medication costs using the average wholesale price of each drug at the time of this study; when a range was provided, we used the median.²³ We did not include a high-cost, low-complexity patient vignette in this study, as this is a less realistic scenario.

We pilot-tested the vignettes for clarity and face validity with four palliative care and hospice clinicians throughout survey development using a think-aloud cognitive interviewing approach. Next, we pilot-tested the survey and vignettes with 38 attendees at the National Hospice and Palliative Care Organization Leadership and Advocacy Conference in April 2019, revising study materials per feedback.

Study Design

We designed this study to test for the influence of three factors (cost, complexity, and disease rarity) on the likelihood of acceptance to hospice care, using seven comparisons between the six patient vignettes: for **cost**, *high-cost*, high-complexity heart failure vs. *low-cost*, high-complexity heart failure and *high-cost*, high-complexity cystic fibrosis vs. *low-cost*, high-complexity cystic fibrosis; for **complexity**, low-cost, *high-complexity* heart failure vs. low-cost, *low-complexity* heart failure, and low-cost, *high-complexity* cystic fibrosis vs. low-cost, *low-complexity* cystic fibrosis; and for **disease**, low-cost, low-complexity *heart failure* vs. low-cost, low-complexity *cystic fibrosis*, low-cost, high-complexity *heart failure* vs. low-cost, high-complexity *cystic fibrosis*, and high-cost, high-complexity *heart failure* vs. high-cost, high-complexity *cystic fibrosis*.

Using block randomization to ensure relative balance across vignettes, we assigned one of the six vignettes to each survey respondent. Our primary dependent variable was respondents' stated percent likelihood of accepting the patient to their hospice organization (0–100%). If the respondent's determined likelihood was <100%, they identified one or more of five possible barriers to acceptance (i.e., treatment cost, diagnosis/familiarity with the disease process, lack of hospice resources/personnel to support the patient's needs, ethical

Table 1 Essential Components of Patient Vignettes for Heart Failure and Cystic Fibrosis with High and Low Cost and Complexity for 2019 Survey

	Heart failure (common)	Cystic fibrosis (rare)
High-cost, high-complexity	Continuous infusion of inotrope Total medications: 9 Weekly costs: \$795.18	Expensive combination of medications necessary for symptom relief Total medications: 16 Weekly costs: \$1503.25 or \$3751.58 (alternating monthly)
Low-cost, high-complexity	Continuous infusion of inotrope; funds from online donation page to pay for medications Total medications: 9 Weekly costs: \$0	Expensive combination of medications necessary for symptom relief; funds from online donation page to pay for medications Total medications: 16 Weekly costs: \$0
Low-cost, low-complexity	Low-cost oral medications Total medications: 8 Weekly costs: \$157.78	Willing to stop all medications; will continue supplemental oxygen therapy Total medications: Oxygen only Weekly costs: \$56

Table 2 Demographics and Organization Characteristics of 495 Respondents to 2019 Survey of Hospice Clinicians and Administrators

