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Inadequate Communication Exacerbates the Support Needs of Current and Bereaved Caregivers in Advanced Heart Failure and Impedes Shared Decision-making

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Background: Clinicians face considerable challenges in identifying patients with advanced heart failure who experience significant symptom burden at the end of life. Often, these patients are cared for in the community by a loved one who has limited access to support from specialist services, including palliative care. **Aim:** The aims of this study were to explore caregivers' experience when caring for a loved one with advanced heart failure at the end of life and to identify any unmet psychosocial needs. **Methods:** This article reports findings of a qualitative study, using semistructured, one-to-one interviews with current and bereaved caregivers, who participated in a larger mixed-methods study. Interviews were conducted by a trained researcher, digitally recorded, transcribed verbatim, and imported to NVivo 11 for data management and coding. Data were analyzed using thematic analysis and an inductive approach. **Results:** The 30 interviews included 20 current caregivers and 10 bereaved caregivers. The central feature of the caregivers' experience was identified as being "a physical and emotional rollercoaster." There were 3 main themes identified: poor communication, living with uncertainty, and lack of service provision. These themes were supported by 6 subthemes: inadequate understanding of palliative care, a 24/7 physical burden, emotional burden, inability to plan, no care continuity, and dying lonely and unsupported. **Conclusions:** Caregivers in advanced heart failure need clearer communication regarding diagnosis and prognosis of their loved one's condition to help with the uncertainty of their situation. Improved identification of palliative care needs and more coordinated service provision are urgently required to address their physical and emotional challenges from diagnosis through bereavement.

KEY WORDS: caregivers, heart failure, nursing, palliative care, qualitative research

Advanced heart failure (HF) symptoms such as dyspnea, edema, fatigue, and pain^{1,2} negatively

impact patients and caregivers' quality of life. The long-term prognosis of HF is worse than that associated with most cancers, with a 14% mortality rate 6 months after diagnosis³ and 47% of patients dying within 5 years.⁴ Heart failure is recognized as a global epidemic affecting

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approximately 26 million individuals worldwide and anticipated to increase over the next 10 years to an estimated healthcare cost of \$70 billion by 2030.^{5,6} In this context, prognostication can present practical challenges,^{7,8} and the symptom burden associated with HF makes it a complex condition for healthcare professionals to clinically manage. Often, clinicians, patients, and caregivers are unaware of the poor prognosis,^{9,10} mitigating the potential for end-of-life conversations, such as patients' preferred place of death.⁷ Evidence indicates that, given a choice, most people would prefer to be cared for and die at home.¹¹ However, despite this, most people with HF continue to die in acute hospitals or long-stay facilities.¹²

Caregivers need to be supported in their role, and in particular, they have identified the need for support when navigating complex healthcare systems and seeking information from specialists regarding the patients' fluctuating symptoms. The emotional burden of caregiving cannot be underestimated, and caregivers often experience social isolation and therefore require psychosocial support from their wider family circle as well as specialist services.¹³⁻¹⁵ Effective palliative care has been shown to address the complex needs of those living with HF and improve the patient and caregiver experience.¹⁶

Recent guidelines highlight the contribution palliative care can have to the care of patients with HF and recommended the need to integrate a palliative approach within the overall clinical management of HF.¹⁷⁻¹⁹ Demographic change and improved acute treatments mean that the incidence of HF has increased exponentially,⁶ with a subsequent rise in the burden placed on caregivers to enable people with advanced HF to stay at home.

Yet, the unpredictable disease trajectory of HF can be a barrier to patients, carers, and healthcare professionals when identifying and addressing the need for and timing of palliative care.²⁰ The literature is replete with sources attesting to the challenges healthcare professionals have in recognizing advanced HF and identifying when palliation should be initiated,^{7,8} and there is no doubt that further education is required to tackle this problem. Disparities in access to palliative care persist, with as little as 4% to 7% of patients with HF receiving a palliative care referral, many of which occur in the last week of life.²¹ Evidence suggests that few people with HF receive specialized palliative care or hospice support.²² Enhancing palliative care services and improving access for patients with HF and their families have the potential to improve patient well-being,²³ reduce caregiver burden,²⁴ and in turn reduce healthcare costs. Caregivers are central to the process of palliative care provision for patients with HF. Therefore, it is vital that their psychosocial needs are identified to help inform the development of supportive interventions for caregivers to maintain some sense of normality and reduce burden.¹⁴ We aimed to explore the

experience of caregivers when caring for a loved one with advanced HF at the end of life and identify their psychosocial needs.

