

Exploring Patient, Caregiver, and Healthcare Provider Perceptions of Caring for Patients With Heart Failure: What Are the Implications?

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Background: Heart failure (HF) is an incurable and frequently progressive disease. Symptoms of HF may impair the ability of patients to perform daily living activities. As HF progresses, patients typically increase their reliance on caregivers. The purpose of this study was to determine what roles patients and caregivers perceive and desire for themselves in managing HF and to compare and contrast these roles with those perceived by healthcare providers.

Methods: A purposive sample (60 patients, 22 caregivers, and 11 healthcare providers) was enrolled in the study. Patients and caregivers individually participated in semistructured interviews, and healthcare providers participated in 1 of 2 focus groups.

Results: Four key themes evolved from interviews with patients and caregivers—education on disease specifics, guidance to enhance quality of life, learning to cope with HF, and future outlook and care decisions—that may guide the development of caregiver interventions in HF. Healthcare providers in both structured focus groups regardless of rank order selected knowledge is powerful, adherence to treatment plan, and compliance with medication as the top 3 issues likely to have the greatest impact, and they identified education on the disease (knowledge is powerful) as the easiest strategy to implement for patients and caregivers in the management of HF.

Conclusion: Interventions among caregivers of patients with HF are needed and should focus on education in family structures, family functioning, and skills training in family assessment and engagement.

Keywords: Caregivers, comprehensive healthcare, heart failure

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INTRODUCTION

Heart failure (HF) poses a substantial burden on patients and the healthcare system.¹ Patients with HF frequently have chronic symptoms, resulting in diminished quality of life.^{2–4} HF is a leading cause of death, frequent hospitalizations, enormous healthcare costs, and disability.^{1,5–6} In addition, the American Heart Association acknowledges that suboptimal self-management of HF is an important contributing factor to adverse outcomes, including hospitalizations and early mortality.⁷ Self-care activities required for ideal HF care can be complex, requiring continuous attention to diet, medication, and symptoms and multiple visits with healthcare providers. HF care can also be a tremendous burden for caregivers who play major roles in the lives of patients with HF.^{8–12}

Given the complexity of this chronic disease, engaging caregivers to promote the health of patients with HF is critical. However, results of interventions directed at

caregivers to improve patient outcomes (usually in terms of reduced healthcare use) have been negative to date,^{9–19} with only one study demonstrating delays in placement in long-term care.²⁰ In addition, only a small number of studies has been conducted in HF populations.^{16,21–24} Although the tasks that caregivers perform for HF patients have been well documented,^{25–28} few studies have asked patients what roles they would like caregivers to provide in their care,²⁹ and fewer have asked caregivers what roles they desire.⁸

Understanding what roles patients and caregivers desire and how to support these roles is vital for healthcare providers and researchers because this understanding may lead to decreased caregiver burden and increased equivalence between patients and caregivers,³⁰ improved patient and caregiver satisfaction with care, and improved health outcomes for patients with HF. The purpose of this study was to determine what roles patients and caregivers perceive and desire for themselves and to compare and

contrast these roles with those perceived by healthcare providers in the management of HF. Findings from this study may inform the design of caregiver interventions aimed at improving outcomes of patients with HF and other chronic diseases.

METHODS

Participants

We recruited patients; caregivers; and cardiologists, nurses, and medical assistants or other staff treating patients with HF (collectively referred to here as healthcare providers) in an outpatient HF clinic at an academic healthcare center. Purposive sampling was used to maximize variability in the age and health status of patients. Eligible patients and caregivers were adults aged ≥ 18 years who were able to speak English and willing to be tape recorded. In addition, patients with a diagnosis of HF from any cause, with New York Heart Association functional classes II-III, were eligible for the study. Patients with a slight limitation of physical activity who are comfortable at rest and for whom ordinary physical activity results in fatigue, palpitation, and dyspnea (shortness of breath) are deemed functional class II; patients with marked limitation of physical activity who are comfortable at rest and for whom less than ordinary activity causes fatigue, palpitation, or dyspnea are class III.³¹⁻³³ Before patients were included in the study, a cardiologist on the research team confirmed the diagnosis of HF. Patients with a history of alcoholism, substance abuse, or dementia were excluded. Caregivers were identified through patients by asking, "Can you think of the one person besides a healthcare provider who helps you the most with your heart condition?"