	Total sample,n(%)	Analytic sample (excluding respondents who did not provide demographic information),n(%)
Respondent demographics		
Age		
18–24	0 (0%)	0 (0%)
25–34	25 (5%)	25 (6%)
35–44	88 (18%)	88 (21%)
45–54	115 (23%)	115 (27%)
55–64	146 (30%)	146 (34%)
65–74	50 (10%)	50 (12%)
75+	2 (0%)	2 (0%)
Missing data	69 (14%)	–
Gender		
Male	102 (21%)	102 (24%)
Female	323 (65%)	323 (76%)
Missing data	70 (14%)	–
Race*		
American Indian or Alaska Native	2 (0%)	2 (0%)
Asian	16 (3%)	16 (4%)
Black or African American	4 (1%)	4 (1%)
Native Hawaiian or other Pacific Islander	2 (0%)	2 (0%)
White	396 (80%)	396 (94%)
Missing data	75 (15%)	–
Ethnicity		
Hispanic or Latino	14 (3%)	14 (3%)
Not Hispanic or Latino	398 (80%)	398 (97%)
Missing data	83 (17%)	–
Role		
Physician	156 (32%)	156 (37%)
Advanced practice providers	40 (8%)	40 (9%)
Nurse	172 (35%)	172 (40%)
Other	59 (12%)	59 (14%)
Missing data	68 (14%)	–
Administrator		
Yes	296 (60%)	296 (69%)
No	131 (27%)	131 (31%)
Missing data	68 (14%)	–
Years in hospice care		
< 1	12 (2%)	12 (3%)
1–5	95 (19%)	95 (22%)
6–10	99 (20%)	99 (23%)
11–15	89 (18%)	89 (21%)
16–20	61 (12%)	61 (14%)
21+	71 (14%)	71 (17%)
Missing data	68 (14%)	–
Organization characteristics		
Multiple locations		
Yes	236 (48%)	236 (56%)
No	189 (38%)	189 (44%)
Missing data	70 (14%)	–
Daily census		
0–19	32 (7%)	32 (8%)
20–49	58 (12%)	58 (14%)
50–124	127 (26%)	127 (30%)
125–199	73 (15%)	73 (17%)
200–499	85 (17%)	85 (20%)
500+	50 (10%)	50 (12%)
Missing data	70 (14%)	–
Financial status		
Non-profit	313 (63%)	313 (73%)
For-profit	102 (21%)	102 (24%)
Government	12 (2%)	12 (3%)
Missing data	68 (14%)	–
Areas served*		
Urban	122 (16%)	122 (19%)

(continued on next page)

Table 2. (continued)

	Total sample,n(%)	Analytic sample (excluding respondents who did not provide demographic information),n(%)
Suburban	139 (19%)	139 (21%)
Rural	164 (22%)	164 (25%)
Mixed	225 (30%)	225 (35%)
Missing data	100 (13%)	–
Affiliations*		
Hospital	159	159
Nursing home	41	41
Home health agency	137	137
Other health care organization	66	66
Academic partner	35	35
None reported	236	236
Charitable foundation		
Yes	191 (39%)	191 (48%)
No	209 (42%)	209 (52%)
Missing data	95 (19%)	–
	Median	Median
Patients without hospice benefit	10%	10%

*Total exceeds 495, as respondents could choose multiple answers

reasons, or other) and explained each barrier selected in free text responses. Based on the responses, some of the “other” barrier responses were reclassified as either an existing barrier or as a new barrier, “goals of care.” We collected optional self-reported demographic information from participants. Based on self-identified role, we reclassified respondents’ roles in the final dataset (physician, advanced practice provider, nurse, other; administrator vs. non-administrator).

Data Collection

The approved survey (University of Pittsburgh Institutional Review Board #18110148) and the planned analyses were preregistered on the Open Science Framework (Charlottesville, VA, USA; <https://osf.io>). The survey was administered using the Qualtrics online platform.²⁴ We distributed the survey to the National Hospice and Palliative Care Organization, the American Academy of Hospice and Palliative Medicine, and the Hospice and Palliative Nurses Association memberships through organization listservs (via direct email), online message boards, and social media posts. Snowball sampling was also allowed. As an incentive for participation, we offered the opportunity to be chosen randomly for one of four \$50 gift cards.

Statistical Analysis

We used two non-parametric methods to test whether complexity, cost, or diagnosis factors are associated with significant differences in the likelihood to accept referrals. We first tested for differences using Mann-Whitney *U* tests of marginal differences in the raw likelihood scores. We used chi-square tests to evaluate whether these differences were associated with the likelihood to accept, dichotomized as 100% vs.

<100%; we chose to dichotomize as this variable was distributed non-normally. Sensitivity analyses in which the primary outcome variable (i.e., likelihood of acceptance) was treated as a continuous variable showed similar findings. Statistical significance was defined as p value <0.05. All statistical analyses were performed using SPSS V24.0 (IBM Corp., Armonk, NY, USA).

