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A Strategy to Increase Outpatient Palliative Care Referrals in Heart Failure Patients

Brette Svensson

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Abstract

The purpose of this project was to determine if using the Kansas City Cardiomyopathy Questionnaire (KCCQ) as a screening tool for heart failure patients leads to an increase in outpatient palliative referrals. Heart failure is a prevalent disease with both high symptom burden and mortality. Outpatient palliative care could improve quality of life for these patients, but research on outpatient palliative care is new and there is ambiguity surrounding the timing of referral. The project utilized a convenience sample of 21 adult patients in an outpatient facility over a 12-week timeframe. Participants self-completed the short form version of the KCCQ during an initial visit or hospital follow-up. Of the 21 participants, none received a palliative care referral. Ultimately, new patient visits were examined because it was unexpectedly found that no-shows dropped off the palliative clinic schedule, so retaining referral data is one paramount issue to address. Use of a screening tool did not lead to increased referrals in this project, suggesting further research is needed to identify innovative practices that will impact utilization of outpatient palliative services.

Keywords: outpatient palliative care, heart failure, palliative referral, KCCQ

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A Strategy to Increase Outpatient Palliative Care Referrals in Heart Failure Patient

Heart failure (HF) is a progressive chronic disease affecting over six million people in the United States and approximately eight million patients will have a HF diagnosis within the next 15 years (Bakitas et al., 2017). A diagnosis of HF carries a 50% mortality within five years, resulting in approximately 300,000 deaths each year; thus, managing this disease is increasingly important (Bakitas et al., 2017; Yancy et al., 2013). The prognosis in HF varies and many patients experience recurrent exacerbations with high symptom burden such as pain, depression, dyspnea, and anxiety, which negatively affects patients' quality of life (Teuteberg & Teuteberg, 2016). Rehospitalization rates in HF are high, particularly within the first 30 days after hospital discharge, and the Centers for Medicare and Medicaid services apply payment penalties to facilities with excessive 30-day readmissions (Chamberlain et al., 2017). The disease is costly to the healthcare system, averaging \$23,077 per patient for hospitalizations and overall annual expenditures exceeding \$30 billion (Yancy et al., 2013). To improve symptom burden, quality of life, healthcare cost, and overall integrated care of HF patients, the 2013 American College of Cardiology/American Heart Association Guidelines recognize and recommend palliative care services for these patients (Yancy et al., 2013). Additionally, in its report "Dying in America," the Institute of Medicine (IOM) warrants all individuals with "advanced serious illness" should have access to palliative services in all healthcare settings, not just inpatient or hospital units (IOM, 2014, p.3). Some palliative programs have already expanded into the community and skilled nursing facilities, where palliative care is associated with decreased Medicare expenditures (Meier & Bowman, 2017). Outpatient palliative care is one solution to address the needs of HF patients who are not hospitalized, follow patients during the variable disease

prognosis, and assist them in areas such as advance care planning and symptom burden (Rogers et al., 2017).

Meier and Bowman (2017) define palliative care as “specialized medical care focused on providing patients with relief from the symptoms and stress of a serious illness” (p.74). Palliative care is applicable at any point during the lifespan, although frequently it is associated with only end of life care. Instead of traditional fee-for-service payment, alternative payment models are becoming more prevalent which draw attention to treatment of high-cost, high-risk patients. (Meier & Bowman, 2017; Yancy et al., 2013). Responding to Medicare’s initiatives and the drive to reduce cost, hospital palliative programs are growing rapidly and demonstrating savings of up to \$5,000 per admission for some inpatient stays; additional savings are noted when palliative consults are made earlier during a hospital stay (Meier & Bowman, 2017).

Quality Indicators in Outpatient Palliative Care

As palliative care programs grow and expand into the community, the question of quality indicators and measurement has emerged (Mizuno et al., 2017). Outpatient palliative care is a relatively new endeavor and quality indicators for heart disease in this field are not well-established (Mizuno et al., 2017). Furthermore, the current evidence base is not robust and no standardized practices yet exist (Gandesbery, Dobbie, & Gorodeski, 2017). However, recent research suggests translating quality indicators in cancer patients to those with heart disease as both patient populations experience similar symptoms of dyspnea, pain, and fatigue, particularly in advanced illness (Mizuno et al., 2017). Mizuno et al. (2017) define several potential quality indicators for heart disease, including: infrastructure, human resources, availability of palliative teams, frequency of documentation, disease-specific patient assessment, and screening and timing of palliative services implementation.

Uncertainty of Timing as a Barrier to Referral

One barrier to palliative care referral is the uncertainty of when to refer, which is affected by multiple factors such as conflicting provider perceptions, patient understanding, lack of knowledge, or limited time (Bekelman et al., 2016; Smith et al., 2013; Ziehm et al., 2016). One proposed quality indicator in palliative care is the screening and timing of services (Mizuno et al., 2017). Use of a screening tool could address the uncertainty of timing for outpatient palliative referral by providing patient-reported data on symptoms (Mizuno et al., 2017). The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a validated patient-centered tool recommended for routine use, in which higher scores indicate better health status (Hawwa et al., 2017; Kelkar et al., 2016). Green, Porter, Bresnahan, and Spertus (2000) developed this self-reported tool as a disease status measure specifically for HF patients. The KCCQ measures quality of life, symptoms, social domains, and functional status (Green et al., 2000). Use of the KCCQ may help standardize practices of screening and timing palliative care implementation, and possibly lead to increased outpatient palliative referrals.

Applicability to Practice

Benefits of palliative care outweigh risk. Patient-centered care involves customized plans that reflect individual values and needs such as pain management or advance care planning (Meier & Bowman, 2017). The variable prognosis in HF also requires care that is not only evidence-based but focused on symptom burden and mental health needs throughout disease progression (Bekelman et al., 2011a; Bekelman et al., 2013; Rogers et al., 2017). Because the evidence base for outpatient palliative care is not yet robust, both qualitative and quantitative studies provide valuable data; qualitative studies can provide insight into human experiences and should not be disregarded (Williamson, 2009). As a medical specialty, palliative care merits

consideration in practice despite few randomized control trials. Qualitative evidence provides understanding of the current state of palliative care, barriers and facilitators to referral, and provider and patient needs.

