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State of Research on Palliative Care in Heart Failure as Evidenced by Published Literature, Conference Proceedings and NIH Funding

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Abstract

Background—Heart failure (HF) is the most common diagnosis in hospitalized patients over 65 years of age. Although these patients often need specialist-directed palliative care, <10% ever receive these services. This may be due to a lack of evidence examining the benefits of palliative care for these patients. To understand the current state of research on the interface of palliative care and HF, we examined trends in publications, presentations at national meetings, and NIH funding.

Methods—Using key terms, we identified items about palliative care and HF in the following sources: 1) the tables of contents of nine leading cardiology journals, 2) abstracts of conference proceedings from four cardiology societies, and 3) all NIH grants from 2009 to 2013.

Results—Of the journals reviewed, less than 1% of their publications related to palliative care. Less than 2% of HF-related sessions in conference proceedings mentioned palliative care. Of the NIH's \$45 billion directed to HF research, only \$14 million (0.03%) was spent on palliative care research.

Conclusions—Despite calls for improving palliative care for patients with advanced HF, a lack of sufficient attention persists in research abstracts, concurrent sessions at national meetings, and NIH funding to increase the evidence base. Without these improvements, the ability to deliver high quality specialist palliative care to patients with HF and their families will remain severely limited.

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Disclosures

None

Keywords

heart failure; aging; morbidity; palliative care

Background

Heart failure (HF) is the most common diagnosis in older hospitalized patients. It is associated with a high symptom burden, 50% mortality within 5 years of diagnosis, decreased quality of life, and costs in the United States of \$30.7 billion per year (CDC, 2016). Palliative care is dedicated to relieving the pain and symptoms of serious illnesses for patients and their families at all disease stages (Center to Advance Palliative Care n.d.). It is provided simultaneously with medical treatments aimed at curing disease or prolonging life. Studies have shown palliative care can improve quality of life and survival in patients with cancer (Rabow 2013, Smith 2014, Temel 2010, Gomes 2013). Given the complex trajectory of HF, the data from cancer may not be generalizable to HF patients. For some, HF is a progressive, fatal illness, but for others, newer medical therapies, including implanted devices, can improve outcomes. Palliative care for HF patients is necessary yet integrating it remains challenging.

To better understand the current state of research on palliative care in HF, we examined the publications on palliative care in major cardiology journals, the conference proceedings devoted to palliative care at major cardiology meetings, and the funding for palliative care research from the National Institutes of Health (NIH). We also compared publications on HF research in palliative care journals to that of palliative care research in nine major cardiology journals. It is important to note that primary palliative care (symptom management and conversations provided by frontline providers) must be distinguished from specialist palliative care, which involves more complex skills in symptom management and communication that take years of training to develop (Quill 2013). This manuscript focuses on specialist-level palliative care, given the calls for its integration into the plans for advanced HF patients.

Methods

Data Sources and Search Strategy

We searched for palliative care key terms in titles and abstracts of 9 cardiology journals (Table 1). We used the same terms to search conference proceedings and online program planners of 4 major cardiology conferences (Table 2). Our search differentiated between seminar sessions and poster presentations. Next, we searched grant titles in the NIH Research Portfolio Online Reporting Tools Expenditures and Results (RePORTER) system to find funding relevant to palliative care and HF (National Institute of Health 2015). We reviewed grant abstracts where titles may have been ambiguous.

The palliative care key terms were derived from our previous work (Gelfman 2008, Gelfman 2013): *palliative care, end of life, hospice, goals (of care), preferences (for treatment)*,

decision making. At least one HF term (*(heart) failure, end-stage, defibrillator*) was included in each article.

Search terms erred on the side of being overly inclusive to prevent exclusion of articles of interest.

Assessment of Relevance

The primary author (KX) reviewed each article to assess whether palliative care in HF was the “Main Topic”, constituted a “Significant Mention”, or was “Not Relevant.” A second reviewer (NG) reviewed a subset of the items. Their ratings were compared to calculate inter-rater agreement. Conflicts were resolved by consensus.

Review of Palliative Care Literature

We used similar strategies to search for the HF terms in 2 palliative care journals to determine if the research was being done but not being published in the cardiology literature.

