

ORIGINAL RESEARCH

Exploring Health Care Providers' Experiences of Providing Collaborative Palliative Care for Patients With Advanced Heart Failure At Home: A Qualitative Study

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BACKGROUND: The HeartFull Collaborative is a regionally organized model of care which involves specialist palliative care and cardiology health care providers (HCPs) in a collaborative, home-based palliative care approach for patients with advanced heart failure (AHF). We evaluated HCP perspectives of barriers and facilitators to providing coordinated palliative care for patients with AHF at home.

METHODS AND RESULTS: We conducted a qualitative study with 17 HCPs (11 palliative care and 6 cardiology) who were involved in the HeartFull Collaborative from April 2013 to March 2020. Individual, semi-structured interviews were held with each practitioner from November 2019 to March 2020. We used an interpretivist and inductive thematic analysis approach. We identified facilitators at 2 levels: (1) individual HCP level (on-going professional education to expand competency) and (2) interpersonal level (shared care between specialties, effective communication within the care team). Ongoing barriers were identified at 2 levels: (1) individual HCP level (e.g. apprehension of cardiology practitioners to introduce palliative care) and (2) system level (e.g. lack of availability of personal support worker hours).

CONCLUSIONS: Our results suggest that a collaborative shared model of care delivery between palliative care and cardiology improves knowledge exchange, collaboration and communication between specialties, and leads to more comprehensive patient care. Addressing ongoing barriers will help improve care delivery. Findings emphasize the acceptability of the program from a provider perspective, which is encouraging for future implementation. Further research is needed to improve prognostication, assess patient and caregiver perspectives regarding this model of care, and assess the economic feasibility and impact of this model of care.

Key Words: aging ■ health services ■ heart failure ■ palliative care ■ prognosis ■ qualitative

Advanced heart failure (AHF) is defined as advanced, persistent heart disease with symptoms at rest despite repeated attempts to optimize pharmacological and non-pharmacological therapy as shown by 1 or more of the following factors: frequent hospitalizations (≥ 3 per year), chronic poor quality of life with inability to accomplish activities of daily living, need for intermittent or continuous intravenous

support, or consideration of assistive devices as destination therapy.¹ More than 600 000 Canadians are currently living with heart failure, with approximately 10% of these patients having a diagnosis of AHF. Management of patients with heart failure costs more than 2.8 billion dollars per year.²

Specialist palliative care is a multidisciplinary intervention that focuses on optimizing quality of life for patients

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Supplementary Material for this article are available at <https://www.ahajournals.org/doi/suppl/10.1161/JAHA.121.024628>

For Sources of Funding and Disclosures, see page 10.

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CLINICAL PERSPECTIVE

What Is New?

- The HeartFull Collaborative integrates interdisciplinary cardiac and palliative care in a regionally organized model of collaborative, home-based palliative care for patients with advanced heart failure.
- Care is available on a 24 hour, 7 days per week basis through phone support as well as home visits by palliative health care practitioners.

What Are the Clinical Implications?

- This collaborative, shared model of care delivery improves knowledge exchange, collaboration, and communication between specialties, and leads to more comprehensive patient care.
- Barriers identified highlight areas for improvement as the program expands.
- This work highlights the need for system-level change to address limited access of homecare services and equipment for this patient population to help improve care delivery, as well as a need for review of admission criteria to inpatient specialist palliative care units.

Nonstandard Abbreviations and Acronyms

AHF	advanced heart failure
HCP	health care provider
NP	nurse practitioner
TLCPC	Temmy Latner Centre for Palliative Care

and families affected by life-threatening illness. Palliative care has been shown to improve quality of life, symptom burden, and family caregiver burnout, as well as reduce health care expenditures and hospitalizations.^{3–6} There is growing evidence that palliative care reduces distress, improves care satisfaction, and enhances perceived control and care activation among patients with AHF.^{3–6} Furthermore, adults with AHF who received palliative care services near the end of life were twice as likely to die at home compared with those who did not receive it.^{7,8} The Canadian Cardiovascular Society, American Heart Association, and the European Society of Cardiology guidelines each call for inclusion of palliative care support for patients with AHF.^{1,9–11} Care models for patients with AHF have been proposed that adopt an integrated community-based multidisciplinary team, including palliative care.^{12–14} While the trend for these models is growing, there are currently few supportive palliative care programs in existence that serve this population, and none of these models have been thoroughly

evaluated.¹⁵ To meet the needs of patients with AHF and their caregivers, efforts focused on evaluating optimal collaborative models for providing primary palliative care for this population are needed.^{13,16,17} While existing studies address patient and caregiver perceptions of palliative care for patients with AHF, the recent randomized clinical trials in palliative care and AHF did not include qualitative clinician feedback nor the option for practitioners to talk about their experiences with delivering care.^{18–29}

The HeartFull Collaborative integrates palliative care physicians, cardiologists, community palliative care nurse practitioners (NPs), hospital-based cardiology NPs and primary care physicians in a regionally organized model of collaborative, home-based palliative care for patients with AHF.³⁰ Care is available on a 24-hours, 7 days per week basis through phone support as well as home visits by palliative HCPs. Referral to this model requires that patients have a diagnosis of AHF (as defined above), but enrollment is otherwise unrestricted by prognostic criteria. Continuing Medical Educational sessions were specifically created to educate palliative care practitioners in the management of severe AHF at home, including the use of a diuretic management protocol escalating therapy from oral to parenteral.³¹ Cardiology practitioners received targeted education to initiate goals of care conversations and to recognize the benefits of early referral to palliative care. In this model of care, palliative care practitioners remain connected to the cardiology team with the goal of maintaining continuity of care. In another study using health administrative data, those who received care from Heartfull had a 48% lower associated risk of dying in hospital (relative risk 52%; [95% CI 41 to 66%]; $P < 0.01$) compared with matched controls (hospital death: 28% [n=68] vs 69% [n=803]; $P < 0.01$) (K.L. Quinn, et al., unpublished data, 2022). The success of this model of care is contingent upon extensive collaboration between palliative care and cardiology practitioners. As such, this study sought to identify barriers and facilitators in the development of a collaborative model of care through the exploration of the experiences of HCPs from 2 specialties (i.e., palliative care and cardiology) to optimize coordinated palliative care for patients with AHF.

