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"If I have any problems, I just want to see my [primary care] doctor": perspectives on a proposed collaborative RUral PALliative care intervention (RuPal)

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Abstract

Background People living with advanced heart failure in rural areas have poorer quality of care as their disease progresses, which may be due to lack of access to specialty palliative care. A collaborative care model, connecting specialty palliative care clinicians to embedded complex care teams in primary care practices, may increase access to palliative care in this population.

Research objectives

To explore perspectives on a proposed collaborative palliative care intervention and whether this intervention would be appropriate for people living with heart failure in rural areas.

Methods We conducted a qualitative study (*n*=26), including patients with heart failure (*n*=7), caregivers (*n*=2), complex care team members working in primary care practices (*n*=5), primary care providers (*n*=5), interdisciplinary specialty palliative care clinicians (*n*=4), and cardiologists (*n*=3) all living and/or practicing in a rural community in Maine. Interviews were audio recorded and professionally transcribed. We used Max-QDA, line-by-line coding, and grounded theory analysis.

Results We found people living and working in rural areas wanted palliative care integrated into primary care. Participants voiced suspicion about care "from outsiders" and that introduction of a specialty palliative care team into their medical care might not be well received. As one primary care provider noted "rural [people] are less influenced by … seeing the latest specialist," so describing palliative care as a specialty may not be appealing. However, participants felt that patients would be open to receiving palliative care delivered by their primary care teams. Palliative care specialists and primary care clinical staff were enthusiastic about a collaborative care model to navigate patients' desire to avoid a new team while increasing access to specialty palliative care expertise.

Conclusion A collaborative palliative care model may be welcomed by patients, caregivers, and clinicians in rural areas.

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Introduction

Patients with heart failure (HF) have a mortality rate similar to, or worse than, many patients with cancer and have similar or greater palliative care needs [1, 2]. Yet patients with HF feel insufficiently supported by their medical teams [3], perhaps in part because symptoms other than dyspnea often go unaddressed [4]. Patients with HF who live in rural areas are understudied compared to those who live in urban and suburban areas, and the limited research suggests poorer quality end-of-life care for rural patients [5, 6]. Rural patients living with HF are more likely to have an Intensive Care Unit admission at the end of their lives and are less likely to be admitted to hospice [6]. Prior work has described barriers that disproportionately impact rural patients, including access to palliative care and necessary supportive care services [7].

HF guidelines recommend annual goals-of-care conversations covering prognosis and advanced care planning [8, 9], yet studies show low rates of goals-of-care conversations [10–12] and advance care directive completion [13–15]. Unfortunately, perhaps because of the lack of goals-of-care conversations, patients with HF are more likely to die in the hospital and less likely to receive hospice than patients dying of other causes [16, 17], and more likely to receive care inconsistent with their wishes [18, 19]. Palliative care can improve quality of life for patients with HF [20–25]. Additionally, patients who receive palliative care are more likely to die at home [22, 26]. Patients and their caregivers report a desire for palliative care integrated alongside specialty HF care [27]. However, palliative care remains underutilized for patients with HF and frequently occurs late, 1–2months prior to death [14, 28–30]. Problematically, access to palliative care is more limited in rural as compared to urban areas [31].

Given the shortage of specialty palliative care providers in rural areas and the disease burden of HF in rural areas [32], creative solutions are needed to provide palliative care in rural areas [33]. We set out to develop an intervention to meet the needs of people living with HF in rural areas using a collaborative care model. Collaborative care is a model that connects nurses in rural primary care offices with specialists in urban areas. It has proven benefit for depression in HF [34–36] and in rural environments in which mental health specialists [37, 38] meet regularly with primary care nurses to provide case-specific guidance. Collaborative care is a model that blends primary palliative care (e.g. palliative care delivered by clinicians without specialty training) with specialty palliative care. Our model utilized a complex care team already embedded in rural primary care clinics, composed of a registered nurse (RN), health coach (similar background and training as a community health worker), and bachelor's level social worker. In our model, this team would meet with interdisciplinary palliative care specialists including a physician, RN, social worker and chaplain weekly to receive case-specific guidance and coaching. Prior to piloting this intervention, we conducted the present study to: 1) understand patients' and providers' experiences of HF in rural areas; 2) gather patient and provider understanding and expectations of palliative care; and 3) elicit perspectives and feedback on the proposed intervention. By conducting this study, we hope to understand if the proposed intervention is appropriate for people living in rural areas with HF, their caregivers, and the clinicians providing care, and if there are ways to refine and adapt the intervention to improve it.