Problem Statement

Outpatient palliative care for HF patients could improve symptoms and quality of life (Bakitas et al., 2017). However, ambiguity exists surrounding the timing of referral (Gandesbery et al., 2017). Use of a screening tool addresses this uncertainty by providing objective patient data on symptoms to determine necessity of a palliative consult (Mizuno et al., 2017).

Purpose

The purpose of this project was to increase palliative care access for heart failure patients. The primary objective was to increase the number of referrals to outpatient palliative care in a population of adult patients living with heart failure through use of the KCCQ.

Clinical Question

In adult patients with a diagnosis of heart failure, does use of the Kansas City Cardiomyopathy Questionnaire increase total referrals to outpatient palliative care by 25% over a 12-week timeframe? The diagnosis of heart failure included New York Heart Association classifications I - IV to capture a patient population with a wide range of symptoms, with the intent to increase referrals regardless of disease stage. The KCCQ was the instrument of choice and 12 weeks was chosen as the implementation timeframe.

Review of Literature

A search of PubMed, CINAHL, and Cochrane Library databases was performed. The search was limited to studies in English and published from the years 2000-2017, which included one study accepted for publication in 2017 although not published yet in print. Qualitative and

quantitative studies, systematic reviews, meta-analyses, and clinical practice guidelines were included in the search. Although an abundance of published evidence exists for general palliative care, studies specific to outpatient clinics are recent and few. Therefore, the search had few limitations, no geographical limits, and key words remained broad because increased specificity yielded no results.

The search produced 116 articles. No systematic reviews from Cochrane were identified, which was not unexpected as outpatient palliative research is recent (Bekelman et al., 2011a). Duplicates and articles that did not address key terms in the title or abstract were removed, yielding 40 articles for review. Articles were included if they addressed palliative care services for HF patients in the outpatient setting, or the time frame and structure of referral processes. Articles were excluded if they focused on inpatient care, palliative for other disease processes with no mention of heart failure, palliative care for non-adults, or palliative care focused solely on end of life. Application of inclusion and exclusion criteria yielded 18 articles and after initial literature review a new randomized control trial emerged, which was added and appraised. A clinical practice guideline was identified using reference lists which yielded a count of 20 articles for in-depth analysis (Appendix B).

Overall, two literature reviews, one case report, four qualitative studies, and 12 quantitative studies (six descriptive studies, two pilot trials, two randomized control trials, one case series, and one case control) were appraised (not including the practice guideline). Quantitative studies often included some qualitative components as well. The articles were evaluated using GRADE criteria, in which grade of recommendation ranges from weak with very low-quality evidence to strong with high-quality evidence (Guyatt et al., 2008).

General Results

Studies commonly used convenience samples and had small sample sizes. These limitations affect generalizability so conclusions were examined with careful consideration of each study's potential bias. In addition to the human experience, qualitative studies help discover full descriptions to understand a reality and explain an individual's perceptions (Williamson, 2009). Therefore, although outpatient palliative care is a newer field and often difficult to measure, qualitative studies containing patient or provider experiences and preferences were not discounted.

Literature Reviews and Studies with Provider Samples

The literature reviews and studies with provider samples demonstrated overall weak recommendations but provided valuable insight into the current state of outpatient palliative care. A literature review by Quaglietti et al. (2000) examined issues associated with integrated care of HF patients and supports a multidisciplinary approach to outpatient management. However, the authors did not define their methods, so their conclusions cannot be affirmed. Mizuno et al. (2017) identified seven potential quality indicators for heart failure in their literature review using well-established indicators for cancer patients, and supported use of the KCCQ as a disease-status measure.

Studies with provider samples reported poor communication, limited time, and lack of knowledge as barriers to palliative referral (Bekelman et al., 2016; Smith et al., 2013; Ziehm et al., 2016). Furthermore, conflicting viewpoints of different providers (nurse, internal medicine physician, specialist) contributed to confusion on if or when to initiate palliative services (Ziehm et al., 2016). Authors therefore suggested continued education for both patients and providers (Bekelman et al., 2016; Ziehm et al., 2016).

Smith et al. (2013) performed a cross-sectional survey of outpatient palliative care clinics. The authors found that clinics varied widely in structure, staffing, and clinic days, and there is currently no consensus on optimal clinic structure (Smith et al., 2013). There were also diverse definitions of success depending on clinic foundation (hospital, hospice, cancer center); thus, a hospital-based program might be more focused on rehospitalization rates, whereas hospice-based might focus more on symptom management. Therefore, because outpatient clinics are diverse, innovation was touted as key to sustainability of outpatient programs (Smith et al., 2013).

Studies with Patient Samples

Studies with patient samples demonstrated a large range of sample types, study purposes, and outcomes, with one current published randomized control trial. Implementation of palliative care interventions generally yielded improvement in symptom burden, quality of life, and advance care planning (Bekelman et al., 2013; Evangelista et al., 2012a; Evangelista et al., 2012b; Evangelista et al., 2014b). Bakitas et al. (2017) performed a small clinical trial, the ENABLE-CHF trial, to study feasibility of early palliative care and longitudinal outcomes for patients and caregivers. Using a purposive sample from cardiology clinics, palliative care was associated with a significant decrease in hospital days. Rabow et al. (2004) explored the effect of outpatient palliative consultation on multiple patient outcomes over the course of one year. The authors did not find statistically significant differences in depression or quality of life; however, during post-study feedback the authors noted 69% of patients in their randomized control trial expressed desire to receive palliative care earlier in the treatment course. Other studies also supported earlier palliative referral as a beneficial adjunct to treatment (Bakitas et al., 2017; Bekelman et al., 2011b; Gandesbery et al., 2017).

Rogers et al. (2017) performed the first randomized control trial of a longitudinal palliative care intervention (PAL-HF) with adequate sample size and gender representation. In this single-center clinical trial, participants' scores on the KCCQ ($p = 0.030$) and Functional Assessment of Chronic Illness Therapy-Palliative Care Scale ($p = 0.035$) both showed significant improvement when palliative care was added to usual care. Additionally, patients reported improvement in depression, anxiety, and spiritual well-being, demonstrating interdisciplinary palliative care is both feasible and beneficial to HF patients (Rogers et al., 2017). This finding is supported by Gandesbery et al. (2017) who described experiences of an integrated outpatient palliative and HF clinic initiative.