METHODS

Transparency and Openness Promotion Statement

Further details regarding the methods used in the analysis, and materials used to conduct the research that support the findings of this study (e.g., interview guide, demographic data collection form, qualitative codebook) are available from the corresponding author upon reasonable request. Due to the sensitive nature of the data collected and requirements set out by our ethics board, data are not available.

Qualitative Approach and Research Paradigm

This qualitative study used an interpretivist perspective and inductive thematic analysis approach³² to understand HCPs' experiences with the collaborative delivery of a palliative approach to care to patients with AHF at home.

Context/Setting

The Temmy Latner Centre for Palliative Care (TLCPC) and the Miles Nadal Heart Centre are located in Toronto, Ontario, Canada as a part of Sinai Health – a tertiary urban academic teaching centre affiliated with the University of Toronto. The TLCPC consists of over 30 specialist palliative care HCPs who deliver home palliative care to approximately 800 patients annually. At the time of referral, specialist palliative care HCPs liaise with each patient's primary care provider to determine if the palliative care HCP will take over responsibility for primary care, or if they will act only in a consultant role with the primary care provider continuing to provide primary care.

Study Participants, Sampling Strategy, and Recruitment

Purposive sampling was conducted to recruit HCPs (cardiology or palliative care) involved in collaborative care for patients with AHF at the Miles Nadal Heart Centre and TLCPC from April 2013 to March 2020. Two authors (S.M. and L.S.) identified colleagues who were involved in this collaborative care model over the past 7 years. C.G. sent email invitations describing the goal of the interview to eligible participants requesting their participation, with reminder emails sent to non-responders twice at 6-week intervals. All participants were aware that the principal investigators were clinicians and researchers affiliated with TLCPC and Sinai Health.

Data Collection

We conducted semi-structured interviews to gain comprehensive insight into experiences and provider perspectives. Interviews were held between November 2019 and March 2020 and conducted by 3 trained qualitative researchers (C.G., R.S. and S.R.I.) using an interview guide (Data S1) designed by an interdisciplinary team composed of a qualitative research scientist (S.R.I.), a palliative medicine physician (L.S.) and a heart failure cardiologist (S.M.). Two pilot interviews were held with L.S. and S.M., after which the interviewers critically reviewed the interview guide and adjusted the questions accordingly. Interviews with participants were carried out one-on-one, in-person, at the participants' workplace. Prior to the interview, participants completed demographic information (Data S2). Field notes were taken

during each interview, which were then used to summarize the interview to provide context for the analysis. Interviews were audio-recorded and transcribed verbatim by 2 authors (C.G. and R.S.) and a research student (D.V.), and subsequently de-identified. All participants were assigned a unique study ID for data collection and analysis. Interviews were conducted until the team deemed that thematic saturation had been achieved.³³ Given confidentiality concerns due to limited number of NP participants, quotes were labeled as either "cardiology HCP" or "palliative care HCP" regardless of whether the HCP was a physician or NP.

Data Analysis

We used an iterative, inductive process to consolidate emergent topics into themes. Consensus meetings were held with all authors to review randomly selected transcripts to identify and refine themes into a finalized coding structure. Using this finalized coding structure, 2 authors (S.R.I. and C.G.) consensus coded 2 transcripts using MAXQDA 2018 (VERBI software).³⁴ One author (C.G.) then thematically coded 4 transcripts. S.R.I. reviewed the coding on the 4 transcripts and provided feedback before C.G. coded the remaining transcripts. Once major themes were identified, the study team selected salient quotes to support each major theme, which elucidated the narrative that emerged from the interviews. Throughout the analysis and writing process, the results were repeatedly discussed with all coauthors at regular meetings. Researchers used various approaches to address qualitative rigor and trustworthiness, including attention to reflexivity (Data S3).

Ethics

We obtained written, informed consent from all study participants using a standardized consent form, which highlighted the voluntary nature of participation and the ability to withdraw from the interview or pass on any question at any point in time. Ethics approval was obtained from Sinai Health System's research ethics board (REB 19-0016-E).

RESULTS

Sample Demographics

The initial number of HCPs identified who were involved in the collaborative care model over the past 7 years, and who we sent recruitment emails to, included 34 HCPs: 8 cardiologists, 22 palliative care physicians, and 4 NPs. The final sample who participated in our study consisted of 17 HCPs: 5 (29%) cardiologists, 10 (59%) palliative care physicians and 2 (12%) NPs. Seven (41%) HCPs were female, and the mean age of HCPs was 50 years.

The mean number of years in specialty practice was 20 years for palliative care HCPs and 28 for cardiology HCPs. Location of practice was hospital only for 7 (41%) HCPs, home only for 8 (47%) HCPs, and a combination of home and hospital for 2 (12%) HCPs (Table 1).