Methods

We conducted 19 semi-structured interviews and one focus group (n =7) to answer our research questions. The focus group included home health and complex care teams, while interviews occurred with patients, caregivers, physicians, and advanced practice professionals to maximize recruitment by being flexible when scheduling. The semi-structured approach allowed for in-depth responses and follow-up questions [39].

Recruitment

We recruited healthcare providers by emailing clinicians caring for rural HF patients (e.g. primary care physicians, cardiologists). Up to two follow-up emails were sent. The emails stated there would be no professional consequences to choosing whether to participate. Those who participated were entered into a drawing for a $100 gift card.

The study team recruited patients and caregivers through multiple means: (1) a poster was sent to various clinical and community sites asking for participants with hospitalizations or emergency department visits for HF and their caretakers; (2) Primary care providers in the rural clinics were invited to describe the study, provide a pamphlet and obtain verbal permission to have the research team contact interested patients. A study team member then called to explain participation and schedule an interview. Patients were asked if they had a caregiver who would be willing to participate. Patient and caregiver participants were each given a $25 gift card for their time. All participants gave informed consent before participating. This study was approved by the MaineHealth Institutional Review Board.

Interviews and analysis

We utilized semi-structured interview guides for the focus group and individual interviews which focused on: 1) experiences of living/working in rural areas and how that relates to HF; 2) experiences and perceptions of palliative care; and 3) questions related to the proposed intervention (see supplemental online materials for complete interview guides). To provide context for the discussion about the proposed intervention, interviewed participants were given the following basic information: *"This intervention involves having home care nurses receive education on palliative care. This education will include training the nurses in primary palliative care and then meeting weekly with a palliative care team to provide case-specific guidance for each patient."* The fundamental concept of collaborative care was also discussed. The one focus group occurred via videoconferencing and lasted 111 minutes in the spring of 2022. Individual interviews were conducted via videoconferencing or over the phone in the spring and summer of 2022. The length of the interviews ranged from 17–62 minutes. The focus group was video recorded to account for voice association. All of the interviews were audio recorded and transcribed verbatim. The quotations presented here were edited for readability.

Analysis was ongoing throughout the interview process. Three study members (RNH, NH, SDM) read the first three transcripts, engaged in descriptive coding and generated a list of initial codes [40]. These codes were put into a temporary codebook. Next, NH, MN, SDM, and RNH reviewed three additional transcripts to apply the temporary codebook. They also added additional codes not already in the codebook. The authors then met to review how each author coded the transcripts. Disagreements were discussed until consensus was reached, at which point a new codebook was established with secondary codes. Two to three authors coded each remaining transcript, which resulted in an agreed-upon set of coded transcripts. These coded transcripts were then used to establish the themes presented below.

Table 1 Characteristics of study participants

Characteristics (*n* = 26)	Clinicians	Patients	Caregivers
No. (%)	17	7	2
Age			
30–39 years	2 (13%)	0 (0%)	0 (0%)
40–49 years	3 (20%)	0 (0%)	0 (0%)
50–59 years	4 (27%)	0 (0%)	0 (0%)
60–69 years	6 (40%)	4 (57%)	1 (50%)
≥ 70	0 (0%)	3 (43%)	1 (50%)
Missing	2		
Gender			
Male	4 (24%)	5 (71%)	0 (0%)
Female	13 (76%)	2 (29%)	2 (100%)
Race			
White	17 (100%)	7 (100%)	2 (100%)
Ethnicity			
Non-Hispanic	17 (100%)	7 (100%)	2 (100%)
Years in practice			
≤5	3 (20%)		
6–10	1 (7%)		
11–15	4 (27%)		
16–25	2 (13%)		
≥26	5 (33%)		
Missing	2		
Type of clinician			
RN	3 (18%)		
SW	3 (18%)		
Health coach	1 (6%)		
Nurse Practitioner	3 (18%)		
Physician	7 (41%)		
Specialty Palliative Care	3 (18%)		