Written informed consent was obtained from patients, caregivers, and healthcare providers prior to the start of the study. Lunch was provided during the healthcare provider focus groups, and each patient and caregiver received a snack and a \$25 stipend for their participation in the study. The study protocol, procedures, and consent form were reviewed and approved by the Pennington Biomedical Research Center Institutional Review Board.

Design and Procedures

Two interviewers with experience in qualitative methods conducted semistructured interviews in the HF clinic that lasted approximately 30 minutes with patients and caregivers separately from October 2015 to February 2016. The interview questions were based on the National Consensus Project's conceptual model and included 6 major domains on patient and caregiver experiences of dealing with HF (Table 1).^{8,34} Questions included overall unmet needs, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, future of illness, and structure and processes of care that patients and caregivers think will improve their health and quality-of-life outcomes. For example, caregivers were asked, "If you could have anything you wanted to help you with (patient name's) heart condition, what would it be?" The interviews were conducted to gain an understanding of the roles that patients and caregivers fulfill and to identify areas in which these roles are unsupported or in conflict with how they think their roles are understood by healthcare providers. Prior to conducting one-on-one interviews, the investigative team pilot-tested

the interview questions with participants similar to the study population to ensure that the questions would capture the intended responses. Interviews were digitally recorded, transcribed verbatim, and entered into ATLAS.ti for coding and analysis.³⁵

Patient and caregiver data were analyzed and are presented concurrently. We used the method of constant comparison derived from grounded theory,^{36,37} employing a team approach to analysis and maintaining an audit trail documenting the analytic process. Initial codes were developed by the interviewers, who met weekly to discuss coded data, reconcile differences, and reach consensus on code labels and their definitions. These meetings resulted in several iterations of tables with summarized coded data of patients only, patients with a caregiver, and all patients with or without a caregiver to compare and contrast differences and similarities in responses within each interview domain (major concerns and needs, physical aspects of care, psychological and psychiatric aspects of care, social aspects of care, future of illness, and structure and processes of care), searching for patterns, similarities, and differences, comparing across and within patient and caregiver interviews to develop consensus on final themes and implications for caregiver interventions. All investigators reached a consensus on the final set of themes.

Focus Groups

In addition to determining patient and caregiver perceptions, we considered understanding healthcare provider perspectives important. Therefore, the Nominal Group Technique (NGT), a qualitative method of data collection, was used to determine providers' perceptions of the roles patients and caregivers play in the management of HF. NGT, a brainstorming tool for quality improvement and highly structured small group discussions, is used to elicit and prioritize a list of answers to a specific question.³⁸⁻⁴² Similar to traditional focus groups, having 4-12 participants per group is ideal for NGT sessions.⁴³

The multistep NGT design systematically stimulates meaningful interpersonal statements among participants by gathering equally weighted responses to a specific question, and these statements tend to be a valid representation of group views.⁴⁴⁻⁴⁷ The NGT does not require audio recording and transcription because verbatim responses are written on a flipchart, thereby providing a concise summary of the session that is readily available for dissemination.

During lunch in March 2016, healthcare providers participated in 1 of 2 NGT sessions conducted in the breakroom of the HF clinic. Each group consisted of 5-6 healthcare providers, both males and females, and a cardiologist was included in each group. Each group session lasted approximately 30 minutes.

After welcoming providers, the purpose of the session and ground rules for participation were discussed. Preliminary questions were not discussed because of the limited amount of time healthcare providers had to participate. Therefore, the facilitator, accompanied by a cofacilitator, posed the main question to providers: "What is your perception of the roles heart failure patients and their caregivers should play in the management of their heart condition from your perspective as healthcare providers?"