Themes

Our results are presented in 2 sections: (1) perceived facilitators to the delivery of collaborative home-based palliative care for patients with AHF and (2) on-going perceived barriers to the delivery of collaborative home-based palliative care for patients with AHF.

1. Perceived facilitators to the collaborative delivery of home-based palliative care for patients with AHF

Perceived facilitators to the delivery of home-based care for patients with AHF were identified at 2 levels of health care: (i) the individual HCP level (cardiologist, palliative care physician, NP) and (ii) interpersonal level (relationships between HCPs).

(i) Individual level - On-going professional education to expand competency.

HCPs identified participation in continuing medical education that focused specifically on the delivery of palliative care for patients with advanced heart failure as a key facilitator to the delivery of home-based palliative care for patients with AHF. The educational experiences that participants found helpful varied between medical specialties.

From a palliative care perspective, HCPs found that a variety of educational strategies were helpful in improving comfort and competence with regards to caring for patients with AHF. These included self-directed reading, formal and informal peer-to-peer support from palliative care colleagues, formal and informal education from cardiology colleagues, and on-the-job experience.

Table 1. Participant Characteristics

Characteristics	Participating physicians (n=17)
Age – y, average (median, range)	50.2 (50, 31–65)
Female sex – n(%)	7 (41)
Specialty – n(%)	
Palliative care	11 (65)
Cardiology	6 (35)
Location of practice – n (%)	
Hospital	7 (41)
Home	8 (47)
Combination	2 (12)
# yrs practicing in specialty – yrs, average (median, range)	
Palliative Care	20.6 (20, 6–42)
Cardiology	28 (27.5, 16–41)

My learning came partly through self-directed learning...a lot of reading, going back to the initial physiology and sort of foundational ideas around heart failure and then reading a bit about symptom control, often that was more palliative oriented, in other words just treating the symptoms, and then reading articles about treating heart failure. ... [A cardiologist and a palliative care doctor] gave a few presentations that were very helpful, where they reviewed, first of all, that it was quite possible for us to manage heart symptoms, and second of all an outline of how to do that. ...
-P4, Palliative care HCP

Education was predominantly focused on medications used in the management of AHF, specifically how and when to adjust or stop these medications.

I feel better equipped to manage patients with heart failure at home. And I think largely because of the conversations that I've had with colleagues. Because of some of the advice that we've been given in terms of management, I feel much more comfortable using some of the more hardcore medications in order to get people feeling better. I feel more equipped to manage patients with heart failure at home, and I think that's partly related to the communications and the training and teaching that we've received.
-P14, Palliative care HCP

From a cardiology perspective, most learning was done either through didactic teaching sessions or observation of palliative HCP interactions with patients/caregivers. Learning was largely centered around having effective advance care planning and/or goals of care conversations, and recognition of the value of a holistic approach to care brought by the palliative care team.

One thing that I've observed is that when we had an educational session on palliative care and interfacing with palliative care physicians, is that it's instructive to hear the views of patients, in terms of what their goals are. And so I think that ... the presence of this program really widened my horizons about the role of palliative care in congestive heart failure care."
-P3, Cardiology HCP

(iia) Interpersonal level (relationships between HCPs)
- Shared Care between Specialties.

Improved collaboration between specialties was the prominent theme that arose in most interviews, both from palliative care and cardiology HCPs. Overall, HCPs felt that care transitions were facilitated (between outpatient/inpatient/home) by having team members positioned in each of these settings to take on primary responsibility for patient care.

This model was not created as a substitutive model, it was created as care in partnership. The partnership organically becomes very imbalanced, and the cardiologist becomes very much a consulting background role in HeartFull and that's wonderful. But it provides a safety net for the patient and family to transition. It's a co-management model and the flexibility of not having a single care pathway changes everything.

-P6, Cardiology HCP

Because this collaborative model of care was designed as a co-management model of care rather than a transfer of care, most HCPs stayed involved in care until end of life, with varying levels of involvement over the disease course. Many cardiology HCPs noted that they did not necessarily stay involved in direct patient care, but rather as an intermittent consultant to the palliative care team when contacted. Many HCPs indicated that this degree of collaboration provided improved continuity of care from all HCPs, creating a model for patients that is flexible, decreases the risk of patient perceptions of abandonment by the cardiologist, and allows more seamless transition between different care settings.

All of a sudden there with the sense that we were all in this together. That the cardiologists were really very responsive to our queries and our requests, and they were happy to ... be helpful because they also knew that if we weren't there, the patient was going to be in the emergency department. So there was this real shared understanding about the opportunity which translated into direct and very immediate communication. And it was so great for the families to know that the history and continuity wasn't lost. That we're all part of the same care team.

-P5, Palliative care HCP

HeartFull itself allows me to accompany the patient in a different way, to their actual death. I think there's something quite comforting to patients' families, as well as a greater sense of satisfaction [to the HCP] to know that you were with them on their entire journey. I do think that this [program] has definitely given me the opportunity to be more intimately involved, even without seeing the patient, without being directly involved, you participate in their care.

-P2, Cardiology HCP

(iib) Interpersonal level (relationships between HCPs)
- Effective communication.

Prior to the development of the collaborative model of care, communication between cardiology and palliative care HCPs was quite sporadic, as the number of referrals to palliative care from cardiology was infrequent. With the development of the collaborative model of care, both cardiology and palliative care providers indicated that there was an increased awareness of the role of the other specialty, including services and limitations of the care each specialty provides.