Methods

Study Design and Recruitment

This article reports findings of a qualitative study, using semistructured interviews with caregivers participating in a mixed-methods study.²⁵ The reporting of the qualitative methods was checked against the COREQ checklist.²⁶ The mixed-methods study involved a postal survey with a range of standardized assessments that identified factors associated with caregiver burden in advanced HF, including quality of life, anxiety, and depression, from April 2014 to June 2016. Clinical teams within specialized secondary care centers (n = 3) across the United Kingdom and Ireland identified patients with advanced HF (Table 1). Patient inclusion criteria for advanced HF were decided upon following consultation with Consultant Cardiologists and Palliative Care specialists, to best identify patients who were in the last year of life. The patient nominated their informal caregiver to take part in the postal survey, during which current caregivers could volunteer to be interviewed and give permission to be contacted by the research team. These participants were purposively selected, taking into account geographical spread, gender, and relationship to the patient. Bereaved caregivers were recruited through email and social media via a voluntary organization (Reg No NIC 103593), a university, and a secondary care center. Bereaved caregivers interested in being interviewed contacted the research team, and this process continued until an adequate sample size was reached.

TABLE 1 Patient Inclusion and Exclusion Criteria

Patient Inclusion Criteria	Patient Exclusion Criteria
Aged 18 y or older	
NYHA class III or IV	
Ejection fraction \leq 40%	
Deemed physically and mentally suitable	Memory concerns reported or dementia diagnosis
Have an informal caregiver (individual not associated with a formal caregiving service)	Patients residing in residential care homes in receipt of formal caregiving
AND meet any ONE of the following:	
(1) Brain natriuretic peptide (BNP) $>$ 400 pg/mL	
(2) NTproBNP $>$ 2000 pg/mL	
(3) \geq 1 unscheduled hospital admission 12 mo before the study recruitment phase	
(4) On IV diuretics during the previous 12 mo	

Abbreviations: IV, intravenous; NYHA, New York Heart Association.

Participants

Current caregivers were deemed eligible if they were 18 years or older, an informal caregiver (not associated with a formal caring service; neither a paid worker nor a volunteer), and able and willing to provide informed consent. Caregivers were excluded if they were younger than 18 years or a formal caregiver. In addition to these criteria, bereaved caregivers were excluded if they were bereaved less than 6 months or more than 5 years previously.

Data Collection and Analysis

Semistructured interview guides were developed for the current and bereaved caregivers, following consultation with experts in the area of HF and palliative care, to elicit details on the background of the patient's illness, caregivers' perceptions of needs, service provision, and the caregiving experience (Table, Supplemental Digital Content 1, <http://links.lww.com/JCN/A67>). Trained researchers (L.C.D. and M.M.), with no clinical relationship to the participants, conducted one-off, face-to-face interviews with the caregivers alone, although in 1 instance, the patient was present for part of the interview. Interviews lasted, on average, 61 minutes and were conducted at a location of the caregivers' choice, which was usually in their home ($n = 21$) or an alternative quiet place convenient to them ($n = 9$). Field notes were taken during and directly after the interviews to allow the researchers to document caregivers' non-verbal responses. The interviews were digitally recorded,

transcribed verbatim, and imported into NVivo 10 for data management and coding.