RESULTS

Respondent Demographics

Between October and December 2019, 495 respondents completed the survey (Table 2); 81% provided complete demographic data. Of respondents who provided demographic data, 76% ($n=323$) were female and 94% ($n=396$) were white. Forty percent ($n=172$) were nurses, 37% ($n=156$) were physicians, and 9% ($n=40$) were advanced practice providers. Most respondents (69%, $n=296$) held an administrative (versus purely clinical) role at their organization. Most (97%, $n=415$) had worked in hospice for at least 1 year, and 52% ($n=221$) had worked in hospice for more than 10 years.

Organization Characteristics

Among respondents who completed demographic information, 21% ($n=90$) reported their organization had a census of <50 patients per day and 12% ($n=50$) reported a daily census of >500 patients (Table 2). Seventy-three percent ($n=313$) of respondents represented non-profit organizations, 24% ($n=102$) for-profit, and 3% ($n=12$) governmental. Forty-eight percent ($n=191$) had a charitable foundation that supports otherwise prohibitively costly treatments, thus serving as a potential method of financial assistance.

Likelihood of Acceptance to Hospice Care

Mean likelihood of acceptance to hospice care for each patient vignette ranged from 96.6% (low-cost, low-complexity heart failure) to 65.9% (high-cost, high-complexity heart failure) (Table 3). When considering *cost* (high-cost, high-complexity vs. low-cost, high-complexity), respondents were significantly more likely to accept the *low*-cost, high-complexity patient than the *high*-cost, high-complexity patient for both heart failure and cystic fibrosis (heart failure: 87.3%

vs. 65.9%; cystic fibrosis: 92.4% vs. 79.8%; all $p<0.001$, see Fig. 1). When examining *complexity*, respondents were significantly more likely to accept the low-cost, *low*-complexity heart failure patient than the low-cost, *high*-complexity heart failure patient (96.6% vs. 87.3%; $p=0.01$). However, complexity did not have a statistically significant effect on the likelihood of accepting patients with cystic fibrosis to hospice (91.5% vs. 92.4%; $p=0.07$). When considering *disease*, we found that cost may play a mediating role in likelihood to accept. We observed no difference in likelihood of accepting patients with low-cost, low-complexity heart failure or cystic fibrosis (96.6% vs. 91.5%; $p=0.41$), or for low-cost, high-complexity heart failure or cystic fibrosis (87.3% vs. 92.4%; $p=0.14$); however, when both cost and complexity were high, respondents were more likely to accept the patient with cystic fibrosis vs. heart failure (79.8% vs. 65.9%; $p=0.02$).

Barriers to Acceptance

Treatment cost was the most common barrier to acceptance for five of the six patient vignettes (Appendix Table 7). “Other” was the most common barrier for the low-cost, low-complexity heart failure patient vignette. For this vignette, the free text explanation of barriers varied but included concerns about family’s ability to provide care at home (“single elder spouse as caregiver with high [activities of daily living] demand”).

Across vignettes, “other” barriers to patient acceptance included degree of support at home and disease trajectory/recent functional decline, as well as organization factors, such as needing to discuss with the organization’s physician leadership.

Respondents’ reported barriers demonstrated that hospice organizations must weigh the benefit of caring for one patient with the threat of losing financial viability and being unable to care for any patients at the end of life. One respondent labeled treatment cost of a high-cost vignette as a barrier as it may “limit [their] ability to provide quality care to other patients.” Another respondent stated that “lack of adequate coverage for this patient’s medications would cause the hospice agency significant financial loss and hardship.” A third respondent concluded that there was “no reason to put the future of an entire hospice organization at risk because of medication costs.”