There is much less need to explain the intent of the program now – it's much more streamlined right. People [HCPs] understand their role, and their colleague's roles much more immediately now, so it's a more efficient process once it gets underway. The groups of physicians that I work with, their comfort level [with this patient population] has increased dramatically.

-P2, Cardiology HCP

With increased exposure to and engagement with one another, both services became much more comfortable reaching out directly to the HCP taking care of their mutual patient, and felt it was important to respond promptly when asked questions to maintain positive working relationships.

It's that sort of partnership, a true care providing partnership, which I think has changed...It's just something that's integrated into my practice life now. So part of my practice life includes my regular contact with palliative care physicians who are taking care of my patients so if

now I transitioned to a home based palliative care program, you know you're not cut off at a certain point of the relationship, and it's really like the partnership of palliative care that really connects that particular piece right and it completes the circle of life in terms of caring for a patient.

-P6, Cardiology HCP

For me I still feel like I'm flying by the seat of my pants [with patients with heart failure], but at least I know that there's somebody in the co-pilot's seat [cardiology]. So really that extra support, that ability to reach out, so that I don't feel like I'm getting too far out of my own comfort zone. I can check back in - "is this the right thing to do?" But also over time my comfort zone has expanded. So by having this sort of expert consultation, the ability to talk to people, I'm now more comfortable titrating diuretics and I'm more comfortable adjusting their meds. And I'm just more comfortable asking for help.

-P5, Palliative care HCP

(2) On-going barriers to the delivery of home-based palliative care for patients with AHF.

In this study, barriers to the provision of home-based palliative care for patients with AHF were identified at 2 levels of health care: (i) the individual HCP level (cardiologist, palliative care physician, NP) and (ii) the system level (organizations that provide infrastructure and resources to support the individual HCPs).

(ia) Individual-level – Apprehension with fluctuation in disease course and prognostic uncertainty.

From a palliative care perspective, our participants identified ongoing apprehension with fluctuation in disease course and prognostic uncertainty for patients with AHF, which made it difficult to discuss with patients what the future may look like, and how long they may have to live. Additionally, many home visiting physicians were concerned that by managing symptoms at home rather than having patients present to hospital, patients may be missing opportunities to prolong their life. Goals of care were often difficult to ascertain, as patients had previously improved from exacerbations, thus goals tended to fluctuate depending on whether patients were feeling well or feeling ill.

One challenge that comes to mind is there are still some palliative care doctors that get very nervous about these patients. I think because the trajectory's up and down and the palliative care doctor in the home sees their tools as very much symptom-based only and I've been told they worry that if they palliate a person with heart failure that they are missing out on an opportunity for them to improve, and have some more time. Unlike the oncology patient where they're kind of really isn't anything to do that's really going to turn them around.

-P1, Palliative care HCP

I think in general, the heart failure patients do carry a bit more of a load for us, because they're brittle, and they're symptomatic, and they're needing that kind of frequent change. So to be completely honest, I don't like having like too many heart failure patients on my list, because I feel like, "oh my gosh, this could be intense." I think that the weight for me, for the heart failure patients, is greater, because I worry about them. I think their trajectories are unpredictable, sometimes they're longer than our average patients. And I'm just not, I'm just still never sure what to, what to expect, you know, so I feel a bit powerless."

-P10, Palliative care HCP

(ib) Individual-level – Lower levels of job satisfaction (palliative care HCPs)

As a result of these issues, a number of palliative care clinicians noted lower levels of job satisfaction when caring for patients with AHF, as they find it difficult to ascertain and meet expectations of patients and their caregivers.

I find these cases more draining for me, psychologically draining. Less clear and kind of muddier about what I can get, what I can do. The symptoms are more distressing to everyone, there are tougher things to watch. Like seeing someone struggle with every breath really is tough. Weeping legs, weeping arms. We don't have good strategies yet.

-P15, Palliative care HCP

(ic) Individual-level – Time constraints in clinic, non-abandonment of patients (cardiology HCPs)

From a cardiology perspective, the biggest individual barrier identified was a reluctance to introduce palliative care to patients with AHF. Our participants identified that this reluctance stemmed from 2 factors. First, time constraints in clinic which limited the ability to have a nuanced conversation about the role of palliative care.

One of the stumbling blocks is it takes some time to introduce this concept, right? So you have to A) remember to do it and you have to B) actually have to have time to do it. And it's a pretty rough and tumble place in the clinic... so I need to identify that this patient might benefit from it, and then I need to be able to take the time to introduce it in a way that I don't walk out of the room and they actually think "what the hell is he talking about – I'm gonna die so I need palliative care?"

-P3, Cardiology HCP

Second, there was concern that the introduction of palliative care would take away hope from this patient population and may negatively impact the relationship between the patient, caregiver and cardiologist by causing patients to perceive they are being abandoned by their cardiologist.

I think many cardiologists of my generation are similar to me in that we need to lower our threshold to use this resource [palliative care]. Because we tend to be moving in a hurry and our patient population, they continue to have hope...so you have this slight friction develop where you don't want to take away that hope. You're trying to provide them with something that will make life easier for them, but you're sensitive to the fact that you can scare the heck out of them if you don't approach it correctly.

-P3, Cardiology HCP

(ii) System-level – Difficulty obtaining community resources with unclear prognosis.