Rigor

All transcripts were checked for accuracy, and analysis was carried out by the experienced researcher who conducted the interview. An inductive analysis of the data was undertaken using Braun and Clarke's²⁷ (2006) 6 phases of thematic analysis (see example in Figure 1). This involved in-depth recoding to combine codes and form overarching themes, which were then reviewed and refined through discussions with the research team (L.C.D., M.M., D.F., and S.M.) to establish consensus and generate final themes and subthemes.²⁸

Ethical Approval

The investigation conforms with the principles outlined in the Declaration of Helsinki. Ethical approval was granted by the Office of Research Ethics Committees (13/NI/0186) and university ethics committees, and research governance was sought from the respective secondary care centers. All caregivers provided written informed consent before the interview, and process consent was followed throughout each interview.

Findings

Characteristics of Caregivers

The 30 interviews comprised 10 current caregivers from the United Kingdom, 10 current caregivers from Ireland,

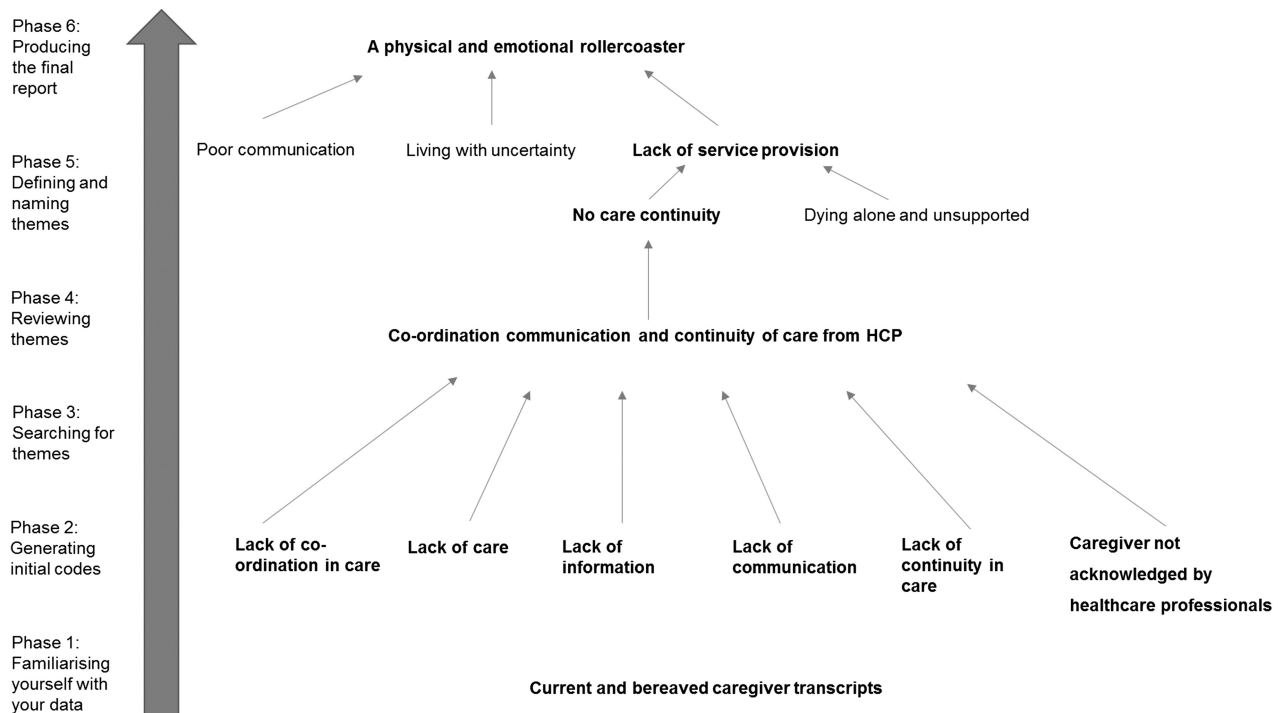


FIGURE 1. Coding tree to illustrate the application of Braun and Clarke's²⁷ (2006) 6 phases of thematic analysis.