Likelihood of Acceptance by Respondent Variables

We examined the likelihood of acceptance to hospice by respondent and organization characteristics, including respondent role and administrative status, organization profit status, the presence of a charitable foundation, and size (average daily patient census of <125 vs. \geq 125 patients). We found no statistically significant differences in likelihood of acceptance when comparing organizations based on profit status ($p=0.97$; Appendix Table 8), organization size ($p=0.92$;

Table 3 Likelihood of Accepting Patient to Hospice Care

Patient	No. of respondents	Mean likelihood of acceptance (SD)
<i>Heart failure</i>		
High-cost, high-complexity	75	65.9 (35.1)
Low-cost, high-complexity	89	87.3 (24.6)
Low-cost, low-complexity	85	96.6 (10.9)
<i>Cystic fibrosis</i>		
High-cost, high-complexity	77	79.8 (30.3)
Low-cost, high-complexity	85	92.4 (20.0)
Low-cost, low-complexity	84	91.5 (22.1)

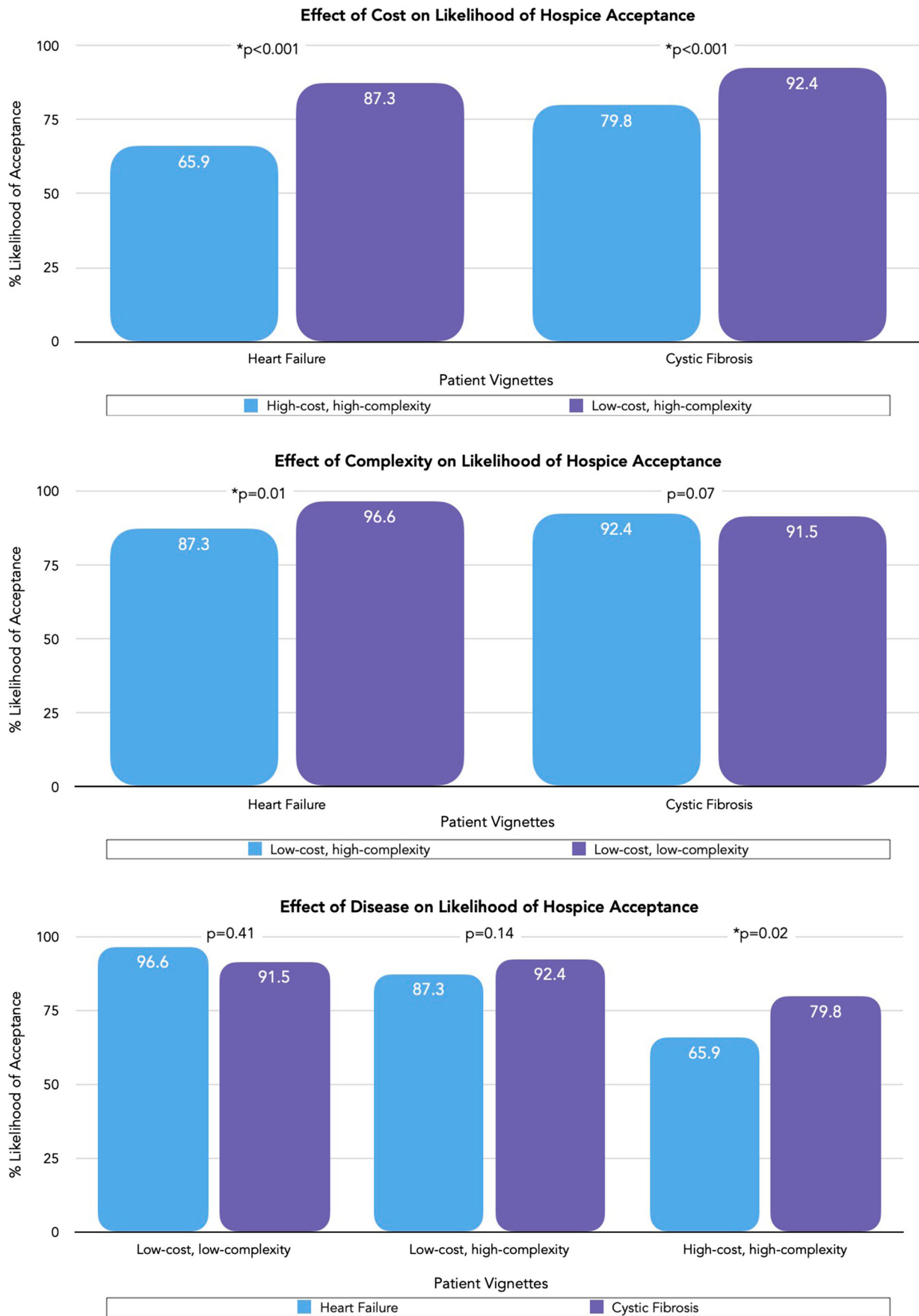


Figure 1 Effect of cost, complexity, and disease on likelihood of accepting patient to hospice care, among 495 hospice administrators and clinicians surveyed in 2019.

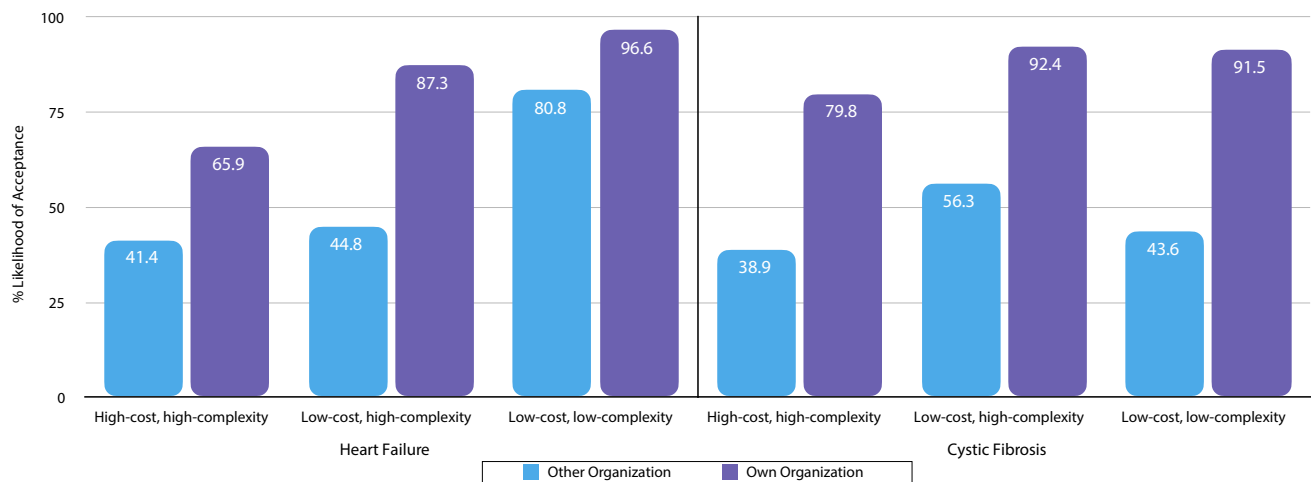


Figure 2 Among hospice administrators and clinicians surveyed in 2019, likelihood of acceptance to hospice at another organization. Note: Only respondents who chose a likelihood <100% for the survey item “Please rate your likelihood (0–100%) of admitting this patient to your hospice” were asked for “Other Organization” data ($n=13-40$).

Appendix Table 9), or existence of a charitable foundation ($p=0.91$; Appendix Table 10). We also examined likelihood of acceptance based on these demographic differences for several vignette subgroups (high-cost vignettes, heart failure vignettes, etc.) and again did not find any statistically significant differences (Appendix Tables 8–10).

We found no differences in likelihood of acceptance to hospice care by either respondent role or administrator status (respondent role: $p=0.30$, Appendix Table 11; administrator status: $p=0.79$; Appendix Table 12).

We also investigated the relationship between organization-level characteristics and likelihood of accepting heart failure vs. cystic fibrosis patients. In our data, we found that small hospices were more likely to accept patients with cystic fibrosis than patients with heart failure (74% vs. 60%, $p=0.03$; Appendix Table 13).