Participants identified a number of themes at the organizational or system level that continued to act as barriers to the delivery of home-based palliative care for patients with AHF. These system-level issues were largely related to the fact that in Ontario, the provision of home/community services for patients with a palliative care diagnosis was designed based on the

prognostic models of patients with a diagnosis of terminal cancer. Unlike AHF, terminal cancer has a clear disease trajectory and more accurate clinical tools for prognostication. Patients with AHF have a variable disease trajectory requiring different levels of support when a patient is experiencing a heart failure exacerbation as opposed to when they feel well.

I think the 2 main distinguishing points between heart failure and patients with other palliative diagnoses meaning advanced illnesses or life-limiting illnesses is the challenges based around prognostic uncertainty and overall illness trajectory as it related to symptoms and supports. It affects what home supports would be provided. Patients who need maybe a lot of nursing, personal support work and then don't, and the structure of the support isn't structured in such a way that we can add or subtract. So in terms of coordinating all the supports, it can be hard to do, because they don't fit nicely to a palliative case load for the LHIN [Local Health Integration Network].

-P13, Palliative care HCP

Additionally, overall survival is very difficult to predict, and patients with AHF often need services for longer than the traditional 3-month palliative timeframe that has been set by the local health administrative regions. Our participants identified that for patients with AHF, there was decreased availability of nursing support, personal support worker hours and equipment (hospital beds, oxygen, etc). Additionally, they noted that provision of support was not consistent across local health administrative regions.

I think the biggest issue is more home and community resources. Mainly just the foundational paradigm of understanding the natural course of advanced heart failure. ... The challenge is that these patients don't fit nicely into either a geriatric frailty population or a traditional palliative population. And as such they're sometimes limited in things like equipment, [personal support worker] hours, how long they have a [personal support worker] for in terms of how long they're alive and then also in turn referrals to hospice and to palliative care units because of the difficulty in prognosis. These patients need more low-level but

longer periods of care. And I think that's very challenging to find space for, even though economically providing that low-level but longitudinal for a long period care will be financially sounder than sending patients to hospital."

-P13, Palliative care HCP

(iib) System-level – Difficulty accessing palliative care unit beds due to unclear prognosis.

Participants also identified that it was difficult to access beds in palliative care units for patients with AHF, which unfortunately limits the care provision for these patients to home and acute care hospitals.

Accessing palliative care beds is a huge challenge, particularly since over the years, certain palliative care units have actually created more limited guidelines. So having a PPS [palliative performance score] of 30% with heart failure is no longer sufficient to necessarily get a bed, sometimes you actually have to have a PPS of 20%. Having a PPS of 40% you'd never get a bed. So I do find that getting palliative care service like [palliative care unit] admission for heart failure is very difficult.

-P14, Palliative care HCP

(iic) System-level – Difficulty ascertaining individual HCP role within larger community team.

The final system-level barrier identified by our participants was the need for improved care co-ordination. Providers felt there was difficulty delineating roles between providers.

I guess if there's one other long-term challenge it's to know if you have somebody monitoring these clinical signs, who does what once something changes. Because it could be the cardiologist, it could be the um family doctor, it could be us [palliative care]. Our skills overlap in the end, and so who should respond? That's an ongoing challenge. We continue to need clarity on what shared care means. Shared care is very difficult at the best of time. And with heart failure there's so many things that are uncertain.... So trying to have some

way of establishing who does what would be beneficial.

-P4, Palliative care HCP

HCPs noted that there was a need for an allied health professional who oversees the variety of care tasks, delineates which providers are responsible for which tasks at which time, and aids patients in navigating the medical system.

I think it would be great if there were kind of point people in the community that would be helpful as liaisons between the community, the hospital, and the clinic. I mean, even when it's shared care, I think there's usually a sense of "is the patient making it to clinic or are they not?" And if they're not, then I'm feeling like I'm the primary provider, but the cardiologist is available. And if the person's still making it to clinic then [the cardiologist is the] primary provider, and I'm the backup. You know, so it's shared, but can get confusion. You still sort of need to know who's basically prescribing the meds.

-P10, Palliative care HCP

DISCUSSION

This qualitative study explored the experiences of key clinical stakeholders providing care to patients with AHF and found that an innovative collaborative care model improved knowledge exchange, collaboration and communication between specialties, and led to more comprehensive patient care. This was facilitated through: (1) On-going professional education to expand competency, (2) shared care between specialties and (3) effective communication within the care team.. However, ongoing challenges at the HCP and system level were identified which may allow for further optimization of this care model in the future.

Previous studies have demonstrated that individual medical specialties tend to hold different attitudes towards the delivery of palliative care for patients with AHF. Specifically, there are disparate opinions towards definitions of palliative care, timing of palliative care referral, communication with patients, advance care planning, and responsibilities of each medical discipline.³⁵⁻³⁷ Our study demonstrates that integration of an educational framework that focused specifically on the delivery of palliative care to patients with advanced heart failure within a collaborative model of care, and

improved communication between specialty services fosters mutual understanding of the overall direction for the provision of care. Moreover, this mutual understanding allows the specialty-specific skills to be leveraged more effectively as they are grounded in the same core philosophy of care. We specifically identified that there is an increased openness to advance care planning within the cardiology community and an increased level of comfort with heart failure medications among the palliative care providers. These factors lead to an increased sense of ownership felt by all HCPs. Improved education and communication between specialties led to more active involvement of cardiologists over the entirety of the patient's disease course and improved continuity of care. The literature has demonstrated that for patients, the importance of continuity of care, and maintaining a role for cardiologists is paramount.³⁸ Patients often have strong bonds and trust in their long-standing cardiology HCPs that should be maintained, along with their expert opinion on clinical complexities of cardiac medications and devices.³⁸ In medical ethics, this is often referred to as "non-abandonment", and is traditionally considered one of a physician's central ethical obligations.³⁹ Despite expert guidelines emphasizing the importance of non-abandonment of patients as they transition to a more comfort-focused approach to care, a number of studies have shown that patients and caregivers still experience abandonment around the time of death, and that physicians often report a lack of closure around patient deaths.^{39–41} From the provider perspective, the collaborative model of care creates an environment in which it is possible for cardiologists to stay involved in care until patient's end of life.