TABLE 2 Description of Current and Bereaved Caregivers

	Current Caregivers	Bereaved Caregivers	Total
Gender			
Male	5	—	5
Female	15	10	15
Jurisdiction			
United Kingdom	10	10	20
Republic of Ireland	10	—	10
Relationship to patient ^a			
Partner/spouse	14	1	15
Parent	—	8	8
Son/daughter	5	—	5
Sister	1	—	1
Aunt	—	1	1

^aThe patient is/was my (relationship).

and 10 bereaved caregivers from the United Kingdom. Characteristics of the current and bereaved caregivers are presented in Table 2. Half of the caregivers (n = 15) were female, and current caregivers tended to care for a spouse (n = 15), whereas most bereaved caregivers (n = 8) had cared for a parent.

The overarching feature of this experience was identified as “a physical and emotional rollercoaster,” conveying caregivers' experiences when caring for a loved one with advanced HF at the end of life. There were 3 main themes: poor communication, living with uncertainty, and lack of service provision. Each of these themes, along with 6 subthemes, is presented in Figure 2 and discussed in this section with the support of verbatim quotations.

Theme 1: Poor Communication

Data indicated that most caregivers lacked a basic understanding regarding the patient's condition:

They never told us. They never mentioned heart failure in the hospital. (bereaved caregiver)

As a result, caregivers did not know what to expect as the patients' health deteriorated toward the end of life.

He had obviously deteriorated, but nobody was saying what the deterioration was or what to expect when he got home. (bereaved caregiver)

This lack of information led to problems for the carers.

You are helpless, you can't do anything, you don't get told anything. (current caregiver)

In particular, the bereaved carers identified lack of clear communication as a major stumbling block to their overall caring experience.

Nobody would tell us that- nobody ever once said your mother is dying. (bereaved caregiver)

It was evident that the diagnosis of HF was poorly understood, and carers had little insight as to its consequences and likely prognosis.

I think sometimes I think we were just too nice. We didn't assert ourselves, or ask enough (questions). Maybe we should have said, “Well actually we would like to speak to the doctor.” That was only Sunday and she was dead on Thursday. (bereaved caregiver)

It was a source of frustration to carers that there was so much uncertainty regarding their loved one's condition.

I just would like to have some idea of how far down we are, down that sliding scale, I think we might be coming very close to that. (current caregiver)

The quality and quantity of information presented to carers were not adequate and failed to facilitate their understanding of the clinical issues their loved one was facing, including symptoms, treatment options, and support needs. This lack of information negates the possibility of shared decision making for patients and their caregivers.

Inadequate Understanding of Palliative Care

It was evident in these data that caregivers believed that they did not have adequate basic information as they approached the end of their loved one's life:

I think a definite diagnosis is important if end of life stage—I think family need that, whether they want to hear it or not. (bereaved caregiver)

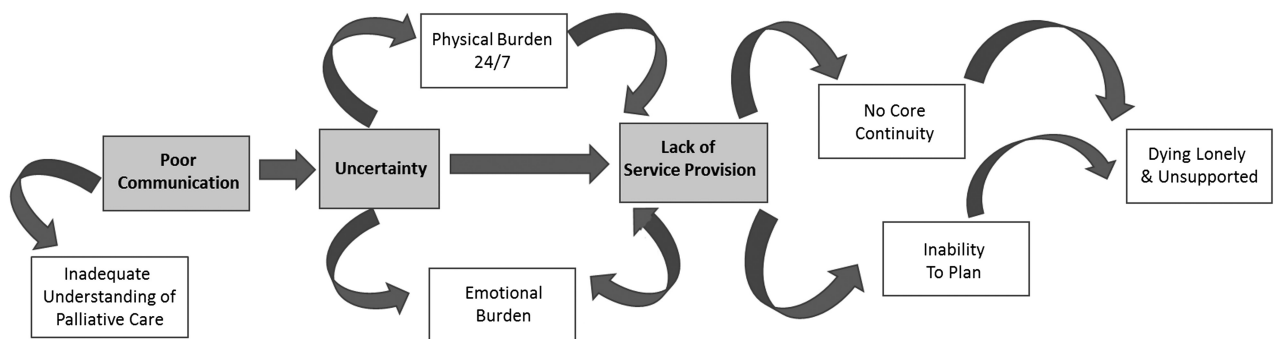


FIGURE 2. Conceptual model: a physical and emotional rollercoaster—caregivers' experiences and burden in advanced heart failure.