Results

Sample demographics

The final sample (n = 26) consisted of 17 clinicians, 7 patients, and 2 caregivers (Table 1). Clinicians included 3 registered nurses, 3 nurse practitioners, 3 social workers, 1 health coach, and 7 physicians. Most of the clinicians were experienced with only 3 reporting ≤5 years of practice and only 3 practiced in specialty palliative care. The majority of the clinicians were women (n= 11), and half occasionally saw patients in the patients' homes (8 did, 7 did not). The patients and caregivers were all 60 years or older and relatively evenly split in terms of gender; all identified as white. Their education levels varied with 43% of patients having achieved high school or GED diploma or less. All patients had co-existing medical problems, such as chronic obstructive pulmonary disease (n=6) or kidney disease (n=4). Five patients had previously completed an advance directive or living will, and two had not.

Rurality and heart failure care

Respondents described multiple factors impacting the care for patients living in rural areas which we categorized into the following: preference for primary care integration; cultural features of rural life; closer knit community; social drivers of health; access to healthcare; and increased reliance on acute care (emergency room and inpatient hospitalization) (Table 2).

Preference for primary care integration

Cardiologists, primary care providers (PCPs) and patients all noted a strong preference for care to be integrated into primary care. This was described as a barrier to seeing specialists, including cardiology and palliative care. PCPs reported negotiating with patients to see