Table 1. Patient and Caregiver Interview Domains and Sample Questions

Interview Domains	Sample Questions^a
Major concerns and needs	What is the most difficult or distressing for you about (your/patient name's) heart condition? If you could have anything you wanted to help you with (your/patient name's) heart condition, what would that be?
Physical aspects of care	Can you tell me about any of (your/patient name's) symptoms that might need better treatment? How do you deal with symptoms?
Psychological and psychiatric aspects of care	What would you do if you or (patient name) felt down, frustrated, or worried? What do you think might help you if you had these feelings?
Social aspects of care	Who do you talk to about (issues mentioned throughout interview)? Caregiver only: How do you help (patient name)? What is it like to care for (patient name)?
Future of illness	When you think about (your/patient name's) heart condition and what lies ahead for you (say, the next months or 1-5 years), what comes to your mind? What information would help you plan for the future?
Structure and processes of care	Who should be involved with helping you with (your/patient name's) symptoms, feeling down, talking about the future?

^aCaregivers were asked questions adding the patient's name where applicable; patients were asked similar questions omitting the name.

In response to the question, the healthcare providers were asked to work silently and to independently write down as many responses in short phrases as possible that represented their individual views. In a round-robin manner, healthcare providers were then asked to share their answers (one response at a time), and each response was written by the cofacilitator verbatim on a flipchart without discussion. Each recorded response was discussed for the sole purpose of clarification and not for evaluation or debate as to its relative importance. During this step, healthcare providers were asked to combine responses that they perceived to be significantly similar. Finally, during the voting phase, healthcare providers privately selected what they considered to be the top 3 items from the generated list of responses likely to have the greatest impact on managing HF. Subsequently, they ranked the top 3 responses that would be the easiest to implement.

Each healthcare provider prioritized his or her selections on his or her own and without discussing with others, assigning a rank of 3 to the most influential and 1 to the least influential strategy and likewise for the easiest to implement strategies. The facilitator recorded the votes on the flipchart in front of all providers and tallied the votes for each response. A small number of idiosyncratic ideas were discarded, a standard procedure in the NGT. The primary results were the top 3 strategies identified within each group; the secondary results were all other ideas. Through an iterative process, the facilitators categorized responses into common themes until consensus was obtained.

Demographic Data Collection

Using survey instruments, demographic information was collected from the patients, caregivers, and healthcare providers, including age, race, sex, education, employment, annual household income, and marital and health status. In addition, patients provided the number of years they had been diagnosed with HF and other chronic diseases;

caregivers reported their relationship to the patient, the number of hours they spend caring for the patient per week, and if applicable, their number of years of experience in healthcare; healthcare providers selected their primary occupation and their number of years of experience in their specialty.

RESULTS

Select demographic characteristics of the 93 participants (60 patients, 22 caregivers, and 11 healthcare providers) are shown in Table 2. Of the 60 patients recruited in the study, 24 had no caregiver, 12 caregivers could not be reached, and 2 refused. Additionally, 55% of patients had been living with HF for >6 years, and 83% had high blood pressure. Caregivers' relationship to patients was 55% spouse/significant other, 86% of caregivers lived with the patient, 82% provided >8 hours of care per week, and 77% had no prior healthcare experience. Of the healthcare providers, 73% were registered nurses/licensed practical nurses or medical assistants. All healthcare providers had been in their profession >10 years.

Key Themes From Patient and Caregiver Interviews

Patients and caregivers described their ordeal of the HF diagnosis, the impact on their livelihood, the fear and uncertainty about managing the condition long term, and what would help overall in managing the disease. Many patients and caregivers expressed relief in having direct telephone and text messaging access to their cardiologist. Other than expressing the desire to have someone to check on them from time to time, patients without caregivers did not respond any differently than those with caregivers. Table 3 shows the results of interviews structured to reflect 4 key themes: education on disease specifics, guidance to enhance quality of life, learning to cope with HF, and future