In addition, or perhaps as a consequence of this poor communication, carers reported an inadequate understanding of palliative care.

The palliative care nursing team came once every week. To this day, I don't know why they were here. (bereaved caregiver)

There was generalized uncertainty regarding the role of palliation and a perception from carers that palliative care was mostly associated with cancer.

They are for cancer, really at the moment aren't they? The palliative care, is that just for cancer? (current caregiver)

However, many of these carers would have welcomed more information and support.

Even to get information on palliative care would be something. What goes on? What it involves? To have that would be something. (current caregiver)

This lack of information reported by caregivers demonstrated the need for not only improved communication between healthcare professionals, patients, and their family, regarding the patient's condition, but also a deeper explanation about palliative care services to prevent misconceptions about the role of palliative care in advanced HF.

Theme 2: Living With Uncertainty

A pervasive feature of carers' experience in this study was living with uncertainty, which stemmed from the lack of information provided.

The fact that no doctor would come and discuss his case and nobody would give us information to go home with. (bereaved caregiver)

As a result, carers felt ill-equipped to deal with the demands of the situation in which they were placed.

I was scared; I was angry.... Why is this happening to me? Why is this happening to [patient]? (current caregiver)

From the carers' perspective, there were many unanswered questions:

Again I wasn't told very much. I found it frustrating. (bereaved caregiver)

As these extracts articulate, carers felt a pervasive sense of uncertainty but perceived that they had no one to turn to for information or support, leaving them isolated and concerned.

A 24/7 Physical Burden

All the caregivers reflected on their role as being "24/7." They were living with caring responsibilities 24 hours a day, there was no such thing as a day off, and they were constantly watching the patient, waiting for something to happen.

I find that he is very unsteady on his feet so I am 24/7 keeping an eye on him. Where he is going? What he is doing? (current caregiver)

The condition was so unpredictable that the caregivers were afraid to leave the patient alone and, when they did, they felt guilty.

He would start sitting up in bed and get out of bed, but he couldn't stand, so he would just fall on the floor. I am here on my own. I had nobody, no backup, no nothing and I had to sleep on the floor to stop him getting out of bed. (bereaved caregiver)

It was clear that caregivers understood they needed greater support:

And they (family) should also be given contact numbers of every resource that is available to them—occupational therapy is a big one, for the wee practical things! (bereaved caregiver)

In several instances, caregivers drew parallels with the perceived support that was available to others, such as people with cancer:

The world and his wife wants to offer you support when you have cancer, but if you've got HF you just get on with it. (bereaved caregiver)

The sheer physical burden of caring for someone with advanced HF was demonstrated in the following extract, as was the pressure of a "24 hour a day, 7 days a week" responsibility.

I just think it has taken an awful lot out my health. Is that normal? Is that part of looking after somebody? Not being well myself. I don't know. (current caregiver)

Emotional Burden

Given the uncertainty and physical burden outlined previously, it is unsurprising that there were negative emotions associated with the caregiving role, such as stress, worry, sadness, loneliness, fear, blame, and denial.

So, I was second-guessing how bad he was. It was a very, very stressful time. It was stressful because I felt completely, completely, alone. I felt completely responsible. (bereaved caregiver)

Caregivers felt problems were endless, and given how unpredictable HF symptoms can be, they found it difficult to cope day-to-day with their loved one's condition.

Just panic and hopelessness. Not able to do anything and sad, all the emotions that go with this I suppose. (current caregiver)

These emotions had a negative impact on caregivers' quality of life and daily living, with sleep disturbances, depression, and anxiety being widely reported.

Theme 3: Lack of Service Provision

Many of the caregivers described instances when they were unhappy with the care the patient received from healthcare professionals.

When he comes home “No”, there's nothing in place.... Now I lost it when he came home, I just exploded. Burst out into tears and really got very upset. (current caregiver)

Most patients had comorbidities and were receiving specialist care from multiple disciplines, making caring for them at home more complex.