Table 2 RuPal Themes

Theme	Sub theme	Quote
Rurality & Heart Failure Care		
	Preference for Primary Care Integration	And there's just... In rural areas, my experience has been there is a higher number of people who they want all of their care from one person. They say, "Doc, I trust you. I just want you to take care of me. I don't want anybody else to take care of me." Some of it is mistrust of the system. Some of it is lack of knowledge. Some of it might be because they saw a provider before that was different than them, and so that makes them leery of going to a place that is more diverse. So I think there's a multitude of factors that are unique to rural people that leave them to just want their primary care doctor to really manage everything for them … Will you do two visits with a cardiologist? And then I'll talk to your cardiologist. And if everything's good, then I'll take care of things from there." (PCP, #P5) Interviewer: "If your doctor suggested [palliative care] would you consider it? Patient: "I would have to talk with her more about it because I put all my faith in my doctor. If I have any problems, I want to see my doctor, you know what I mean"? (Patient, #8)
	Cultural Features of Rural Life	Our older generation grew up on the farms, in the woods, logging, trucking, construction, hard workers, very proud, very independent… So, you faced the obstacles in, number one, having the conversation with the patient, and then number two, actually convincing them to accept services. Because oftentimes they feel that other people need it more than them, want to be able to take care of themselves for as long as possible, somewhat stubborn at times, but in a positive way, just determined. They grew up hardworking and everyone kind of did for themselves. If you could provide for others, you did. (Complex care team member, #P11)
	Closer Knit Community	We have patients in our catchment area … who have lived here almost all their lives, and there's these pockets of communities near our hospital where friends and family become family and friends and they look out for each other… there is a safety net in these small communities of the goodness of Mainers looking out for each other. … There's a lot of mutuality and people support each other. I think that's a really positive thing of the more rural, hardy, as Mainers, we can do things and we're stronger together. (Palliative care social worker, #P4)
	Social Drivers of Health	I can't tell you how many times a patient will come in and just, the elderly man taking care of his elderly wife with heart failure or vice versa. And, "I can't get her onto the commode. I can't move her. And we need help, and we have no money, and we live way out wherever, and they want all this money for a private duty caregiver, I don't have it." (Palliative care nurse practitioner, #P6)
	Access to Healthcare	Really, right now, everywhere is staffing shortages. So, staffing in provider practices, staffing in pharmacies. Pharmacy hours are decreasing. Home health is hard to get staffing and nurses out there. And so, certainly, private duty caregivers, they're just not. So, the whole system is short, it's falling short, and it feels like it's falling shorter. The need is so great. (Palliative care social worker, #P4)
	Reliance on Emergency Room and Hospitalization	I find that ED utilization is higher. I think because patients aren't reaching out to their providers or aren't able to get there, so then it gets to a point where it's exacerbated and they have to seek medical treatment. So the utilization tends to be a little bit higher because they get to a point of no return. (Complex care team member, #P11)
Perception of Palliative Care		
	Lack of Desire for 'Another Team'	[Interviewer describes palliative care] Patient: I don't think I need anything like that. Interviewer: Nope. You would not be interested? Patient: No, I am keeping busy as I can and I don't need any extra, I don't think. (Patient, #P2)
	Conflation with Hospice	And in the past I … [talked] to a patient about palliative care and he just called me the death nurse, because that's what he likened it to. So I don't know where we could begin, but at the beginning, somewhere to explain it as a separate program. Because he just likened it to hospice and I tried to explain to him the difference, but he didn't hear what I was trying to say. (Complex care team member, #P8)
Feedback on Intervention		
	Conversations Occurring in the Home	Sometimes when they're in your office, it's that white coat problem. They're on your turf. When you're on their turf and they're in their comfortable recliner and their home and they're looking at their wall of their pictures, their life, they might be in a different space to share more comfortably what they want. (PCP, #P7)
	Connection to Specialty Palliative Care	So part of it really is that little bit of training, not so little, that would really determine how good they are at [palliative care]. And I think being part of a team much like the hospice nurses are really does make a difference rather than operating independently. So if indeed they're getting reviewed once a week with the team, that's a great model, and I think that would be wonderful going forward. (PCP, #P2)
	Registered Nurses Facilitating Conversations	So a resource like a nurse, they may be in the patient's home. It's a comfortable setting. … I don't think you need to be a [physician] to do that. (Cardiologist, #P23)
	Patients Who May Be Resistant to Advance Care Planning Conversations	Interviewer: Have you ever talked to a doctor about completing a form that documents who would make decisions for you and what type of care you'd want if you were unable to talk for yourself? …. Can you tell me what that conversation was like? Patient: It was kind of... I don't want to say it bothered me, but it's just thinking of the end of my life is near. (Patient, #P8)

Table 2 (continued)

Theme	Sub theme	Quote
	Bandwidth and Time of Complex Care Teams and Primary Care/Cardiology Teams	That's a lot to put on a nurse who has a full boat day scheduled, and she's got to drive all over and get her charting done and do what she's doing there on the skilled benefit. Home health skilled nursing, they have a lot of documentation and a lot of things they have to check off and get done. These aren't conversations that you can squeeze in. "Have you moved your bowels? Have you peed? Are you eating?" It's hard to squeeze in an in-depth quality, high quality, palliative conversation in that. (Palliative care nurse practitioner, #P6)
	Need for Close Integration with Primary and Cardiology Teams	… how would you to capture that information going forward so that it can be helpful and not just in that nurse's head? (Palliative care social worker, #P4)
	Need for Palliative Care Training	Well, I think the training would have to be excellent. I think these are conversations that absolutely can be had by any number of providers, nurses, primary care physicians, but it does require development of a set of tools in how to do it, so that you feel comfortable doing it. It can feel hard and heavy and I think there's a fine line between exploring care options, and then also conversely feeling like you're the bearer of bad news and you're always talking about the hard side of things. So it can be uncomfortable to have these conversations if you don't have a lot of practice. So I think the training would be really important. (PCP, #P3)

specialists: *"Will you do two visits with a cardiologist?"* (#P21). The resistance was attributed both to the distrust of things considered external as well as a preference for care to be delivered by the PCP. As one PCP recalled from a conversation with his patient: "*Doc, I trust you. I just want you to take care of me."* (#P5).