Table 2. Participant Characteristics

	Patients, n (%) n=60	Caregivers, n (%) n=22	Healthcare Providers, n (%) n=11
Demographics			
Age, years			
18-35	4 (7)	4 (18)	0
36-55	29 (48)	10 (45)	10 (91)
56-65	21 (35)	6 (27)	1 (9)
>65	6 (10)	2 (9)	0
Race			
Black	51 (85)	16 (73)	8 (73)
White	8 (13)	4 (18)	1 (9)
Other	1 (2)	2 (9)	2 (18)
Sex			
Male	35 (58)	6 (27)	3 (27)
Female	25 (42)	16 (73)	8 (73)
Education			
Grade 0-8	2 (3)	1 (5)	0
Some high school	10 (17)	3 (14)	0
High school	25 (42)	14 (64)	0
Some college (1-3 years)	19 (32)	4 (18)	5 (45)
College	3 (5)	0	3 (27)
Postgraduate	1 (2)	0	3 (27)
Employment			
Full-time	7 (12)	10 (45)	11 (100)
Part-time	9 (15)	2 (9)	
Medical disability	38 (63)	3 (14)	
Unemployed	3 (5)	4 (18)	
Retired	3 (5)	3 (14)	
Total annual household income, \$			
<10,000	31 (52)	10 (45)	0
10,000-19,999	16 (27)	6 (27)	0
20,000-29,999	8 (13)	2 (9)	4 (36)
30,000-39,999	3 (5)	1 (5)	1 (9)
40,000-49,999	1 (2)	2 (9)	1 (9)
50,000-59,999	0	1 (5)	1 (9)
60,000-69,000	1 (2)	0	1 (9)
>\$70,000	0	0	3 (27)
Marital status			
Never married	20 (33)	7 (32)	4 (36)
Married	22 (37)	11 (50)	3 (27)
Divorced/Separated	14 (23)	3 (14)	4 (36)
Widowed	4 (7)	1 (5)	0
Health status			
Excellent	1 (2)	0	1 (9)
Very good	5 (8)	6 (27)	7 (64)
Good	22 (37)	13 (59)	2 (18)
Fair	23 (38)	3 (14)	1 (9)
Poor	9 (15)	0	0

Table 3. Key Themes From Structured Interviews With Patients With Heart Failure (HF) and Their Caregivers

Key Themes	Definition	Representative Responses
Education on disease specifics	Explanation on the disease process, checklist, what to expect, and how to proceed	“I am unable to do a lot of things for myself. I have lost my independence.” “This is happening; what should I do?”
Guidance to enhance quality of life	Importance of following doctor orders: Eat healthy Take medications as prescribed	“I have the best doctor you could ever have; my doctor tells me what to do, and I do it.” “Nutrition education.” “She’s getting good treatment; she just won’t take her medicine.”
Learning to cope with HF	Importance of following treatment plan: Seek counseling or therapy Support group	“Talk to someone”; “Pray, read Bible, talk to other people, vent to my mom or my husband.” “Talk to each other—good support system between the two.”
Future outlook and care decisions	Importance of team approach to care	“Healthcare providers; medical team.” “Social worker, case manager, and doctor.”

outlook and care decisions that may guide the development of caregiver interventions in HF.

I. Education on Disease Specifics. Overall, the major concerns and needs that patients with HF said caused the most difficulty for them were limited ability to perform any activity because of shortness of breath and fatigue. For example, some patients who were able to work prior to their diagnosis are now limited or unable to work, so they perceived a loss of independence to be a result of their condition. Patients perceived that the solutions to this difficulty were to obtain a new heart, for their original heart to start working as it should, or to obtain a pacemaker that really works. However, some patients stated that “medicine that could fix/cure the problem” would also alleviate their heart condition. Patients also stated, “I would like to learn more about my HF and what brought it on.” Caregivers considered the uncertainty of HF and not knowing what is going to happen and what is expected of them most difficult. If caregivers could have anything they wanted to help them with the patient’s HF, it would be “someone to call and say this is happening, what should I do?”