It is that kind of feeling. They will palm you off to somebody else rather than sit with you and have a straight conversation. (current caregiver)

The frustration and dissatisfaction that caregivers felt with this level of service provision are evident in these extracts.

Inability to Plan Ahead

Heart failure limits not only the patient's life but also the caregivers', which led to caregivers feeling their life was no longer their own but “ruled by the patient's condition.” The following extract reflects these feelings.

It was very strenuous. For me it was very strenuous. The long hours that you had to sit with her and I am thinking that I could be down in my own house...but she needed me so that was it. (current caregiver)

It was a common feeling among caregivers that the patients' needs were their first priority, and they often made reference to putting things on hold because of the patients' health.

I don't have a life. My life is sitting in the chair watching. (current caregiver)

Clearly, caregivers struggled with the unpredictability of the patient's condition and their consequent inability to plan ahead.

No Care Continuity

Caregivers expressed the need for improved service provision, in particular, better continuity of care within the HF services and better coordination between different disciplines.

Then you ring and one tries to pass it off to the other... One Dr says yes, one Dr says no, one Dr says yes, one says no. (current caregiver)

Frequent hospital appointments were a considerable burden on both the patient and the caregiver, especially as their condition deteriorated.

Yet he would go to appointments, he maybe had four appointments a week which he wasn't fit to go to. He would go and I couldn't understand why people who are so ill, are asked to go to appointments. (bereaved caregiver)

Others commented on the lack of forward planning and focus on management of acute episodes, rather than the long-term condition.

And there was nothing really decided, no check-ups through the heart team unless he was rushed to hospital. (current caregiver)

Indeed, carers reported that, at times, they welcomed a hospital admission for the patient as this provided the opportunity for some respite from their sense of continued responsibility.

And to get him into hospital was such a relief that somebody else had the responsibility because I couldn't do anything else. (current caregiver)

These data illustrate the frustration that carers felt and their desire for a much more coordinated approach to care management in advanced HF.

Dying Lonely and Unsupported

The data from the interviews with bereaved carers confirmed that the dying phase of the patient's illness trajectory was often a lonely experience and they felt ill-supported to deal with it:

It's actually quite frightening, that you're in charge of somebody so sick and you don't know what to do for them and yet you know they need serious medical help. (bereaved caregiver)

The previous data outlining lack of information, living with uncertainty, and the resultant emotional burden help explain why carers found it so difficult and overwhelming to be responsible for someone dying at home:

I was at that stage where I wanted somebody to tell me what to do. I was too stressed, too tired, too emotional. I don't know what it was...everything I suppose. (bereaved caregiver)

The lack of this support—even someone “to tell me what to do”—really concerned caregivers, and many wished that communication had been better and things had been planned differently:

If she could have been moved to the hospice, it would have been wonderful because she would have had a nice dignified death. But I didn't know, because she didn't have cancer...you know... With cancer you are sort of given...well your mother is going to live for a few weeks. With this, there was no end to it. As a human being, you want to know, you want an end, you want to prepare. (bereaved caregiver)

It is recognized that palliative care should not stop when the patient has died, but data from the bereaved carers suggest otherwise:

Because I have gone from so many people across my door, to nobody. That sometimes is where the system fails. Everybody just walks away...But nobody once came back to say, “Are you alright?” Suddenly everything just stopped. (bereaved caregiver)

These are the main themes from the current study, and although there were few positives described within the data, caregivers did report having no regrets in devoting their time to caring for their loved one. In particular, the bereaved caregivers reported a great deal of satisfaction knowing they enabled their loved one to die at home and this feeling surpassed any difficulties that they encountered. Given the

enormous responsibility and significant burden that caregivers in this study carried, it is regrettable that they do not receive adequate follow-up care during the early bereavement phase.