Cultural features of rural life

There were several cultural differences noted by participants about people living in rural areas: a ruggedness and independence, an increased distrust in anything perceived as external, and a dislike of anything considered 'city.' Participants reported distrust of things that are perceived as external as a possible barrier to accepting palliative care. Additionally, people living in rural areas and their clinicians reported a dislike of urban environments, with the general sentiment of 'any community with a traffic light may be too urban.' Participants described how the value placed in independence creates challenges in accepting outside help. As one complex care team member said: *"Our older generation grew up on the farms, in the woods, logging, trucking, construction, hard workers, very proud, very independent." "So, you faced the obstacles in, number one, having the conversation with the patient, and then number two, actually convincing them to accept services. Because oftentimes they feel that other people need it more than them, want to be able to take care of themselves for as long as possible, somewhat stubborn at times, but in a positive way, just determined."* (#P11).

Closer knit community

Both patients and clinicians alike noted that people in rural communities tend to take care of each other. A palliative care social worker described it as: *"a safety in these smaller communities of the goodness of Mainers looking out for each other."* (#P4).

Social drivers of health

All participants noted that social drivers (determinants) of health, such as finances, transportation, and access to healthy food, create barriers to caring for rural people living with heart failure. One cardiologist noted the multiple factors in access to food: *"Access to good food can be challenging. If you live alone and you're on a fixed income, … It's tough to deal with those low-sodium restrictions."* (#P23).

Access to healthcare

Participants noted that rural areas have decreased access to specialists as well as home care and other ancillary services. A palliative care nurse practitioner discussed how access to healthcare services were exacerbated by COVID-related staffing challenges: "*The whole system is short, it's falling short, and it feels like it's falling shorter. The need is so great."* (#P6).

Reliance on emergency room and hospitalization

Perhaps as a result of the cultural differences, and/or limited access to healthcare, clinicians noted their rural patients rely more on acute care services for their healthcare. They described patients as avoiding reaching out to their providers until symptoms were much worse. As a complex care team member explained "*so then it gets to a point where* [their heart failure] *is exacerbated and they have to seek medical treatment* [in the emergency room or hospital]*."* (#P11).

Perception of palliative care

Participants described patients' reluctance to accept palliative care as stemming from two factors: not wanting another team involved with their care; and conflation of palliative care with hospice and/or end-of-life care.

Lack of desire for 'another team'

As noted above related to the role of PCPs in rural areas, patients noted a lack of desire for another healthcare service and/or team. As one patient said after the interviewer providing definition of palliative care: *"I don't think I need anything like that.* Interviewer: *"Nope. You would not be interested"?* Patient: *"No, I am keeping busy as I can and I don't need any extra, I don't think."* (#P2). Notably, spiritual and/or religious support is often an important component of palliative

Conflation with hospice

The physicians and Advanced Practice Professionals understood that palliative care is helpful early in the disease trajectory with serious illness. However, as described in extensively in the literature, they noted that their patients (and their caregivers) were reluctant to seek palliative care because of the strong association with hospice and/or end-of-life care.

Feedback on intervention

Participants were enthusiastic about the proposed collaborative palliative care intervention, noting a few specific factors which were appealing. These factors included: conversations occurring in patients' homes; a connection to specialty palliative care in collaboration with their PCP; and having a registered nurse facilitate goals of care conversations. Participants also shared a few concerns, especially around: patients who may be resistant to goals of care conversations; the bandwidth of complex care teams and primary care/cardiology providers; the need for close integration with primary/cardiology teams; and the need for palliative care education and training.

Conversations occurring in the home

Many of the participants noted the benefit of having some palliative care conversations occurring in patients' homes, an occurrence that is more frequent for complex care teams as compared to clinic-based staff. One PCP said: *"I think when patients are in the comfort of their own home, they probably think more clearly because they're comfortable."* (#P7). Having conversations in a place of comfort could be helpful for all patients, but healthcare settings, and urban specialists' offices, might be particularly uncomfortable for patients coming from rural areas.