Likelihood of Acceptance to Hospice Care at Another Organization

Respondents estimated how likely the vignette patients would be to find hospice care at another hospice organization if their own organization was unable to accept the patient. Perceived likelihood of acceptance to hospice care at another organization ranged from 80.8% (low-cost, low-complexity heart failure) to 38.9% (high-cost, high-complexity cystic fibrosis) ($n=13-40$; Fig. 2). For all vignettes, the mean perceived likelihood to accept the patient was higher for respondents’ own organization than at another organization.

Examining the low-cost, low-complexity cases demonstrated a stark contrast between the two diseases: While the likelihood of accepting the low-cost, low-complexity patient with heart failure was 81% at another organization

(versus 97% at their own organization), the likelihood of accepting the low-cost, low-complexity patient with cystic fibrosis was only 44% (vs. 92% for their own organization)—a 48% difference.

DISCUSSION

Our study suggests that restrictive, cost-driven hospice admission practices may contribute to fundamental inequities at the end of life; some patients with terminal illnesses may be unable to access hospice. Respondents illustrated that in the current *per diem* payment model, razor-thin margins mean hospice organizations must weigh the benefit of helping one costly patient versus the ability to care for others.²⁵

Complexity of care was associated with likelihood of hospice acceptance in heart failure, but not in cystic fibrosis. We propose several hypotheses for this difference: First, several respondents mentioned continuous IV medication as a significant barrier for the patient with heart failure. As the cystic fibrosis vignette did not include IV medications, it may have been seen as comparatively less complex. The age of the patient with cystic fibrosis—and the fact that this disease is genetic—may also have created a “tugging at the heartstrings” phenomenon. Respondents may have felt pressured to avoid denying hospice care to this young patient with a genetic disease.

When comparing the low-cost, low-complexity patients with cystic fibrosis and with heart failure, we did not find a significant difference in the likelihood to accept patients based on disease rarity. This result countered our hypothesis that respondents would be less likely to accept the patient with cystic fibrosis due to a potential lack of knowledge of this rare

disease and its management. However, when examining the likelihood of accepting the low-cost, low-complexity patients at *another* organization, respondents reported likelihoods of 81% for the patient with heart failure and 44% for the patient with cystic fibrosis—a 37 percentage point difference. This imbalance further demonstrates the possibility of a social desirability bias and implies that patients with rare diseases such as cystic fibrosis may actually have more difficulty accessing end-of-life care than indicated in our results. Additionally, as hospices are most familiar with caring for patients with advanced cancer, it is possible that both diseases used in our survey may be barriers to hospice when compared to cancer.

Patients who meet criteria for hospice may have difficulty accessing hospice care if they require costly or complex treatments for their symptoms—demonstrated by the fact that the high-cost, high-complexity patient with heart failure in our survey had a mean likelihood of acceptance to hospice care of only 66%. Perhaps even more notable, respondents rated this vignette's likelihood of acceptance at another organization at only 39%. Overall, this analysis adds to the ongoing discourse regarding the need to reevaluate the Medicare hospice benefit, particularly the financial model and how it may implicitly exacerbate inequities in end-of-life care.^{12, 26–28} Expanding the Medicare Advantage hospice carve-in, a value-based payment model currently being tested, could expand opportunities for palliative and hospice services for patients whose needs fall at the edges of what hospices currently can offer. Patients with complex needs or uncertain trajectories might benefit from better care coordination. However, financial incentives for a carve-in could also increase the type of cost-controlling pressures observed in this study.²⁹

There are several limitations to this study. To minimize participant burden we did not include a cancer case as a positive control; therefore, we cannot assess likelihood of acceptance for cystic fibrosis or heart failure relative to cancer. Our results nonetheless support our hypothesis of cost potentially influencing hospice admissions in heart failure and cystic fibrosis. Respondents may not have responded with the true likelihood of acceptance as they would have with real patients, potentially increasing their own estimated likelihood of acceptance, or decreasing the likelihood of acceptance they predicted at other hospices, due to social desirability bias. Respondents also frequently indicated that hospice admissions decisions involve negotiations among hospice organizations, referring physicians, and the patients themselves; this process was not available through our survey format. We used average national wholesale prices, which may differ from actual costs to the respondents' respective hospices; we did not include labor hours in our vignettes, which may have influenced estimations of cost or complexity. Our sample also has a greater proportion of non-profit hospice organizations than the national hospice market. By recruiting through the largest national groups representing the hospice community, we