Among studies with patient samples the KCCQ was utilized or mentioned by four different author groups (Bakitas et al., 2017; Bekelman et al., 2011a; Mizuno et al., 2017; Rogers et al., 2017). The Edmonton Symptom Assessment Scale (ESAS) was also frequently used; however, three of four studies that used the ESAS were published by the same primary author which may indicate the researcher's preference rather than applicability in multiple settings. The KCCQ, however, shows applicability in numerous settings and emerged as a preferred measure. Overall, the studies with patient samples show diversity in outcomes, demonstrating that palliative care is beneficial to patients but warrants additional research.

Conclusions from Literature

Due to limits in generalizability the overall grade of evidence on available literature on outpatient palliative care in HF is a weak recommendation with moderate quality evidence (Guyatt et al., 2008). Generally, the studies in this project's literature review contained very specific population characteristics. Convenience samples of mostly males were common which likely reflects the overall increased prevalence of HF in men compared to women (Yancy et al.,

2013). The PAL-HF trial was the only study to contain approximately equal gender representation in an effort to reflect a more diverse cohort (Rogers et al., 2017).

Although the limits in generalizability are evident, the diversity of outpatient palliative clinics shows that services can be adjusted for different types of patient populations and healthcare settings. The KCCQ is confirmed as a recommended patient-reported outcome measure, which is consistent with findings by Bekelman et al. (2011a), Hawwa et al. (2017), and Kelkar et al. (2016). Future use of validated tools in well-designed trials (such as replication of the PAL-HF or ENABLE-CHF trials) is needed to build a larger evidence base. Additionally, qualitative data demonstrate that innovation, strategic financial planning, and adaptability are necessary for clinic sustainability, and definitions of success should be defined (Smith et al., 2013).

Conceptual Framework: Rosswurm and Larrabee Model

Mary Rosswurm and June Larrabee developed a “model for change to evidence-based practice” and published it in 1999 (Rosswurm and Larrabee, 1999, p.317). One unique aspect of the model is derivation from both qualitative and quantitative data. Qualitative data, although not considered high-level, provides important insight into human experiences (Williamson, 2009). Therefore, the model is applicable to this project because many articles in the literature review contained qualitative components.

The Rosswurm and Larrabee Model uses change theory to guide practitioners through its process, which can adapt to various healthcare settings (Rosswurm and Larrabee, 1999). Feasibility should be considered as the model is based on the use of existing evidence and does not create new knowledge (Rosswurm and Larrabee, 1999). Rosswurm and Larrabee point out that if evidence is weak, practice or policy changes may not be recommended until additional

research is accomplished. The model is comprised of six steps: 1. Assess need for change in practice, 2. Link problem interventions and outcomes, 3. Synthesize best evidence, 4. Design change, 5. Implement the change and evaluate, and 6. Integrate and maintain (Rosswurm and Larrabee, 1999). The steps follow a logical sequence and allow for backward or forward flow until integration and maintenance are achieved.

Project Connection to Conceptual Model

In assessing a need for practice change it is imperative to include stakeholders, as noted in Step 1 of the model. Stakeholders are instrumental in an intervention's sustainability pending results at the project's conclusion (Rosswurm and Larrabee, 1999). Project preparation involved key providers and staff who participated in the planning and implementation phases. In Step 2, problem interventions are linked to outcomes. The proposed intervention in this project was a valid, reliable screening tool; the outcome was number of referrals to an outpatient palliative care clinic. Step 3, synthesis of best evidence, is demonstrated in the systematic review of literature. Feasibility, benefit, and risk of the proposed intervention were considered. The anticipated risk was very low and did not outweigh potential benefit. In Step 4, design a change in practice, simplicity and ease of integration of the intervention are factors in acceptance of the change (Rosswurm and Larrabee, 1999). Input from key staff and outside experts guided the plan for integration of the tool in an attempt to create simplicity in the change.

Implementation in Step 5 of the model is typically viewed as a pilot study. After a designated time, the coordinator or student investigator elicits staff feedback, patient feedback, and quality improvement input to determine whether to adapt, adopt, or reject the change (Rosswurm and Larrabee, 1999). This project gathered data over a 12-week timeframe. Although

the primary outcome was number of referrals, staff and provider feedback on the intervention was useful for discussion and future directions.

If project goals are achieved or there is positive feedback the intervention can progress to Step 6, integrate and maintain. Strategies to maintain the practice in this step involve monitoring process and outcomes (Rosswurm and Larrabee, 1999). Presenting staff with continued education on the change is also feasible. If outcomes change, the logical flow of the model allows the investigator to revisit any steps in the process, whether the intervention was unsuccessful or if it sustains for a long period of time.

Implementation and Evaluation: Subjects

The participants of this quality improvement study were adult patients with a primary diagnosis of heart failure seen in a comprehensive care clinic. Participants were recruited by convenience sampling when they arrived for a first-time appointment or as a hospital follow-up visit; these visits are allotted at least one hour. The purpose of using longer patient visits was to minimize impact on clinic workflow as well as reduce potential cost, therefore established visit patients were not approached for the study. The total sample size was set at 200 participants. Inclusion criteria included 18 years of age or older presenting for a first-time visit or a hospital follow-up, a diagnosis of heart failure, and English speaking. Exclusion criteria included unable to provide voluntary consent, inability to read and complete the KCCQ without assistance from another person, or a diagnosis of dementia.

Setting

The study site was a public suburban outpatient facility located in the southeastern United States in operation since 2016. Within the facility are heart failure and palliative specialty clinics sharing clinic space, and the facility maintains nine total exam rooms. Patients seen in both

specialty clinics are those who have been referred by another healthcare provider, from either the hospital or another clinic. The heart failure clinic is nurse-managed and employs the following: two registration staff, one charge capture analyst, one manager, one assistant manager, one social worker, seven registered nurses, four medical assistants, two pharmacists, and four nurse practitioners. The palliative clinic is staffed primarily by the palliative medical director as well as a licensed clinical social worker. The heart failure clinic is open full time, five days a week. The palliative clinic is open two days a week and utilizes two of the nine exam rooms. Patients for both clinics therefore share a waiting room.

Instrument

The instrument of choice for this project was the KCCQ, a patient-reported, disease-specific health status measure for heart failure patients (Green et al., 2000). The KCCQ is a valid tool in which lower scores indicate worsening disease status, and scores range from 0 to 100. Reliability of the KCCQ (Cronbach's alpha) is high at 0.94 (Arnold et al., 2012). The tool presents questions that quantify physical limitations, symptoms, self-efficacy, social interference and quality of life (Green et al., 2000). Other studies have compared patient-reported instruments and confirmed the KCCQ's validity and reliability, and recommend it for routine use (Hawwa et al., 2017; Kelkar et al., 2016).