Past qualitative studies have highlighted barriers to integrating palliative care into care for patients with AHF, and our study builds upon these findings. Schallmo *et al* conducted a systematic literature review to explore perceived barriers of HCPs in offering a palliative care approach to patients with AHF, and participants identified difficulty with discussing death and palliative care needs with patients, optimal timing of introducing palliative care, navigating the logistics of a hospital interdisciplinary team with unclear roles and communication structure, and lack of knowledge of palliative care.³⁶ A study by Kavalieratos *et al* examined HCP knowledge and attitudes regarding palliative care in patients with HF, but it looked at the barriers to palliative referral rather than experiences within a specific model of care itself.⁴² They reported providers having misperceptions of palliative care as being a service reserved for those near death. Our participants described that some of these barriers continue to exist despite the implementation of a collaborative care model; many cardiology HCPs identified that they continue to have difficulty with introducing the concept of palliative care to patients.

However, this was not due to a lack of knowledge of palliative care or poor communication with palliative HCPs or navigation of health care system logistics, but rather due to time constraints faced in clinic, the need to balance hope with truth-telling, and the worry that the recommendation of a transition in model of care may cause patients to perceive they are being abandoned by their cardiologist. A study by Brannstrom *et al*, interviewed 15 geriatric physicians working within palliative care for patients with AHF. These physicians reported feeling uncertainty regarding maintaining active care, such as cardiopulmonary resuscitation and implantable cardioverter defibrillators, or withdrawing care.²⁷ Many palliative care HCPs in our study similarly expressed uncertainty regarding level of care as an ongoing concern about providing care for patients with AHF at home, given that there is a lack of an obvious transition point from active care to palliative care for the majority of these patients. Specifically, they worried that by providing care at home rather than having patients present to hospital, patients may be missing opportunities to prolong their life, particularly given that goals of care are often less clear in this population. Additionally, our participants identified that they continue to struggle with the uncertain trajectory in heart failure, as it is more difficult to ascertain an advance care plan and the community support for patients with AHF is significantly less compared with patients with terminal cancer.

The rarity of existing integrated palliative care models for heart failure is likely because many palliative care programs were initially developed for people with advanced cancer. The trajectory, prognosis, symptom management, and comorbidities in AHF are significantly different, with variable and unpredictable peaks of quality of life and valleys of hospitalization.⁴³ This uncertainty makes it challenging to develop a uniform palliative care program, particularly within the framework of a community and home services program that is prognostication-based. In our study, practitioners from both cardiology and palliative care noted that there are on-going barriers at the system level that prevent optimal care from being provided. They commented that there needs to be better clarification of who is principally responsible for the patient's medical care in the community, and that it would be beneficial to appoint an allied health professional who oversees the variety of care tasks, delineates which providers are responsible for which tasks at which time, and aids patients in navigating the medical system. This need for better coordination of care between inpatient, outpatient clinics and community settings, and clarification of roles of the medical team members has been previously demonstrated in the literature.⁴⁴ Additionally, it is necessary to re-examine the way in which resources are distributed in the community. Patients with AHF have a

variable disease trajectory, requiring different levels of support over that trajectory, with an unclear prognosis. This does not align with the way that palliative care resources (e.g. nursing hours, personal support worker hours, palliative care unit beds, etc.) are currently distributed in the community. As well, most people with HF receive care from community cardiology clinics, not in academic teaching hospitals, which typically have pall care resources. As a result, patients with chronic illnesses including AHF have access to fewer palliative care resources in the community, which could result in sub-optimal palliative care. System-level improvements are required to provide and evaluate integrated care between HCPs to optimize patient care and family caregiver support.

Our study has several limitations. Interviews were limited to specialist palliative care and cardiology physicians and NPs, and did not include all types of physicians or other interdisciplinary providers involved in the provision of care for patients with AHF. We focused on physician and NP perspectives in this study as they typically act in a leadership role within the interdisciplinary team, however other perspectives would certainly be insightful. Additionally, we did not interview patients with AHF or their family caregivers, who may have differing opinions with regards to the limiting and facilitating factors associated with delivery of home-based palliative care. Future studies should further integrate provider, patient and caregiver perspectives. Our study is limited to the Toronto setting; however, there are factors that allow for these results to be generalizable to the American system: disease process and trajectory of illness are the same for patients, scope of practice for palliative care physicians and cardiologists are comparable, both systems have resources that are constrained by cost (albeit one by a single-payer system, and the other by a multi-payer system) and patient outcomes at the end of life are similar. Despite these limitations, our results suggest that a collaborative, shared model of care delivery between palliative care and cardiology improves knowledge exchange, collaboration and communication between specialties, and leads to more comprehensive patient care.