Connection to specialty palliative care

All of the palliative care specialists, and some of the PCPs, specifically appreciated the connection of the complex care team to specialty palliative care. They noted the training of complex care teams is unlikely to be sufficient to have the benefit associated with specialty palliative care. The ongoing connection with a specialty palliative care team, therefore, is critical for the intervention to be effective. One PCP noted: *"if indeed they're getting reviewed once a week with the [specialty palliative care] team, that's a great model"* (#P2). A cardiologist similarly said, "*and if they have additional resources through physicians and the [collaborative care] meeting, I think that would be a great benefit for patients."* (#P22).

Registered nurses facilitating conversations

All clinicians felt that nurses are quite capable of leading goals of care conversations. As one cardiologist noted, "*I don't think you need to be a* [physician] *to do that."* (#P23). Clinicians understood that PCPs and specialists often did not have the time to have a goals of care conversations with patients. Having nurses complete that task would ensure the conversations take place.

Patients who may be resistant to advance care planning conversations

Participants noted that some patients might avoid advanced care directive documentation conversations because they may be emotionally unpleasant.

> *Interviewer: Have you ever talked to a doctor about completing a form that documents who would make decisions for you and what type of care you'd want if you were unable to talk for yourself?*
> *Patient: I have talked about that with my doctor.*
> *Interviewer: Okay. Can you tell me what that conversation was like?*
> *Patient: It was kind of... I don't want to say it bothered me, but it's just thinking of the end of my life is near. (#P8).*

Patients may struggle with the conversation, regardless of who had the conversation because of the negative feelings of their mortality.

Bandwidth and time of complex care teams and primary care/cardiology teams

Some of the primary care and cardiology clinicians were worried that these conversations might generate more uncompensated work. Participants were also concerned about how goals-of-care conversations can be time consuming and the challenges of integrating this into the already busy schedule. As one palliative care nurse practitioner said: "*That's a lot to put on a nurse who has a full boat day scheduled, and she's got to drive all over and get her charting done. These aren't conversations that you can squeeze in. "Have you moved your bowels? Have you peed? Are you eating?" It's hard to squeeze a[n] in depth quality, high quality, palliative conversation in that."* (#P6).

Need for Close integration with primary and cardiology teams

Participants noted that for the intervention to be successful, the conversations with the complex care team would need to be shared with other members of the care team so that it appropriately influence the care patients receive. This would require close integration between primary care, cardiology, and the specialty palliative care teams. As one palliative care social worker noted: *"How would you capture that information going forward so that it can be helpful and not just in that nurse's head?"* (#P4). Without a way to efficiently share the information with the whole team, the intervention would potentially not be effective.

Need for palliative care training

Training in navigating difficult conversations was a frequently cited need for complex care teams to be successful. Practitioners working with home care and/or complex care noted a lack of this training. One physician noted: *"Well, I think the training would have to be excellent. I think these are conversations that absolutely can be had by any number of providers, nurses, primary care physicians, but it does require development of a set of tools in how to do it, so that you feel comfortable doing it. It can feel hard and heavy and I think there's a fine line between exploring care options, and then also conversely feeling like you're the bearer of bad news and you're always talking about the hard side of things. So it can be uncomfortable to have these conversations if you don't have a lot of practice. So I think the training would be really important."* (#P3). Without proper training, the complex care team could face numerous challenges.

Discussion

The goal of this study was to understand if a collaborative palliative care intervention would be appropriate for people living in rural areas with HF. In this study we interviewed patients, caregivers, and clinicians and identified themes related to: HF and care in rural areas; perceptions of palliative care; and feedback on the proposed collaborative care intervention. Participants expressed strong desires to have palliative care integrated into their primary care without having to introduce a new team or service. Participants also described how people living in rural areas are more rugged, independent, and distrusting of external medical services. In general, patients, caregivers, and clinicians expressed enthusiasm for this collaborative care model that builds on the trust rural patients place in their PCPs to deliver their healthcare.