The original KCCQ is a 23-item questionnaire but a short form was developed, the KCCQ-12, which retains the reliability and validity of the original form (Spertus & Jones, 2015). The concordance between the KCCQ-12 and original format range from 0.93 to 1.0 among all domains, demonstrating high correlation, and scores also range from 0 to 100 (Spertus & Jones, 2015). The KCCQ-12 is more feasible to implement in practice. Therefore, although the original version was available for use in the facility's electronic charting system, the short-form version

was chosen for feasibility and ease of use in practice. Furthermore, a paper format of the questionnaire was utilized for participants to mark their own answers as well as retain for data collection purposes.

Intervention and Data Collection

The study protocol was approved by the institutional review board at Georgia State University. Support staff included four nurses who agreed to complete human subjects research training through the Collaborative Institutional Training Initiative (CITI). These CITI-trained nurses performed the recruitment, informed consent, and administration of the questionnaire after obtaining institutional review board approval from Georgia State University. When a potential participant arrived to check-in, front desk staff notified one of the trained nurses. The nurse approached the potential participant for recruitment and introduced the purpose of the study. If the participant expressed interest, the nurse interviewed the participant for eligibility in a private room using a recruitment script. If the participant volunteered for the study, consent was obtained by the trained nurse and the paper questionnaire provided for the participant to self-administer. At this point, participation in the study was complete. The clinic visit followed per protocol which included the nurse's SBAR (situation, background, assessment, recommendation) to the provider. The SBAR could include KCCQ-12 data; however, the trained nurses did not disclose the purpose of the KCCQ-12 or recommend palliative care because nurse practitioners and physicians were excluded from the study to reduce bias. The investigator was available for questions by phone or email at all times during the study period for participants and clinic staff, and checked in by email or phone at least bi-weekly during the implementation phase. The implementation phase of the project occurred from August 28, 2018 to November 20, 2018.

Data Collection

Patient name and date of birth (DOB) were recorded on the paper copies of the KCCQ-12 when participants self-completed the questionnaire. The paper questionnaires were then stored in an envelope in a locked file cabinet in a locked office with limited personnel access. Name and DOB were used for chart review. Participants' personal health information was de-identified once chart review occurred in order to track and digitally store primary diagnosis, documentation of KCCQ administration, and presence or absence of a palliative referral. Name and DOB were removed and replaced with a numerical code in such a manner the participant could not be identified. These data were kept on an encrypted flash drive accessible only by the investigator and project chair. Final published data for this study are reported in aggregate form. Once data collection concluded the paper questionnaires were destroyed in a manner compliant with the study site's health system that rendered data recovery infeasible. Encrypted digital files with de-identified data will be kept for two years for potential future use and availability to other researchers.

Components of Analysis

Pre-implementation and post-implementation referral data were obtained from the palliative care medical director. These data did not include any personal health information. The number of referrals over the 12-week study timeframe were compared to numbers for the 12 weeks preceding the study start date to determine if total referrals increased. Microsoft Excel was used to store data but no additional statistical software was needed for this project.

Results

In the 12 weeks preceding implementation there were 39 total new patient visits to the palliative clinic. Of the 39 visits, 10 had a primary diagnosis of heart failure and 27 had a different diagnosis (Appendix A). Of the 10 heart failure patients, nine were referred from the heart failure clinic. Based on pre-implementation data, 12 referrals from the heart failure clinic to palliative care were needed to determine success. After implementation the palliative clinic saw 42 new patients. Of the 42 visits, seven had a primary diagnosis of heart failure and 35 had a different diagnosis. Of the seven heart failure patients, five were referred from the heart failure clinic. Thus, there was a 7.7% increase in total visits to palliative care but a 44.4% decrease in visits originating from the heart failure clinic.

There were 21 total participants in the study. Of the 21 participants, none received a referral to the palliative care clinic. The average age of participants was 60 years and ranged from 35 to 85, thirteen were male, and eight were female. Heart failure patients seen in palliative care were therefore all from outside the study sample.

It is important to note that new patient visits to palliative care are reported because it was discovered after the study began that no-show patients dropped off the schedule, so only actual visits were retrievable. Furthermore, such visits are reported because any study participant receiving a referral would be considered a new patient; this study did not examine follow-up visits. Data mining is possible to retrieve all referrals from the electronic health record but this task was beyond the scope of this project.

Discussion

The goal of a 25% increase in palliative care referrals for heart failure patients was not achieved. In fact, total referrals are unknown due to no-shows dropping off the palliative clinic

schedule. Addressing the retrieval of referrals is therefore one paramount issue that could be accomplished through adjustments in the electronic health record. If the true number of referrals was higher but no-shows were also higher, this could be one potential reason for fewer heart failure palliative visits. There was also an increase in palliative visits for diagnoses other than heart failure. This increase in visits may represent referrals from other specialty clinics or referrals originating from an inpatient stay.

None of the study participants received a palliative referral but the nature of the heart failure clinic visits could itself have been a barrier. Initial and hospital follow-up visits were chosen to allow for more time to complete the questionnaire and reduce workflow impact. However, these patients saw multiple professionals during a visit including a nurse, nurse practitioner, pharmacist, and sometimes social worker. The focus of these visits is more likely to establish or re-establish care, so adding palliative care as an additional intervention is not likely to occur. Examining established patients or patients who were actually referred to palliative care is an opportunity for future study. In particular, retrospective review of palliative referral origin (initial visit, hospital follow-up, established visit) in addition to the stage of HF may reveal insight into the circumstances of referral.

Data analysis for this project did not include severity of heart failure, such as New York Heart Association classification, or actual KCCQ-12 score. To the author's knowledge there is also no current recommendation for a cut-off KCCQ-12 score in relation to palliative referral. The age range of participants reflects the possibility of variable symptoms and disease stages among the sample, which is consistent with prior findings and contributes to uncertainty of referral timing in patients who are not hospitalized (Rogers et al., 2017).