may have had a selection bias toward larger organizations with more resources, although allowing snowball sampling may have mitigated this issue. We were unable to calculate response rates, as several of the listservs used in this study do not maintain accurate rosters of active and unique email addresses; as well, our use of snowball sampling, while increasing reach, also prevented us from knowing the true denominator of our study population. Due to concerns regarding confidentiality, we were unable to identify and control for respondents from the same hospice organization. Additionally, our survey had imperfect comparisons between cost and complexity between the two diseases, as the high-cost cystic fibrosis vignette was more costly and the high-complexity heart failure vignettes required IV medications. While patients with cystic fibrosis may require intermittent IV medications at the end of life, we attempted to create “average” vignettes for each case, and thus, for generalizability we could not capture the breadth of medication options available, which include both continuous or intermittent IV infusions. A sizable proportion of the sample opted not to answer the optional demographic questions; we cannot address the representativeness of the sample, but our randomization design should mitigate concerns regarding confounding. Lastly, patient prognosis was not an experimental variable in our survey; our study cannot comment on how prognosis influences a hospice's likelihood to admit.

Although the current hospice model is intended to codify access to high-quality, patient-centered end-of-life care, our work suggests that instead it may contribute to inequities for people who do not resemble the archetype upon which traditional hospice policy was designed—people with cancer with a generally predictable prognosis who do not require costly or complex therapies for symptom relief. This work should draw the attention of policymakers and hospice organizations to revisit explicit policies and implicit norms that disenfranchise specific patient populations from receiving end-of-life care that matches their goals and values, simply by virtue of immutable characteristics, such as their illness and the therapies required to ensure their comfort.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s11606-022-07468-7>.

Acknowledgements:

Contributors: The authors sincerely thank Zachariah Hoydich, BS, and Nalyn Sirpong, PhD, for their contributions to this study.

Corresponding Author: Dio Kavalieratos, PhD; Emory University, Atlanta, GA, USA (e-mail: d.kavalieratos@emory.edu).

Funding During the conduct of this study, Dr. Kavalieratos received research support from the National Heart, Lung, and Blood Institute (K01HL133466). Drs. Trandel and Bannon both received internal funding from the University of Pittsburgh School of Medicine to conduct portions of this study.