Role of primary care

First, we found a strong preference for palliative care to be integrated into primary care. Patients in rural areas wanted their care to come from their trusted PCP. This desire might seem challenging for the introduction of traditional specialty palliative care which, by definition, is interdisciplinary and involves the introduction of multiple additional clinicians. This preference for care to come from a local, trusted PCP is consistent with other findings [41] and might, in part, be due to rural patients historically having one source of care (their PCP) and partially due to limited access to specialists throughout their lives [42]. In many ways, this preference for care to be delivered by the PCP suggests that patients living in rural areas may prefer primary palliative care over specialty palliative care. The proposed collaborative care model aligns with this preference while at the same time ensuring primary care teams have the expertise that would be provided by palliative care specialists. Ideally, the model allows the patient to benefit from specialty palliative care all without having to introduce new team members directly to the patient. For example, a palliative care chaplain might be able to coach a patient's complex primary care team to appropriately support spiritual coping, without meeting the patient directly. Similarly, the palliative care chaplain could coach the complex primary team on how to connect the patient with local faith leaders. This approach might enable trusted PCPs, and their teams, to deliver interdisciplinary primary palliative care, which can be augmented as needed with access to specialty palliative care.

Cultural features of rural life

Participants noted a number of ways in which people living in rural areas differ from those living in urban areas. People living in rural areas were described as rugged, independent, and distrusting of anything perceived as external or urban [43]. These rural cultural factors might be barriers for patients to accept traditional palliative care delivered by a new team of specialists. For instance, participants described how the value placed in independence creates challenges for patients in accepting help. People in rural areas often grew up doing demanding work without relying on or being able to access medical specialists for health problems. These rural patients may be less likely to seek medical care in general [44], and referring them to a specialist is particularly challenging because patients want to be able to take care of themselves as long as possible [45]. This issue is exacerbated when the referral is to someone outside of their community or requires them to travel to an urban area. Patients feel urban providers misunderstand rural living circumstances [45] and most specialists are based in urban areas. For both of these geographic and cultural reasons, rural community members are less willing to seek care outside of their community.

On the positive side, in our interviews both patients and clinicians noted that rural communities tend to take care of each other, so social and community support is perceived to be high. A collaborative care model of palliative care might avoid some of the challenges if care is delivered through a local, trusted PCP team. Patients would be able to interact with care providers in their local community, while receiving support from specialists that may live and practice outside their community. Faith communities are also commonly strong in rural areas and collaborative care models can capitalize on these strengths to enhance support for the patient and family.

Social drivers of health

People with HF, their caregivers, and clinicians described multiple ways in which living in rural areas influences peoples' health and medical care. Participants mentioned social drivers (determinants) of health (SDOH) that influence health outcomes for people with HF, like access to healthy food, low sodium dietary needs, and ability to travel to healthcare appointments. Although these are present in many areas, they are common challenges for people living in rural areas. Participants also noted increased utilization of emergency care as a way for rural HF patients to receive healthcare, consistent with previous work finding rural individuals use high intensity hospital care more, and hospice less, at end-of-life [6]. These findings are consistent with American Heart Associations' scientific statement on the importance of social drivers of health in HF [46]. While the RuPal collaborative intervention was not designed to solve social needs, this approach is sensitive to the context in which patients live. For instance, receiving care in their own community makes travel to receive care more convenient and affordable, lessening the impact of transportation and income as drivers of health.

Perceptions of palliative care

In our study, clinicians practicing in rural areas understood the differences between palliative care and end-of-life care and accurately described the value of palliative care. However, patients and their caregivers had many misconceptions about palliative care and frequently conflated it with hospice and/or end-of-life care. This is consistent with previous findings that 42.5% of cancer patients automatically thought of death when thinking about palliative care, and 31.7% of patients equate palliative care with hospice care [47, 48]. This finding highlights the need to carefully introduce palliative care and not assume patients and caregivers are familiar with the services.