Limitations

The inclusion and exclusion criteria could have been limitations and may have introduced bias. Participants who could self-complete the KCCQ may not have appeared to need palliative care, whereas a participant who needs assistance (perhaps due to cognitive impairment or dementia) might be viewed as more likely to benefit from palliative care. Using longer clinic visits also excluded all established patients, who may have stronger rapport with clinic staff. A healthcare provider may be more likely to initiate palliative care referrals for patients if they know them well rather than on a first-time visit. Established patients who positively view their HF clinic experience may be more likely to follow through with a palliative referral (Rabow et al., 2004).

Practice Implications

The clinical setting in this project is unique in that heart failure and palliative specialties utilize shared clinic space. Current evidence recommends innovation in designing palliative programs, therefore, future studies should strategize interventions that are not only evidence-based but individualized for clinic structure, purpose, and desired outcomes. This project demonstrates that use of the KCCQ as a screening tool does not necessarily lead to an increase in referrals, although the KCCQ-12 remains a reliable disease status measure that could be used for quality improvement efforts or symptom management. Organizational, system, or culture change may be necessary to progress palliative care referral to a level that is consistent with recommendations. Although palliative care can be feasibly included with usual care and has potential to reduce Medicare expenditures, there remains ambiguity surrounding the timing of referral (Meier & Bowman, 2017; Rogers et al. 2017; Ziehm et al., 2016). Initiating palliative referral in this project was at the discretion of the provider, so possible conflicting provider

viewpoints should continue to be addressed through education (Bekelman et al., 2016). Overall, palliative care is beneficial to HF patients and could impact rehospitalization rates, healthcare cost, symptom burden, and overall quality of life (IOM, 2014; Yancy et al., 2013).

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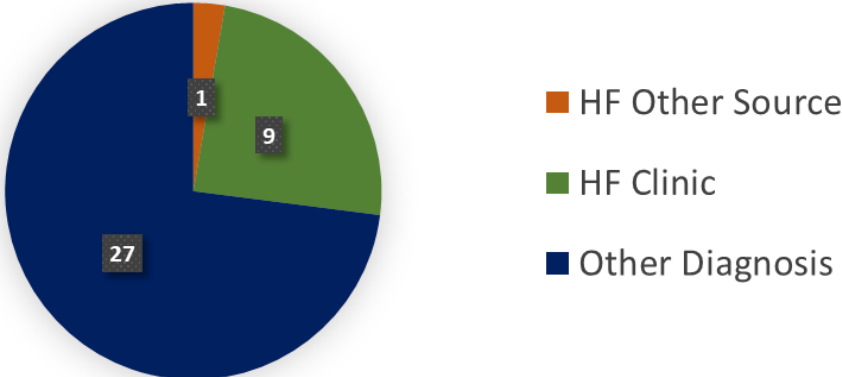
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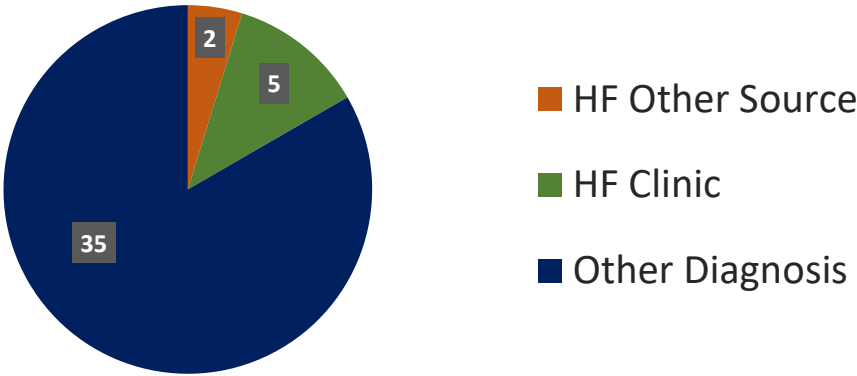
Appendix A

Palliative clinic new patient visits

Pre-Implementation



Post-Implementation



Appendix B

Evidence Matrix

| <p>Ahia, C. L., & Blais, C. M. (2014). Primary palliative care for the general internist: Integrating goals of care discussions into the outpatient setting. <i>The Ochsner Journal</i>, 14(4), 704–711.</p> | | | | <p>Grade Level of Evidence: Weak recommendation; very low-quality evidence (VIII)</p> |
|--|---|--|---|---|
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| <p>Purpose to provide an example of how to incorporate palliative care principles into practice.</p> | <p>Case report of a single patient</p> | <p>71 yr old male patient with COPD, CHF, Alzheimer’s dementia (N=1)</p> | <p>None; no outcomes measured in this study.</p> | <p>Authors outline a six-step approach to setting goals of care.</p> <p>Focus is narrow but offers practical tips.</p> <p>Outlines triggers for initiating or revisiting goals of care discussions in outpatient setting, as well as barriers (eg. time) to revisiting these discussions.</p> |
| <p>Mizuno, A., Miyashita, M., Hayashi, A., Kawai, F., Niwa, K., Utsunomiya, T., ... Anzai, T. (2017). Potential palliative care quality indicators in heart disease patients: A review of the literature. <i>Journal of Cardiology</i>, 70, 335–341. https://doi.org/http://dx.doi.org/10.1016/j.jjcc.2017.02.010</p> | | | | <p>Grade Level of Evidence: Weak recommendation; low quality evidence (VIII)</p> |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| <p>Narrative overview of potential quality indicators in heart disease and appropriate measurement.</p> | <p>Literature review using PubMed; however, total number of studies not reported.</p> | <p>n/a</p> | <p>n/a, no outcomes specifically measured from this review.</p> | <p>Authors used Donabedian Model to develop seven subcategories of quality indicators for palliative care using data from previous cancer studies.</p> <p>Few to no literature on quality indicators for palliative care in heart disease in general.</p> <p>Kansas City Cardiomyopathy Questionnaire has evidence for use as patient-reported outcome measure.</p> <p>Screening and timing are important but no consensus on best practices.</p> |
| <p>Quaglietti, S. E., Atwood, J. E., Ackerman, L., & Froelicher, V. (2000). Management of the patient with congestive heart failure using outpatient, home,</p> | | | | <p>Grade Level of Evidence: Weak recommendation; low quality evidence (VIII)</p> |