II. Guidance to Enhance Quality of Life. The physical aspects of care that the majority of patients perceived as needing better treatment were shortness of breath, fluid retention, uncontrolled blood pressure, and diabetes. Patients dealt with these symptoms and comorbidities by taking more medications, visiting the doctor’s office/clinic to have the fluid reduced, or by praying. Interestingly, many patients responded, “I think my doctor is doing a good job,” “I have the best doctor you could ever have. My doctor tells me what to do, and I do it,” or “I have a good doctor, and all is being taken care of for now.” Caregivers’ perceptions of the symptoms needing better treatment included those noted by patients as well as patients’ eating habits and the importance of taking medications. Several caregivers stated, “Needs more exercise to strengthen his body; he is supposed to walk but can’t because he gets out of breath.” Most caregivers were willing to do whatever the patient required. However, some caregivers stated, “It’s frustrating,” and “She’s getting good treatment; she just

won’t take her medicine.” For dealing with these symptoms needing better treatment, caregivers stated, “Check weight, blood pressure, then call or text doctor if abnormal.”

III. Learning to Cope with HF. Patients and caregivers were asked what they would do if they felt down, frustrated, or worried. Some patients stated that they would “cry, contact or visit doctor, or talk to someone.” However, most patients said they would “pray about it.” Some caregivers appeared to be experiencing some health issues of their own and stated that they also “pray” or “talk to each other—good support system between the two” when feeling down. Going out and talking to somebody or changing their environment was perceived by patients as the help they needed if they felt down. Caregivers perceived prayer, meditation, talking to and encouraging the patient, and seeking counseling or therapy to be the help they needed when frustrated or feeling down.

The social aspects of care dealt with the specific person patients would talk to about any issues concerning their heart condition. Overall, patients indicated they would talk to God, their spouse, mother, sister, doctor or nurse, children, pastor, friends, or other family. However, many patients stated, “I would not talk to anyone.” Caregivers’ tasks for the social aspect of care focused on how they would actually help and what it was like to care for the patient. Many caregivers stated, “Make sure he takes his medicine, prepare meals; if he eats too much I make sure he walks or exercises”; “Always check on him and ask how he feels. He is a good patient”; “I do whatever she needs me to do, from giving medicine to rubbing her back”; and “I make sure that he goes to every doctor visit.” When caregivers were asked what it was like to care for the patient, several implied it was frustrating: “Not the best, sometimes he doesn’t listen”; “I’m not always there because I get frustrated with him”; and “It’s difficult because I don’t want to overstep his bounds.” For other caregivers, caring for the patient was a joyful experience because they considered caring for their loved one to be their duty.

IV. Future Outlook and Care Decisions. Many patients thought about simply living (“Will I still be here?”) when

thinking about their future with a heart condition. They expressed concern for not being around for their kids or grandkids or not being able to handle their financial obligations. Many patients responded that they “really try not to think about it.” Patients perceived that their doctor had or would provide any information that would help them plan for the future and said, “I have all the information I need, just need to do my part.” Many patients also stated “a nurse to help long range plan and to manage care”; “if I could understand menopause and heart condition”; or “personal trainer to keep me on track” may help to increase longevity. Caregivers expressed similar concerns about whether the patient would still be here in the next month or 1-5 years, with at least one caregiver stating the need for “pre-burial programs.” Many were proactive and stated, “I look up things on the internet to find things to help me help him” or “[I] rely on [the] cardiologist[s]; they are on point.” Both patients and caregivers responded similarly when asked who should be involved in helping them in the future, naming “self, spouse, doctor, and children” as key and including all healthcare providers and the medical team.

Nominal Group Technique Sessions With Healthcare Providers

Two NGT sessions were conducted with healthcare providers. The first NGT session with 6 healthcare providers generated 17 responses to the main question: “What is your perception of the roles HF patients and their caregivers should play in the management of their heart condition from your perspective as healthcare providers?” During the clarification discussions, healthcare providers stated that several responses were repetitive, so these responses were combined. The final list generated 9 responses for the prioritization exercise. These responses were organized into 3 themes identified during the iterative process (Table 4). The relative importance of each healthcare provider’s response—having the greatest impact on HF patients and their caregivers in the management of their heart condition—is reflected by the total number of votes and the sum of the ranks given to that response in Table 4.