Feedback on collaborative care intervention

In general, participants in this study were enthusiastic about the proposed collaborative care model of palliative care. In addition to wanting care to come through primary care (with support by specialty palliative care), participants expressed support for two additional features: a) conversations in patients' homes; and b) nurses facilitating advanced care directive documentation conversations. Technology solutions, such as video telehealth calls, have been proposed to increase access to palliative care in rural areas [49–52]. Early tele-palliative care delivered via video is equivalently effective to in-person visits for quality of life in patients with advanced lung cancer [53], though broadband access maybe an issue for low resource patients in rural areas [54]. Home-based palliative care has been shown to decrease emergency department visits and hospital admissions in rural cancer patients with participating patients being more likely to die at home with better palliation of symptoms [55].

In general, we found that PCPs and complex care nurses were receptive to the idea of having complex care teams facilitate advance care planning (ACP) conversations. However, they noted strong training would be needed. Complex care nurses expressed interest in receiving training and ongoing coaching. Nursing interventions have been shown to be beneficial in community dwelling and emergency department settings [56, 57]. Strategies for training nurses to initiate these conversations have included coaching and access to local experts, training modules, didactic group teachings, conversation guides, and role playing [58–61].

Challenges for collaborative care interventions

Challenges remain in developing and implementing collaborative palliative care interventions in rural settings. For instance, in our study, specialty palliative care clinicians were concerned about how to deliver necessary training to the complex care teams. Lack of adequate training might lead to nurses feeling uncomfortable and avoiding prognostic conversations with patients and families [58]. Additionally, rural nurses have previously described barriers to palliative training, including competing work roles, work load, geographical isolation, and lack of backfill [62]. Understanding the best ways to deliver training will be an important step going forward.

Structural factors in rural healthcare might also limit the ability to implement collaborative care models of palliative care. For instance, high provider turnover and shortages [63, 64] might limit continuity and trusting provider-patient/caregiver relationships which are at the heart of the collaborative care model. Previous work has reported nurses feel pulled in multiple directions and have competing roles in collaborative care palliative care [65]. Scaling up this model could be challenging due

to limited nursing staff, which might be exacerbated by prior work showing the average home visit time increased from 20 minutes to 90 minutes when a HF nurse specialist addressed supportive and palliative care needs [66]. This would put additional stress on already stressed rural healthcare systems. More research is needed to see if improved coaching and training could decrease this visit time, or if these conversations create other savings for health systems justifying the increased time.

Crucially, we also need to understand when collaborative care models of palliative care improve patient outcomes. For instance, the CASA trial found collaborative palliative care led by a nurse and social worker did not significantly improve HF–specific health status (though secondary outcomes of depression and fatigue were improved) [67]. One possibility is that the nurse and social worker trainings were not sufficient, and that more training or specialty palliative care involvement, including direct patient consultations, is sometimes required to address patients' needs. Understanding what features of collaborative palliative care models improve outcomes is an important gap in knowledge for future research.

Study limitations

The present study had several limitations. First, clinicians who volunteered for interviews were likely familiar with palliative care, patients' needs, and the benefits palliative care can provide. These clinicians may have had more positive views of palliative care than the average rural clinician leading to more optimism about collaborative palliative care models. Additionally, our study focused on one rural community in Western Maine with limited ethnic, racial, and cultural diversity of patients and clinicians which limits how these findings might generalize to other rural communities. We did not have interview questions aimed specifically to understand how, and to what extent, local faith leaders and religious communities might influence a collaborative palliative care model. As a result, we may have missed some insights.

Conclusion

People living in rural areas with HF have poor quality of life and end-of-life care, which is partially due to limited access to palliative care. We found our proposed collaborative palliative care model delivered through PCPs and multidisciplinary team members was well-liked by patients, caregivers, and clinicians. More work is needed to test whether this model is feasible, acceptable, and improves patient quality of life and health outcomes.

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

Supplementary Material 4.

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Authors' contributions
RNH, EAJ, and NEG designed the study. NH collected the data. NH, MN, SDM, and RNH analyzed the data. ECA and RNH drafted the manuscript. All authors revised and approved the final manuscript.

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Data availability
Interview guides are included as supplemental materials. The raw qualitative data generated by the current study are not publicly available because they are highly identifiable. Deidentified data from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
All participants gave informed consent before participating. This study was approved by the MaineHealth Institutional Review Board.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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