| and palliative care. <i>Progress in Cardiovascular Diseases</i> , 43(3), 259–274. https://doi.org/doi:10.1053/pcad.2000.19803 | | | | |
|---|--|---|--|---|
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Purpose to review issues associated with integrated care for CHF patients in the clinic setting and at home when palliation is the focus. | Literature review; however, authors do not define the methods. | n/a | n/a, no outcomes specifically measured. | Supports a multidisciplinary approach to outpatient palliative care management, but no best practices exist. Most studies on this topic at the time of review were observational; very few RCTs. |
| Bekelman, D. B., Rabin, B. A., Nowels, C. T., Sahay, A., Heidenreich, P. A., Fischer, S. M., & Main, D. S. (2016). Barriers and facilitators to scaling up outpatient palliative care. <i>Journal of Palliative Medicine</i> , 19(4), 456–459. https://doi.org/10.1089/jpm.2015.0280 | | | | Grade Level of Evidence: Weak recommendation; low quality evidence (VI) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| To understand organizational factors influencing adoption and use of outpatient palliative care using the example of CHF patients. | Cross-sectional qualitative study | Varied health care providers from the Veterans Health Administration; used stratified purposeful sampling. (N=17) | Interviews with semi-structured questions | Small sample with varied professions, limited generalizability. Limited time or PCP capacity a significant barrier. Participants in this study were already considering adoption of outpatient palliative care, so there was bias. |
| Ziehm, J., Farin, E., Seibel, K., Becker, G., & Koberich, S. (2016). Health care professionals' attitudes regarding palliative care for patients with chronic heart failure: An interview study. <i>BMC Palliative Care</i> , 15, 76–83. https://doi.org/10.1186/s12904-016-0149-9 | | | | Grade Level of Evidence: Weak recommendation; low quality evidence (VII) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| To assess health care professionals' attitudes to identify barriers and facilitators in CHF patients' access to palliative care. | Qualitative analysis with purposive sampling | Various health care professionals involved in the care of CHF patients in a German health care system. One general practitioner was trained in palliative care. 61% female (N=23) | Interviews that were examined using Mayring's qualitative content analysis | German study. Barriers: poor communication, different philosophies, lack of knowledge, referral timing. Supports early referral for improved QOL and awareness of services. Late referral reasons: patient misunderstanding. Small sample size. Palliative experience among participants varied. |

| Smith, A. K., Thai, J. N., Bakitas, M. A., Meier, D. E., Spragens, L. H., Temel, J. S., ... Rabow, M. W. (2013). The diverse landscape of palliative care clinics. <i>Journal of Palliative Medicine</i> , 16(6), 661–668. https://doi.org/10.1089/jpm.2012.0469 | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (VI) |
|--|--|--|--|--|
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| In-depth description of outpatient palliative care clinics. | Cross-sectional survey using convenience sample. | N=20 Outpatient clinics across several states. n=7 (hospital-based) n=5 (oncology/cancer center) n=6 (integrated health system) n=2 (hospice-based) | n/a, no outcomes measured specifically from this study. | Detailed information on innovation of outpatient clinics and how it relates to clinic success. Emphasis on strategic planning and financial preparation as key attributes to program sustainability. Definitions of success vary (eg. rehospitalizations, QOL) Wide range of clinic characteristics in staffing, number of clinic days, types of staff. Small sample, no national database to locate all existing outpatient palliative clinics. |
| Bekelman, D. B., Nowels, C. T., Retrum, J. H., Allen, L. A., Shakar, S., Hutt, E., ... Kutner, J. S. (2011b). Giving voice to patients' and family caregivers' needs in chronic heart failure: Implications for palliative care programs. <i>Journal of Palliative Medicine</i> , 14(12), 1317–1324. https://doi.org/0.1089/jpm.2011.0179 | | | | Grade Level of Evidence: Weak recommendation; low quality evidence (VII) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| To describe CHF patient and family caregiver concerns and needs; explore the utility of palliative care for this patient population. | Qualitative study | N=53 n=33 (adult outpatients with symptomatic CHF) n=20 (family caregivers) Purposive sample. NYHA Class II-IV No dementia Median age 64 yrs | Interviews transcribed and analyzed using constant comparative method. | Patient and caregiver needs varied. Used grounded theory to develop intervention themes on content, structure, and timing. Supports palliative care at the beginning of diagnosis and throughout illness rather than advanced or end of life stages. Detailed discussion of limitations, including small sample size that was predominantly white male patients. |

| <p>Ahluwalia, S. C., Levin, J. R., Lorenz, K. A., & Gordon, H. S. (2012). “There’s no cure for this condition”: How physicians discuss advance care planning in heart failure. <i>Patient Education and Counseling</i>, 91, 200–205. https://doi.org/http://dx.doi.org/10.1016/j.pec.2012.12.016</p> | | | | <p>Grade Level of Evidence: Weak recommendation; low-quality evidence (VII)</p> |
|---|---|--|--|--|
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| <p>Evaluate physician engagement in recommended elements of advance care planning (ACP) communication during outpatient visits.</p> | <p>Qualitative study</p> | <p>N=52 Prospective observational cohort at two VAMC hospitals. Patients 65 yrs or older (mean age = 71) and 98% were male. Recently hospitalized for CHF. Mean EF of 34%</p> | <p>Qualitative content analysis of 71 audio-recorded and transcribed visits.</p> | <p>Overall discussion of ACP was infrequent and did not describe life-limiting potential of the disease. Barriers included time, lack of knowledge, and feeling uncomfortable. Physicians in study were mostly male internists. Snapshot view of discussions so future possible discussions not recorded.</p> |
| <p>Bakitas, M., Dionne-Odom, J. N., Pamboukian, S. V., Tallaj, J., Kvale, E., Swetz, K. M., ... Kono, A. T. (2017). Engaging patients and families to create a feasible clinical trial integrating palliative and heart failure care: Results of the ENABLE CHF-PC pilot clinical trial. <i>BMC Palliative Care</i>, 16(1), 45–67. https://doi.org/10.1186/s12904-017-0226-8</p> | | | | <p>Grade Level of Evidence: Weak recommendation; moderate-quality evidence (III)</p> |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| <p>To study feasibility and site differences of an early palliative care trial; explore longitudinal outcomes for patients and caregivers; identify modifications to develop a larger RCT.</p> | <p>Pilot feasibility clinical trial</p> | <p>Purposive sample from cardiology clinics at two health centers. N=109 n=61 (patients) n=48 (caregivers) Patient characteristics: 50 yrs or older NYHA Class III-IV and/or AHA Stage C/D No dementia, no Axis I psychiatric disorder, no non-correctable</p> | <p>ENABLE CHF-PC (telephonic intervention) At baseline, 12, and 24 weeks Kansas City Cardiomyopathy Questionnaire (KCCQ), Memorial Symptom Assessment Scale-Heart Failure, Hospital Anxiety and Depression Scale, Patient Reported Outcomes Measurement Information System, Patient Assessment of Chronic Illness Care.</p> | <p>Relied on effect size (Cohen’s <i>d</i>) rather than hypothesis testing but <i>p</i>-values still reported. Only 50% response rate to recruitment and one site had high attrition which may account for some significant results. Small to moderate improvements in patient reported outcomes. Participants were mostly male. No control group.</p> |