Discussion

Results from this study are unique, in that they document the caregivers' experience and support needs through the HF trajectory, from advanced disease, including the dying phase, and into bereavement. The findings indicated that inadequate communication from healthcare professionals exacerbated the physical and emotional burden of caring for a loved one with advanced HF. The experience is likened to that of a “physical and emotional rollercoaster” resulting in significant caregiver burden. From this analysis, a conceptual framework (Figure 2) has been developed that highlights the areas that can be targeted to support caregivers of those with HF toward the end of life. This framework builds on recent work of Wingham et al¹⁵ (2015) and May et al²⁹ (2016), who proposed conceptual models to clarify the central features of the experience and map the links between these, to more fully explain caregivers' perspectives. The model may be useful to help outline the complexity of the situation and identify key areas that need to be targeted when seeking to develop supportive interventions. The analogy of a “rollercoaster” also conveys the fluctuating and uncertain illness trajectory for HF, corroborated in other studies.²⁰ Significantly, it highlights the importance of early and clear communication that acknowledges uncertainty but still provides carers with ongoing information to reduce the unpredictable situation with which they struggle^{30,31} and to better equip them for shared decision making.

The rising elder population and improved treatments for acute cardiac disease mean that the proportion of people with advanced HF is rising exponentially throughout the world. These people normally reside in the community and have multiple comorbidities, and their informal carers often are spouses of a similar elderly age with their own health issues.¹³ These carers often go unrecognized within our healthcare systems, yet they are crucial to helping reduce patients' morbidity, maximize quality of life, and facilitate independent living.¹³ Policy developments to improve advanced HF care should acknowledge carers' contribution and invest in supporting them more effectively with information, psychosocial interventions, and respite services.

Care systems in HF tend to adopt an acute disease approach, with severe exacerbations usually requiring hospital admission across many countries. This model does not serve the needs of people with advanced disease and their caregivers, especially in the final stages of life. In this study, we captured new knowledge that spans the entire trajectory of advanced HF including the dying

What's New and Important

- The authors present a new conceptual framework highlighting key issues for caregivers in advanced HF and identifying the nature and extent of their unmet needs across the final stages (including death) of their loved one's illness.
- The lack of effective diagnostic and prognostic communication identified in this study left carers without the basic information they required to enable shared decision making.
- The authors confirm an urgent need to provide appropriate information, psychosocial support, and holistic care to patients with advanced diseases and their caregivers.
- Existing systems should be modernized to facilitate the earlier integration of palliative care alongside HF management.^{1,7}
- Carers in advanced HF deserve to be recognized for their contribution and offered appropriate support in the final stages of their loved ones' illness and appropriate bereavement care.

phase from a caregiver's perspective. The compelling picture of patients dying lonely and lacking support due to the lack of basic information and resources is one that should tax the minds of nurses and all healthcare professionals. Dame Cecily Saunders, a proponent of palliative care, said, “How people die, lives on in the memory of those who live on.” There is a need for an urgent action at a systemic and practical level to address the needs of patients and their caregivers in the advanced stages of HF.

Limitations

The transferability of this study should be evaluated in the context of its geographical restrictions and fairly modest sample size. We recruited mostly female caregivers, and the relevance of these findings to male carers or indeed other cultures and healthcare settings cannot be assured. These data form part of a larger, sequential, explanatory, mixed-methods study, and although the qualitative data very much build on the quantitative findings,²⁵ for the sake of clarity and brevity, the two are not integrated in this article.

Conclusion

In this study illustrating caregiver burden, combined with other research highlighting patients' needs in advanced HF,^{32,33} confirm an urgent need for improved information and service provision. At a minimum, this should include effective prognostic communication, early identification of palliative care need, holistic assessment and provision of practical and psychosocial support, and respite for caregivers. These findings also stress the imperative to improve care coordination and continuity across all healthcare

boundaries from diagnosis to dying and bereavement phases. Our data, along with other recent evidence on patient-carer dyads,^{34,35} confirm the need to further explore the dynamic and interactive nature of caregiving and its physical and psychological impact in advanced HF. To address the unmet needs of carers in advanced HF, clinicians need to take action urgently to improve communication early in the disease trajectory in a way that enables shared decision making at the end of life. Further research on the mechanisms to achieve this is needed in tandem with service innovation.

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