CONCLUSIONS

Our results suggest that a collaborative shared model of care delivery between palliative care and cardiology may improve knowledge exchange, collaboration and communication between specialties, and leads to more comprehensive care for patients with AHF. These findings emphasize that providers from both cardiology and palliative care were amenable to the program and found it beneficial for their patients and their own clinical practice, which is encouraging

for future implementation of this model of care. Additionally, this work highlights the need for system-level change to address limited access of homecare services and equipment for this patient population to help improve care delivery, as well as a need for review of admission criteria to inpatient specialist palliative care units. Further research is needed in this area to improve prognostication, assess patient and caregiver perspectives regarding this model of care, and assess the economic feasibility and impact of this model of care.

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Received November 8, 2021; accepted May 10, 2022.

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Acknowledgments

The authors would like to thank Desiree Vaz for her assistance with transcription.

Sources of Funding

This study was funded through the Global Institute of Psychosocial, Palliative & End-of-Life-Care (GIPPEC) grant at the University of Toronto Division of Palliative Medicine and the Dalla Lana School of Public Health, and a generous donation from the Grafstein Family to the Sinai Research Foundation.

Disclosures

During the conduct of this study, Dr. Kavalieratos received research support from the US National Institutes of Health and the Cystic Fibrosis Foundation.

Supplemental Material

Data S1–S3

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SUPPLEMENTAL MATERIAL

Data S1. Final Interview Guide

Over the past six years, there has been an effort to provide support for your patients with advanced heart failure through the HeartFull Collaborative Program. These questions are aimed at understanding your experience of the impact of the support and to drive further improvement.

General questions for all health care providers:

Experiences managing patients before the HeartFull Collaborative:

1. If cardiologist:
 - a. Please describe your experience caring for advanced heart failure patients with palliative care needs before the HeartFull Collaborative started promoting integrated care.
 - i. What were your experiences of end-of-life care and transitions to home-based care before the HeartFull collaborative?
2. If palliative care provider:
 - a. Please describe your experience caring for advanced heart failure patients before the HeartFull Collaborative started promoting integrated care.
 - i. What were the barriers and challenges you faced caring for advanced heart failure patients before the HeartFull Collaborative started?
 - b. Is the experience of managing heart failure patients at home different than your other palliative patients? If so, how?

An attempt was made to integrate care for Sinai Health System patients with cardiology – the HeartFull Collaborative. We would now like to ask you a few questions about this experience.

Experiences with the program:

1. Please describe your experiences and involvement with the HeartFull Collaborative program.
2. What kind of support, if any, did you receive from the program to support patients with advanced heart failure at home?
 - a. Prompt: Connection with cardiology or palliative care (depending on participant)? Any advice on diuresis or other cardiac management? Any ability to send patients back to clinic for reassessment?
3. What has been the impact of HeartFull on your ability to care for this patient population?
 - a. Prompt for palliative care physician: Did your comfort level with adjusting diuresis or other cardiac medication change? Did your relationship with the referring cardiologist change? Did your access to getting questions answered about the cardiac management of the patient change?
 - b. Prompt for cardiologist: How did your relationship with your patient change after referral to HeartFull? Did your relationship with the palliative care team change? Did your comfort level with providing palliative care, referring to palliative care, or engaging in advance care planning discussions change?
4. Were there any challenges you encountered with the HeartFull program?

- a. Prompt for palliative care provider: Did you encounter any barriers or challenges when accepting and seeing patients referred to the program from cardiology?
5. Has participation in HeartFull had any financial impact on your practice? Is this a barrier?
6. Did you feel that there was good integration of care across all settings (home, hospital, clinic)?
7. Other than the palliative care physician, cardiologist, and nurse practitioner, were there other health care providers who seemed integral to this collaborative program?

Outcomes with the program:

8. Do you think the program had an impact on patient's location of death? If so how?
9. Do you think the program had an impact on patient's health utilization (i.e., number of hospitalizations and emergency room visits, length of stay, use of invasive procedures)?
10. What components of the program do you think most contributed to these health outcomes?

Continued care for this patient population:

11. Since the HeartFull Collaborative program started trying to integrate care for heart failure patients, are there any challenges you continue to experience regarding heart failure management with a palliative care approach?
 - a. Prompt: Eg. Accessing palliative care beds? LHIN resources? Communication between the care team?
12. What additional supports would be helpful?
 - a. Prompt: Additional education on advanced heart failure management?
13. Based on your experience, is there anything that you would like to share with other health care providers about providing a palliative approach to advanced heart failure management?
14. Has your experience with caring for patients with HeartFull's integrated approach evolved over time? If so, how?

Questions for cardiologists only:

1. At the beginning, how did it feel letting someone else care for your patient at home? How do you feel about it now?
2. How did you feel about approaching patients about HeartFull? Were you hesitant?
3. Can you describe the contacts that you had with the palliative care physicians?
 - i. Prompt: Did the palliative care physician contact you? Were you asked to provide advice or support? What kinds of information or discussion did you have with the palliative care physicians?
4. For your patients in HeartFull, did you continue to be involved in your patients' care until the end-of-life?
 - i. Prompt if answer is "no": Did you want to be more involved? How?
5. Was the patient's family physician involved? What was their role?

6. Is there anything else you would like to share about your experience?

Questions for palliative care physicians only:

1. At the beginning, how did it feel sharing care with a cardiologist? How do you feel about it now?
2. What was it like to escalate diuretics/other cardiac medications in the home? Did you have experience with it before? If not, do you feel comfortable doing it now?
3. Was there anything in the heart failure management plan that you felt uncomfortable with?
4. Do you feel that you got accessible, timely support from cardiology?
5. Have you provided in-time mentoring or support to cardiologists? If so, did you find providing that support was onerous?
6. For your patients in HeartFull, did the patients' cardiologists continue to be involved in the patients' care until the end-of-life?
7. Was the patient's family physician involved? What was their role?
8. Is there anything else you would like to share about your experience?