Declarations:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

REFERENCES

1. National Hospice and Palliative Care Organization. NHPCO Facts and Figures: 2020 Edition.
2. Kleinpell R, Vasilevskis EE, Fogg L, Ely EW. Exploring the association of hospice care on patient experience and outcomes of care. *BMJ Support Palliat Care*. 2019;9(1):e13.
3. Meier DE. Increased access to palliative care and hospice services: opportunities to improve value in health care. *Milbank Q*. 2011;89(3):343-380.
4. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *JAMA*. 2004;291(1):88-93.
5. Teno JM, Shu JE, Casarett D, Spence C, Rhodes R, Connor S. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007;34(2):120-125.
6. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol*. 2010;28(29):4457-4464.
7. Aldridge Carlson MD, Barry CL, Cherlin EJ, McCorkle R, Bradley EH. Hospices' enrollment policies may contribute to underuse of hospice care in the United States. *Health Aff (Millwood)*. 2012;31(12):2690-2698.
8. Johnson KS, Payne R, Kuchibhatla MN, Tulskey JA. Are hospice admission practices associated with hospice enrollment for older African Americans and whites? *J Pain Symptom Manage*. 2016;51(4):697-705.
9. Gray NA, Boucher NA, Kuchibhatla M, Johnson KS. Hospice access for undocumented immigrants. *JAMA Intern Med*. 2017;177(4):579-580.
10. Lorenz KA, Asch SM, Rosenfeld KE, Liu H, Ettner SL. Hospice admission practices: where does hospice fit in the continuum of care? *J Am Geriatr Soc*. 2004;52(5):725-730.
11. Davis FA. Medicare hospice benefit: early program experiences. *Health Care Financ Rev*. 1988;9(4):99-111.
12. Mor V, Teno JM. Regulating and paying for hospice and palliative care: reflections on the Medicare hospice benefit. *J Health Polit Policy Law*. 2016;41(4):697-716.
13. Medicare Learning Network. Update to hospice payment rates, hospice cap, hospice wage index and hospice pricer for FY 2021. *Medicare Learning Network*. 2020.
14. Cross SH, Kamal AH, Taylor DH, Jr., Warraich HJ. Hospice use among patients with heart failure. *Card Fail Rev*. 2019;5(2):93-98.
15. Chen-Scarabelli C, Saravolatz L, Hirsh B, Agrawal P, Scarabelli TM. Dilemmas in end-stage heart failure. *J Geriatr Cardiol*. 2015;12(1):57-65.
16. Goldstein NE, Lynn J. Trajectory of end-stage heart failure: the influence of technology and implications for policy change. *Perspect Biol Med*. 2006;49(1):10-18.
17. Sands D, Repetto T, Dupont LJ, Korzeniewska-Eksterowicz A, Catastini P, Madge S. End of life care for patients with cystic fibrosis. *Journal of Cystic fibrosis*. 2011;10:S37-S44.
18. Dellon EP, Chen E, Goggin J, et al. Advance care planning in cystic fibrosis: current practices, challenges, and opportunities. *J Cyst Fibros*. 2016;15(1):96-101.
19. Lemond L, Allen LA. Palliative care and hospice in advanced heart failure. *Prog Cardiovasc Dis*. 2011;54(2):168-178.
20. Estrada-Veras J, Groninger H. Palliative care for patients with cystic fibrosis #265. *J Palliat Med*. 2013;16(4):446-447.
21. Chen E, Homa K, Goggin J, et al. End-of-life practice patterns at U.S. adult cystic fibrosis care centers: a national retrospective chart review. *J Cyst Fibros*. 2018;17(4):548-554.
22. Centers for Medicaid & Medicare Services. Update to hospice payment rates, hospice cap, hospice wage index and hospice pricer for FY 2021. MLN Matters MM11876. Sept. 24, 2020. Accessed Dec. 9, 2021: <https://www.cms.gov/files/document/mm11876.pdf>
23. UpToDate. <https://uptodate.com>. Accessed August-September, 2019.
24. Trandel ET, Bannon ME, Krishnamurti T, Kavalieratos D. Identifying disparities in hospice access for patients with complex or costly illnesses. osf.io/pem5y. Published January 2, 2020.
25. O'Neill SM, Ettner SL, Lorenz KA. Paying the price at the end of life: a consideration of factors that affect the profitability of hospice. *J Palliat Med*. 2008;11(7):1002-1008.
26. Casarett DJ, Fishman JM, Lu HL, et al. The terrible choice: re-evaluating hospice eligibility criteria for cancer. *J Clin Oncol*. 2009;27(6):953-959.
27. Fishman J, O'Dwyer P, Lu HL, Henderson HR, Asch DA, Casarett DJ. Race, treatment preferences, and hospice enrollment: eligibility criteria may exclude patients with the greatest needs for care. *Cancer*. 2009;115(3):689-697.
28. Dressler G, Garrett SB, Hunt LJ, et al. "It's case by case, and It's a struggle": a qualitative study of hospice practices, perspectives, and ethical dilemmas when caring for hospice enrollees with full-code status or intensive treatment preferences. *J Palliat Med*. 2021;24(4):496-504.
29. Ankuda CK, Morrison RS, Aldridge MD. The 2021 Medicare advantage hospice carve-in. *JAMA*. Published online November 29, 2021. <https://doi.org/10.1001/jama.2021.21161>

Publisher's Note: Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.