Results

Journals Articles

Of HF articles, 0.1% had palliative care as the Main Topic. We found the highest percentage of titles in the Journal of the American College of Cardiology: Heart Failure (1.1%). The Journal of Cardiac Failure published the highest absolute number of titles pertaining to palliative care. The total percentage of HF articles with palliative care as the Main Topic across all cardiology journals was 0.1%. Inter-rater agreement for journal articles was 90.7%.

In the palliative care literature, we found a higher percentage and a larger absolute number of pertinent articles. The Journal of Pain and Symptom Management had 31 articles (1.3%) with HF as the Main Topic. The Journal of Palliative Medicine had 16 articles (1.1%) with HF as the Main Topic. Inter-rater agreement was 98%.

Conferences

Only 1.2% of sessions and 0.4% of posters had palliative care as the Main Topic at conferences. Of all educational sessions, Heart Failure Society of America (HFSA) had the largest representation in Main Topic proceedings, with 9 seminars (3.1%) and 8 posters (0.9%). Overall, 2.8% of educational sessions and 0.8% of posters had any true mention of palliative care for HF. Inter-rater agreement for sessions and posters was 88%.

Grants

NIH funding for palliative care research in HF came from 5 institutes (Table 3). The largest amount came from the National Heart, Lung, and Blood Institute (NHLBI) (1548 grants, ~\$13.1 billion). Yet, based on its overall budget, NHLBI had the lowest percentage of funding for palliative care (3 grants, <0.1% of total HF funding, \$4.9 million). In comparison, National Institute of Nursing Research (NINR), with the smallest amount of funding dedicated to HF research (55 grants, \$590 million), contributed more funding to palliative

care in HF research (20.0% of total HF funding, 11 grants, \$5.1 million). Inter-rater agreement on grants was 95%.

Discussion

To our knowledge this is the first study to concretely document the dearth of palliative care-focused literature, conference proceedings, and research funding within the realm of HF. The prevalence we found is considerably lower than the percentage of palliative care in medical literature (0.4% in 2005) and that of palliative oncology in oncology literature (0.6% in 2006) (Tieman 2008, Hui 2011). Funding is particularly low; of \$45 billion in NIH funding for HF, only \$13.6 million funded palliative care topics. Funding for palliative care was 0.03% of overall HF funding.

One of the reasons palliative care is not better integrated into the care of these patients is likely due to the lack of research being published or funded. Although some research on palliative care in HF exists in palliative care journals, it is not being published in cardiology journals. In terms of funding by NIH institute, more funding comes from NINR, which traditionally funds palliative care research and houses the Office of End of Life and Palliative Care Research, than from NHLBI, which is the largest contributor to HF research funding overall. However, NINR has one of the smallest NIH budgets, and this topic does not fall under the purview of palliative care alone. Although HF organizations have called for better integration of palliative care, this study shows these calls are not reflected in publications or funding. Education on palliative care at major cardiology conferences is similarly lacking.

To improve publications, journals could create a series on palliative care in HF because palliative care currently does not fit well into any existing HF subcategory. It is often not even a keyword used to categorize an article for publication. Although some conferences have tracks relating to palliative care, focusing more on these sessions or elevating them to a plenary would emphasize the role of palliative care for patients with advanced HF. Finally, these data can be used to advocate that the NIH provide better palliative care research funding. Having both “set-aside” funds as well as study sections with palliative care expertise would increase this research base.

There are some potential limitations to these findings. Though our search terms were derived from similar studies and expert consultation, some phrases may have been overlooked thus limiting the search yield, such as phrases related to communication, quality of life, and primary palliative care. Another limitation is that variations between journal and conference proceeding formats make it possible that articles or sessions may have been missed. To combat this, we broadened our search using word stems and strung multiple variants together using Boolean modifiers. Given the large number of patients with HF we specifically chose publications and conferences with the broadest reach to the general cardiology community as opposed to focusing on HF specialist-level journals, which might be narrower in focus. In addition this study was directed towards physician-oriented resources and does not take into account non-physician (i.e. nursing) oriented journals and conferences, which constitute a significant amount of palliative care literature. Due to lag

time in bringing our research to publication our search did not include data after 2013. While there have been increases in funding and publications, we still believe that our novel findings add to the current understanding of how much work needs to be done. We believe that this is the first research to specifically quantify the dearth of funding and presentations – so even with these limitations our findings create a concrete starting point from which future progress can be measured. Only by improving the evidence base for patients with HF can we assure optimal symptom control and alignment of treatment with patient preferences – thus assuring a higher quality of care for these patients and their families.