When asked what roles patients with HF and their caregivers should play in the management of their heart condition, healthcare providers responded with the following: “Educate themselves on the disease,” “Patients and caregivers should make sure the patient is taking all medication as directed and on time,” and “Patient and caregiver should follow diet and salt intake that was set by their doctor.” These statements were categorized under the 3 themes identified during the iterative process: knowledge is powerful, compliance with medication, and adherence to treatment plan. The top 3 responses that healthcare providers identified as having the greatest impact on patients and their caregivers in the management of their heart condition were educating themselves first on the disease to understand the concept that knowledge is powerful, compliance with medication, and adherence to treatment plan. Healthcare providers also responded, “Be proactive in their care,” “Understand the disease and medication,” and “Keep scheduled clinic and doctor appointments” as secondary responses that were also categorized under the aforementioned themes.

Table 4. Healthcare Provider Perceptions of Managing Heart Failure

What is your perception of the roles heart failure patients and their caregivers should play in the management of their heart condition from your perspective as healthcare providers?

Group 1 Responses n=6	Total Votes	Sum of Ranks ^a
Knowledge Is Powerful		
“Educate themselves on the disease.”	6	18
“Be proactive in their care.”	5	13
Compliance With Medication		
“Patients and caregivers should make sure the patient is taking all the medication as directed and on time.”	6	16
“Understand the disease and medication.”	4	10
Adherence to Treatment Plan		
“Patient and caregiver should follow diet and salt intake that was set by their doctor.”	6	14
“Keep scheduled clinic and doctor appointments.”	6	12
Group 2 Responses n=5	Total Votes	Sum of Ranks ^a
Knowledge Is Powerful		
“Educate themselves.”	5	15
“Teaching on disease process.”	5	10
Adherence to Treatment Plan		
“Assist patients with treatment plan.”	5	13
“Eat well; exercise.”	3	6
Compliance With Medication		
“Take meds.”	5	11

^aCalculated by summing the ranks of responses (3=most important, 2=second most important, and 1=least important). The relative importance of each healthcare provider’s response—having the greatest impact on HF patients and their caregivers in the management of their heart condition—is reflected by the total number of votes and the sum of the ranks given to that response. Higher scores signify greater perceived importance.

In the second NGT session, 5 healthcare providers generated 18 responses to the main question. During the clarification discussions, healthcare providers indicated that several responses were the same, so these responses were merged. The prioritization exercise generated 5 responses for the final list that were organized into the 3 themes identified during the iterative process.

Some of the healthcare provider responses to the main question were, “Educate themselves,” “Assist patients with treatment plan,” and “Take meds.” These statements were categorized under the 3 themes identified during the iterative process: knowledge is powerful, adherence to treatment plan, and compliance with medication. The top 3 responses that healthcare providers identified as having the

greatest impact on patients and their caregivers in the management of their heart condition were for patients to educate themselves, to adhere to the treatment plan, and be compliant with medication. Healthcare providers also offered, “Teaching on the disease process” and “Eat well; exercise” as secondary responses that were categorized under the aforementioned themes.

Healthcare providers in both NGT sessions regardless of rank order selected knowledge is powerful, compliance with medication, and adherence to treatment plan as the top 3 issues likely to have the greatest impact, and they considered education on the disease (knowledge is powerful) to be the easiest strategy to implement for patients with HF and their caregivers in the management of HF.

DISCUSSION

Patients with HF and their caregivers in this study perceived the role and need for education on the disease process as a critical step in understanding how to deal and live with HF. More than 75% of caregivers had no healthcare experience, >50% of patients and caregivers had only high school or less education, and >70% had incomes in the poverty range. It is likely that caregivers in this study as in others experienced stress, frustration, depressive symptoms, and financial issues, especially when the patient with HF was the main source of income.^{48,49} Likewise, healthcare providers perceived that patients and caregivers should first educate themselves on the disease, labeling HF education a key element to understanding that knowledge is powerful.