| | | hearing impairment. | | |
|--|---|--|--|---|
| Bekelman, D. B., Nowels, C. T., Allen, L. A., Shakar, S., Kutner, J. S., & Matlock, D. D. (2011a). Outpatient palliative care for chronic heart failure: A case series. <i>Journal of Palliative Medicine, 14</i> (7), 815–821. https://doi.org/10.1089/jpm.2010.0508 | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (IV) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Describe patients seen in outpatient HF palliative care and the issues addressed. | Case series, retrospective review 3.5 year time period examined. | Nonprobability sample of patients from a university hospital system. N=50 Median age = 51 yrs Predominantly male and Caucasian. NYHA Class III-IV | KCCQ, PHQ-9 and GAD-7 (anxiety), MSAS-SF (symptom assessment) | 1-year mortality 14% suggesting much of patient population was not near end of life. Issues important to patients addressed first and advance care planning addressed later or not at all. Many patients did not return for follow-up visits, possibly to avoid discussion of care planning as it can be difficult. Substantial mental health needs (i.e. anxiety and depression). Emphasizes collaboration between palliative providers and HF team. |
| Evangelista, L. S., Lombardo, D., Malik, S., Ballard-Hernandez, J., Motie, M., & Liao, S. (2012b). Examining the effects of an outpatient palliative care consultation on symptom burden, depression, and quality of life in patients with symptomatic heart failure. <i>Journal of Cardiac Failure, 18</i> (12), 894–899. https://doi.org/http://dx.doi.org/10.1016/j.cardfail.2012.10.019 | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (IV) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Examine feasibility and effectiveness of palliative care consultation as an adjuvant to standard HF care in an outpatient setting. | Prospective comparative study | N=36 Convenience sample from a single university-affiliated medical center. Mean age = 53.6 yrs A control group was randomly selected from a different RCT performed by the same authors. | Charlson Comorbidity Index (CCI), Edmonton Symptom Assessment Scale (ESAS), PHQ-9, Minnesota Living with Heart Failure Questionnaire (MLHFQ) | Small sample size that authors note could lead to type II error. Women demonstrated more depressive symptoms than men. Improvements noted in symptom burden, depression, and QOL in both control and palliative consultation group, but more pronounced in palliative group ($p = .035$). |

| | | | | Larger RCTs needed to test specific HF-specific patient outcomes in palliative care. |
|---|-------------------------------|---|--|--|
| Evangelista, L. S., Motie, M., Lombardo, D., Ballard-Hernandez, J., Malik, S., & Liao, S. (2012a). Does preparedness planning improve attitudes and completion of advance directives in patients with symptomatic heart failure? <i>Journal of Palliative Medicine, 15</i> (12), 1316–1320. https://doi.org/10.1089/jpm.2012.0228 | | | | Grade Level of Evidence: Weak recommendation; low-quality evidence (VII) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Assess a palliative care intervention’s impact on health perceptions, attitudes, receipt of and knowledge of advance directives (AD), and completion of ADs in patients with HF. | Single descriptive study | N=36 Patients recruited during hospitalization for outpatient palliative care visit post-discharge 69% were NYHA Class II Primarily male Authors do not state if patients were from one hospital or many. | Advance Directive Attitude Survey (ADAS) | Study was very specific to completion of ADs. Results were significant for AD completion, receiving information, and family discussion of ADs, but sample size was small with no control group. Limited time frame; study done at baseline and 3 months. |
| Evangelista, L. S., Liao, S., Motie, M., Michelis, N. D., Ballard-Hernandez, J., & Lombardo, D. (2014a). Does the type and frequency of palliative care services received by patients with advanced heart failure impact symptom burden? <i>Journal of Palliative Medicine, 17</i> (1), 75–79. https://doi.org/10.1089/jpm.2013.0231 | | | | Grade Level of Evidence: Weak recommendation; low-quality evidence (VII) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Describe the nature of outpatient palliative care services. Describe levels of symptom burden during initial palliative consultation and 3 months post-discharge from a hospital stay. | Descriptive-exploratory study | N=36 Mean age = 53.9 years 72.2% male NYHA Class II-III Patients from a single university-affiliated medical center. | ESAS | Significant improvement in pain, anxiety, and dyspnea. Small sample. No control group. Study is a brief report and there is no abstract. |
| Evangelista, L. S., S. Liao, Motie, M., Michelis, N. D., & Lombardo, D. (2014b). On-going palliative care enhances perceived control and patient activation and reduces symptom distress in patients with symptomatic heart failure: A pilot study. <i>European Journal of Cardiovascular Nursing, 13</i> (2), 116–123. https://doi.org/10.1177/1474515114520766 | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (VII) |

| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
|---|---------------------------------|--|---|---|
| Obtain data on efficacy of palliative care services on increasing perceived control and activation in HF patients, and association between perceived control and activation on symptom distress. | Descriptive correlational study | Convenience sample of patients from a single tertiary care medical center. N=42 Mean age 53.9 yrs 69% of patients NYHA Class II | Control Attitude Scale (CAS-R), Patient Activation Measures (PAM), ESAS | 36 of 42 participants completed outpatient consultation and 29 returned for a follow-up visit. Increases in perceived control and activation were associated with a reduction in symptom distress. High proportion of NYHA Class II patients shows potential benefit to initiating earlier palliative referral. Several limitations including small sample, possible bias, attrition rate. |
| Gandesbery, B., Dobbie, K., & Gorodeski, E. Z. (2017). <i>Outpatient palliative cardiology service embedded within a heart failure clinic: Experiences with an emerging model of care</i> . Manuscript submitted for publication. | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (IV) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Describe initial experiences of an outpatient palliative service embedded in a cardiology clinic; characterize patients in an outpatient palliative cardiology service. | Retrospective review | N=80 Patients from a single clinic with 229 encounters from Aug 2015 – Mar 2017 Mean age = 59 yrs 65% male | ESAS, Palliative Prognostic Index (PPI) | Palliative and HF clinic occupy same building space. Integration was viewed as feasible. Pain and ADs by far most frequently addressed topics. Patients seen throughout disease including newly diagnosed. Large drop-off in follow-up visits. |
| Janssen, D. J. A., Spruit, M. A., Uszko-Lencer, N. H., Schols, J., & Wouters, E. F. M. (2011). Symptoms, comorbidities, and health care in advanced chronic obstructive pulmonary disease or chronic heart failure. <i>Journal of Palliative Medicine</i> , 14(6), 735–743. https://doi.org/10.1089/jpm.2010.0479 | | | | Grade Level of Evidence: Weak recommendation; low-quality evidence (VI) |

| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
|--|-------------------------------------|---|---|---|
| Assess severity of symptoms, presence of comorbidities, and provision of health care in outpatients with advanced COPD or CHF. | Cross-sectional observational study | N=80 (CHF patients) Convenience sample from an outpatient clinic in The Netherlands. NYHA Class III or IV 67.5% male | Charlson Comorbidity Index, Visual Analog Scale, Hospital Anxiety and Depression Scale. | Only 46% of CHF patients participated, so limited generalizability. Not representative of longitudinal trends. Multiple comorbidities present, fatigue and dyspnea highly prevalent symptoms. |
| Rabow, M. W., Dibble, S. L., Pantilat, S. Z., & McPhee, S. J. (2004). The comprehensive care team: A controlled trial of outpatient palliative medicine consultation. <i>Archives of Internal Medicine</i> , 164(1), 83–91. https://doi.org/doi:10.1001/archinte.164.1.83 | | | | Grade Level of Evidence: Weak recommendation; moderate-quality evidence (II) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Examine the effect of outpatient palliative consultation on multiple symptoms and patient outcomes. | Randomized control trial | N=90 (n=50 intervention group, n= 40 control group) Not blinded Mean age = 68.6 yrs 64% women | Rapid Disability Rating Scale-2, San Diego Shortness of Breath Questionnaire, Brief Pain Inventory, Profile of Mood States, Center for Epidemiological Studies Depression Scale, Spiritual Well-Being Scale, Multidimensional Quality of Life Scale-Cancer Version, Consumer Satisfaction Survey; exit interviews. Data collected over one year. | No CHF specific data. 69% of intervention patients desired to receive comprehensive care (palliative care) earlier when asked for feedback after study completion. No differences in depression, QOL, or pain, which could be explained by providers not discussing/offering treatments. No difference in utilization within the health care system. Qualitative data provided valuable insight into patient experiences. |
| Bekelman, D. B., Hooker, S., Nowels, C. T., Main, D. S., Meek, P., McBryde, C., ... Heidenreich, P. A. (2014). Feasibility and acceptability of a collaborative care intervention to improve symptoms and quality of life in chronic heart failure: Mixed methods pilot trial. <i>Journal of Palliative Medicine</i> , 17(2), 145–151. https://doi.org/10.1089/jpm.2013.0143 | | | | Grade Level of Evidence: Weak recommendation; low-quality evidence (II) |

| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
|---|---------------------------------------|--|--|---|
| Determine feasibility and acceptability of CASA intervention and identify improvements. | Prospective mixed-methods pilot trial | N=17 Nonprobability sample of patients from outpatient clinics and inpatient units of one medical center. All patients were male. Median age = 63 yrs | CASA (Collaborative Care to Alleviate Symptoms and Adjust to Illness) intervention; self-report measures (surveys) and interviews. | Primarily focused on QOL and symptom management. Intervention demonstrated feasibility in the study. Overall positive results but small sample size, all male, so less generalizability. |
| Yancy, C. W., Jessup, M. J., Bozkurt, B., Butler, J., Casey, D. E., Drazner, M. H., ... Wilkoff, B. L. (2013). 2013 ACCF/AHA guideline for the management of heart failure. <i>Journal of the American College of Cardiology</i> , 62(16), 147–239. https://doi.org/http://dx.doi.org/10.1016/j.jacc.2013.05.019 | | | | Grade Level of Evidence: Strong recommendation; low-quality evidence (VIII) |
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| Clinical guidelines to direct management of issues for adult CHF patients. | Clinical practice guidelines | n/a | n/a | Authors graded evidence by size of treatment effect. Palliative care consultation for newly diagnosed CHF patients may be beneficial. Advance directives are associated with lower levels of Medicare spending, lower likelihood of in-hospital death. Guidelines primarily focused on treatment modalities and have few recommendations on palliative care for HF patients. |

| <p>Rogers, J. G., Patel, C. B., Mentz, R. J., Granger, B. B., Steinhauser, K. E., Fiuzat, M., ... Tulskey, J. A. (2017). Palliative care in heart failure: The PAL-HF randomized, controlled clinical trial. <i>Journal of the American College of Cardiology</i>, 70(3), 331–341. doi: https://doi.org/http://dx.doi.org/10.1016/j.jacc.2017.05.030</p> | | | | <p>Grade Level of Evidence: Strong recommendation; moderate-quality evidence (II)</p> |
|---|---|--|---|--|
| Hypothesis/ Questions | Design | Sample | Measurement | Results/Implications |
| <p>Effect of an interdisciplinary palliative care intervention on various patient outcomes.</p> | <p>Prospective, 2-arm, single-center clinical trial</p> | <p>150 patients randomized to usual care (UC) or usual care + palliative intervention (UC + PAL), pts were screened and enrolled based on rehospitalization risk and severity of illness.</p> <p>Mean age about 70 yrs for both groups and approx. half female</p> | <p>Kansas City Cardiomyopathy Questionnaire overall summary score, Functional Assessment of Chronic Illness Therapy-Palliative Care scale</p> | <p>This is the first RCT of a longitudinal palliative care intervention and it is focused on outpatient care. Authors attempted to select a diverse, high-risk cohort to better reflect the broader population.</p> <p>Not blinded because it was not feasible.</p> <p>Intervention duration was 6 months but patients followed until death or end of the study.</p> <p>Mortality and rehospitalization rates not very different after 6 months.</p> <p>Significant improvement in KCCQ scores ($p = 0.030$) and FACIT-pal ($p = 0.035$), as well as improvement in depression, anxiety, and spiritual well-being.</p> |