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Table 1
Publications on Palliative Care in Heart Failure Treatment (2009–2013)

To determine the number of articles in which palliative care in heart failure was either a Main Topic or Significant Mention, the authors used keywords to query the websites of each of the major cardiology journals. A similar process was used to determine the number of articles in palliative medicine journals in which heart failure was either a Main Topic or Significant Mention.

Cardiology Journals			
	Total # Heart Failure Titles N	Palliative Care as Main Topic N (%)	Palliative Care as Significant Mention N (%)
Circulation	5318	1 (0.0%)	0 (0.0%)
Circulation: Cardiovascular Quality and Outcomes	563	1 (0.2%)	2 (0.4%)
Circulation: Heart Failure	715	1 (0.1%)	0 (0.0%)
Heart Rhythm	2337	1 (0.0%)	0 (0.0%)
Journal of the American College of Cardiology	4956	1 (0.0%)	0 (0.0%)
JACC: Cardiovascular Interventions	1179	0 (0.0%)	0 (0.0%)
JACC: Heart Failure	87	1 (1.1%)	0 (0.0%)
Journal of the American Heart Association	409	0 (0.0%)	0 (0.0%)
Journal of Cardiac Failure	959	5 (0.5%)	4 (0.4%)
Totals	16523	11 (0.1%)	6 (0.0%)
Palliative Care Journals			
	Total # Palliative Care Titles N	Heart Failure as Main Topic N (%)	Heart Failure as Significant Mention N (%)
Journal of Pain and Symptom Management	2340	31 (1.3%)	7 (0.3%)
Journal of Palliative Medicine	1501	16 (1.1%)	10 (0.7%)
Totals	3841	47 (1.2%)	17 (0.4%)

Table 2
Conference Proceedings on Palliative Care in Heart Failure (2009–2013)

To determine the number of conference seminars or posters in which palliative care in heart failure was either a Main Topic or Significant Mention, the authors used a series of keywords to either search electronic copies of the final program books or query the websites of each of the cardiology conferences.

		Total # Heart Failure Titles N	Palliative Care as Main Topic N	Palliative Care as Significant Mention N (%)
American College of Cardiology	Seminar	346	4 (1.2%)	8 (2.3%)
	Poster	1223	1 (0.1%)	5 (0.4%)
American Heart Association	Seminar	875	4 (0.5%)	13 (1.5%)
	Poster	1252	3 (0.2%)	3 (0.2%)
Heart Failure Society of America	Seminar	294	9 (3.1%)	8 (2.7%)
	Poster	929	8 (0.9%)	5 (0.5%)
Heart Rhythm Society	Seminar	295	4 (1.4%)	1 (0.3%)
	Poster	416	5 (1.2%)	2 (0.5%)
Totals	Seminar	1810	21 (1.2%)	30 (1.7%)
	Poster	3820	17 (0.4%)	15 (0.4%)

Table 3
National Institute of Health Funding for Palliative Care in Heart Failure Research (2009–2013)

To determine the unique grants and their dollar amounts for research studies in which palliative care in heart failure was either a Main Topic or Significant Mention, the authors used a series of keywords to query NIH RePORTER, the NIH electronic database that provides information on all NIH-funded research projects.

	# of Heart Failure Grants N	Palliative Care in Heart Failure Main Topic N (%)	Palliative Care in Heart Failure Significant Mention N (%)	Heart Failure Funding million \$	Palliative Care in Heart Failure Funding million \$ (%)
National Cancer Institute	62	1 (1.6%)	0 (0.0%)	\$18,794	\$0.2 (<0.1%)
National Heart Lung Blood Institute	1548	3 (0.2%)	4 (0.3%)	\$13,071	\$4.9 (<0.1%)
National Institute of Aging	128	3 (2.3%)	4 (3.1%)	\$4,615	\$3 (0.1%)
National Institute of Mental Health	22	0 (0.0%)	1 (4.5%)	\$6,062	\$0.1 (<0.1%)
National Institute of Nursing Research	55	11 (20.0%)	4 (7.3%)	\$590	\$5.1 (0.9%)
Other	1106	0 (0.0%)	0 (0.0%)	\$1,654	\$0 (0.0%)
Totals	2921	21 (0.7%)	13 (0.4%)	\$44,785	\$13.6 (<0.1%)