Data S2. Provider Demographic Form

1. **Participant ID:** _____
2. **What is your age:** _____
3. **What is your gender:** _____
 - Female
 - Intersex
 - Male
 - Trans – Female to Male
 - Trans – Male to Female
 - Other (please specify): _____
 - Prefer not to answer
 -
4. **Education level**
 - High school
 - College certificate or diploma
 - Bachelor's degree
 - Above bachelor's degree
 - Prefer not to answer
5. **Which of the following best describes your racial or ethnic group? Check ONE only.**
 - Asian – East (e.g., Chinese, Japanese, Korean)
 - Asian – South (e.g., Indian, Pakistani, Sri Lankan)
 - Asian – South East (e.g., Malaysian, Filipino, Vietnamese)
 - Black – African (e.g., Ghanaian, Kenyan, Somali)
 - Black – Caribbean (e.g., Barbadian, Jamaican)
 - Black – North American (e.g., Canadian, American)
 - First Nations
 - Indian – Caribbean (e.g., Guyanese with origins in India)
 - Indigenous/Aboriginal – *not included elsewhere*
 - Inuit
 - Latin American (e.g., Argentinean, Chilean, Salvadoran)
 - Métis
 - Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
 - White – European (e.g., English, Italian, Portuguese, Russian)
 - Mixed heritage (e.g., Black – African and White – North American) (Please specify): _____
 - Other(s) (Please specify): _____
 - Prefer not to answer
 - Do not know
6. **What is your religious or spiritual affiliation? Check ONE only.**
 - I do not have a religious or spiritual affiliation
 - Animism or Shamanism
 - Native Spirituality
 - Pagan

- Atheism
- Baha'i Faith
- Buddhism
- Christian – *not included elsewhere*
- Christian Orthodox
- Confucianism
- Hinduism
- Jainism
- Jehovah's Witnesses
- Judaism
- Islam
- Protestant
- Rastafarianism
- Roman Catholic
- Sikhism
- Spiritual
- Unitarianism
- Zoroastrianism
- Other (Please specify):
- Prefer not to answer
- Do not know

7. **What is your healthcare provider role (select all that are applicable)?**

- Physician
- Physician Assistant
- Nurse
- Trainee
- Admin coordinator
- Care coordinator
- Other (please specify): _____

8. Number of years working healthcare: _____

9. Number of years in your current role: _____

10. Specialization of work (eg. cardiology, palliative care, family practice):

11. Describe your main responsibilities & tasks:

E.g. Leadership role, Coordinating role

Data S3. Researcher Characteristics and Reflexivity

C.G. is a general internist and palliative care fellow in an accredited Canadian palliative care training program. She has previously provided care for patients within the collaborative model of care both in the inpatient and home setting and interacts regularly with cardiology and palliative care physician participants. During the time of data collection, C.G. was a resident who regularly interacted with several of the cardiology and palliative care HCP participants through her post-graduate medical education with the Department of Medicine at the University of Toronto.

R.S. is an emergency medicine resident at the University of Alberta and completed a geriatric emergency medicine clinical fellowship at the University of Toronto. At the time of data collection, she did not have any prior relationships with any participants.

S.R.I. is a health services researcher at the Bruyère Research Institute and an Assistant Professor in the Department of Medicine at the University of Ottawa. During the time of data collection, S.R.I. was working collaboratively with several of the palliative care physician participants through her prior affiliation with the Temmy Latner Centre for Palliative Care (TLCPC) at Sinai Health.

K.L.Q. is a general internist and palliative care physician at Sinai Health System, and Clinician-Scientist in the Department of Medicine at the University of Toronto. He provides care for patients within the collaborative care model in the acute inpatient and palliative care unit setting, and interacts regularly with cardiology and palliative care physician participants.

S.M. is a heart failure specialist and director of the Anna Prosserman Heart Function Clinic as well as director of the Harold and Esther Mecklinger and Poslund Family Cardiac Catheterization Research Laboratory at SHS. Together with L.S. she developed and implemented the HeartFull Collaborative. She provides care for patients within the collaborative model of care

in the acute inpatient and outpatient clinic settings, and interacts regularly with cardiology and palliative care physician participants.

L.S. is a palliative care physician at TLCPC and SHS. Together with S.M. she developed and implemented the HeartFull Collaborative at SHS. She provides care for patients within the collaborative model of care in the acute inpatient setting, and interacts regularly with cardiology and palliative care physician participants.

S.H.B. is a palliative care physician at Bruyère Continuing Care, Investigator at the Bruyère Research Institute and an Associate Professor in the Department of Medicine at the University of Ottawa, Ottawa, Ontario. She provides care to patients with end-stage heart failure on the inpatient Bruyère palliative care unit, and has international experience looking after patients with AHF in hospital consultation service and community settings.

T.K. is a registered nurse and postdoctoral health research fellow at The Hospital for Sick Children in Toronto, Canada. Her research focuses on improving the experiences of Canadian patients with advanced chronic illness, and their family members, by researching ways to align healthcare treatment with people's personal values and preferences.

D.K. is a health services researcher and Associate Professor of Medicine within the Division of Palliative Medicine at Emory University (Atlanta, GA, USA). His research focuses on the development and evaluation of models of palliative care delivery in chronic illness, including heart failure.