Interventions to support effective HF care should address not only knowledge needs but also other determinants of care such as faith, beliefs, perceptions, and values.⁵⁰ Patients and caregivers in this study were adamant about prayer, meditation, and turning to God as their source of strength. However, education and support for HF care must be individualized because these determinants may vary widely among patients and caregivers.⁵¹ In the same manner that formal knowledge could influence a patient’s capacity to manage HF, lack of knowledge about HF could limit the extent to which caregivers could provide clinically effective care.^{52,53} This common type of caregiver knowledge deficit reflects the need for information that usually must be provided by the healthcare team about the disease, drugs, medication administration, and caregiving tasks.⁵⁴

Patients and caregivers perceived the role of guidance to enhance quality of life as a necessity during the disease progression. This study was unique compared to an abundance of others reviewed (mainly those addressing palliative care)⁵⁵⁻⁵⁷ in that caregivers and patients had direct access to their cardiologist via telephone or text message. The implication is that a strong, established communication relationship existed among patients, caregivers, and healthcare providers in this study as opposed to communication challenges making the role of caregiving difficult as shown in other studies.⁵⁸ Having direct access to the cardiologist was perceived as an advantage in case of an emergency or to report abnormalities while caregivers monitored the patient. Healthcare providers viewed adherence to treatment plan and compliance with medication as prerequisites for patients and caregivers to benefit from 3 of the key

themes they identified during the structured interviews: guidance to enhance quality of life, learning to cope with HF, planning future outlook and care decisions.

Almost half the patients in the study had been diagnosed with HF 1-5 years. When patients are first diagnosed with HF, patients and caregivers should focus on improving quality-of-life issues because as the disease progresses different types of support may be required. For example, in the initial stage of the disease, patient and caregiver support might focus on coping with the new diagnosis and its consequences for future family plans.⁵⁹ In addition, patients may need practical help such as that provided by caregivers in this study to change eating habits or to learn to organize a complex medication schedule.⁵⁹ Providing pill boxes to patients to manage medicines and addressing the purposes of medications with all patients and their caregivers are crucial steps to ensure adherence to the treatment plan and compliance with medication.⁶⁰ Patients diagnosed with HF for ≥ 6 years may need additional motivational or emotional support to adhere to lifestyle changes, attend clinic visits, or deal with loss of independence and possible frustration on the part of both patients and caregivers.⁵⁹

Finally, a team approach to HF care should be considered for planning future outlooks and decision-making as the disease progresses. Fifty-five percent of caregivers in this study were the spouse/significant other to patients, and other family members constituted the remainder of the caregivers. However, patients in this study as in others perceived themselves as playing an important role on their own care team.⁶¹ When asking patients and caregivers whom they talk to or who should be involved with decisions concerning their care, in addition to themselves and their spouse, they included God and their pastor, doctors, nurses, friends, and neighbors. These findings suggest that a broader conceptualization of the HF care team is needed, consisting of unexpected or nontraditional members who, according to these patients and caregivers, can play an important role in their care.⁶¹

LIMITATIONS AND ADVANTAGES

Qualitative data collection can be subjective and may be prone to human error and perception.⁶² It is also local and contextual; findings may not be generalizable to different clinical settings but may be transferable.⁶¹ Findings in this study should therefore be interpreted within the context of the design. Although purposive sampling was used to conduct semistructured interviews among a variety of patients and caregivers, only patients diagnosed with class II or III HF were recruited into the study.

In addition, the NGT used to gain information from healthcare providers in the study had some limitations: training and preparation are required; the discussion is restricted to a single question; and the method does not allow elaboration of other concepts, so the composition and representativeness of participants may limit the generalizability of the results.⁶³ This study is further limited by sampling only one cardiologist’s patients with HF and their caregivers on Monday mornings and within one designated HF clinical site.

With the weight of each participant’s opinion being the same, process loss seems unlikely to occur, an advantage of the NGT.³⁸ Furthermore, the highly structured format of

the NGT provides an opportunity for group participants to achieve a substantial amount of work in a relatively short period of time. Another advantage of the NGT is the deliberate avoidance of interpretation from a facilitator who has the responsibility of exploring but not interfering with or influencing participants in the group.³⁸

CONCLUSION

Findings from this study suggest that caregiver interventions are warranted based on patient, caregiver, and healthcare provider perceptions. Future interventions that link clinicians, academicians, and researchers and include traditional family and nontraditional members as partners in patient care teams, paying close attention to the healthcare needs of family members, are likely to improve health outcomes in patients with HF and their caregivers while helping to eliminate health disparities.

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