

Patient Perspectives on Home-Based Care and Remote Monitoring in Heart Failure: A Qualitative Study

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Abstract

Introduction: As individual interventions, home-based care and remote monitoring have been shown to help prevent hospitalizations for those with heart failure (HF) although both interventions have been limited by scalability and technical constraints, respectively. Few qualitative studies have explored patient perspectives, including acceptability, barriers, and facilitators of HF care inclusive of both interventions. The objective of this study is to explore patient perceptions on HF management at home, the use of home-based remote monitoring, and the value of home-based care. **Methods:** Qualitative interviews (N=27) were conducted via phone (12/2020-3/2021) with adults with HF. A framework analysis was used to identify main themes along with verbatim transcription for coding and analyses. There were 5 key interview domains: general HF knowledge, perceptions of the value of home-based care, unmet needs related to the social determinants of health (SDOH), experience with healthcare technology and remote monitoring, and challenges in HF home management. **Results:** Five major themes emerged. Patients reported: (1) home-based care plan instructions are understood; (2) following medication, diet, and fluid management instructions are challenging due to difficult adherence to and implementation at home; (3) financial limitations serve as barriers to acquiring healthy food; (4) home-based support is a valuable component of managing medications, diet, and fluid; (5) despite limited use of technology, strong willingness to use remote monitoring is present amongst most. **Conclusions:** Participants reported understanding of care plan instructions and challenges adhering to care plans at home. Barriers included needing more home-based support for medications, diet, and fluid management and requiring additional assistance with financial barriers related to unmet social needs. A combined intervention inclusive of remote monitoring and home-based support has potential to improve home-based strategies and clinical outcomes for HF patients.

Keywords

heart failure, home-based care, remote monitoring, readmissions, qualitative study

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Introduction

Heart failure (HF) is the most common cause of 30-day hospital readmissions and up to a quarter of these are considered to be preventable.^{1,2} A number of factors have been associated with HF exacerbations and hospital readmissions. These include both clinical factors^{3,4} (eg, close monitoring of weight, sodium intake, diet, and medication adherence) and factors related to social determinants of health⁵ (eg, transportation, food access, housing stability, and psychosocial support)^{6,7} which have been closely linked to poor outcomes in heart failure care. Both interventions centered on improving clinical management via remote

monitoring with use of digital platforms (eg, monitoring heart rate, blood pressure, oxygenation, weights, etc.)^{8,9} and interventions focused on closing gaps related to social determinants of health have both shown promise as independent interventions.¹⁰⁻¹² However, both home-based and digital platform interventions face limitations of scale and

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technical constraints, respectively. Home-based interventions are generally labor intensive often making it difficult to prioritize care for patients without contacting them directly, a time-consuming process.¹³ Alternatively, digital platform interventions can be technically demanding and intimidating for patients without a background inclusive of digital device use.^{14,15} Combining home-based and digital platform monitoring in a single intervention could help address shortcomings of both interventions and create a more effective strategy than either could offer individually. Scant qualitative studies have been performed that assess patient perspectives on the acceptability, facilitators, and barriers of a single intervention combining these 2 elements which could significantly strengthen the effectiveness of either intervention and improve outcomes. Understanding these domains can help inform design and implementation of digitally-facing interventions in HF.

A number of qualitative studies have described the challenges of managing HF at home. Their findings tend to focus on social isolation, fear, or other emotional elements.¹⁶ The associated burden of living with HF has also been described.¹⁷ Few studies have detailed the most impactful patient-perceived barriers to adherence of HF treatment plans in terms of following instructions at home, compliance with medication, diet, and fluid intake. Even fewer studies have incorporated patient perspectives in terms of the role that financial constraints play. These elements are essential for the success of HF interventions.

In addition, although some HF qualitative studies have examined the feasibility and adoption of digital platforms as a form of remote monitoring in HF or chronic disease populations at home, this has mostly focused on personality characteristics associated with the use of technology (independence) as well as promoters of technology use (ie, gaining knowledge or heightening engagement with care).^{14,15} Few studies have examined patient perspectives on reasons why they would or would not be open to using a digital platform for their HF which can inform the practical application of such platforms.

In order to address these knowledge gaps and better understand how a single intervention combining home-based care and a digital platform could impact care for patients at home, we utilized qualitative interviews to capture patient perspectives on HF. Interview domains included: general HF knowledge, perceptions of the value of home-based care, unmet needs related to the social determinants of health, prior experience with healthcare technology and remote monitoring, and the hardest part of managing HF at home. We aimed to understand both patient perceptions on the use of remote monitoring via a digital platform as well as the role of supportive home-based care.

Materials and Methods

Setting and Study Design

Guided by principles of chronic care management in community, the literature on managing HF, and our goal of improving the lives of people with HF living in community settings, we aimed to conduct in depth 30 to 45-min qualitative telephone interviews with patients living in the community with a diagnosis of HF (December 2020-March 2021) and ≥ 1 hospitalization in the prior 24 months. Researchers identified study participants with the use of an internal hospital network database at an academic medical center. Approximately 2500 patients with HF are served at our heart center each year, with up to 22% of those hospitalized patients with HF returning within 30 days for hospital readmission. Eligible patients were contacted via phone and eligibility criteria were confirmed both with patients and upon review of the electronic medical record (age >18 years old, English fluency, capacity to complete questionnaires, connection to a primary care clinician, and a confirmed diagnosis of heart failure). Patients were excluded if they resided in a long-term care facility, were transitioning to hospice, had an active healthcare proxy, or if they were unable to provide informed consent. The remaining potentially eligible patients were randomly sorted and then purposively sampled for contact balancing gender and race. Participants were offered \$50 remuneration to patients for participating in the telephone interview. Patients were called up to 3 times to complete the interview. All participants confirmed a HF diagnosis.

Interview protocol and measures. The protocol and interview guide were developed through key informant interviews with patients, HF specialists, qualitative research experts, and primary care physicians. This was coupled with a review of literature on HF patient experience surveys and consultations with experts in survey and health services research. We developed a qualitative interview guide that allowed for expansion on topics discussed by interviewees and facilitated consistency among interviews. The interview guide was pre-tested with 3 patients via pilot interviews and no additional changes were made. The final interview guide included 37 items spanning these 5 key domains: general HF knowledge (eg, sodium intake, fluid intake, activity levels, etc.), perceptions of the value of home-based care, unmet needs related to the social determinants of health, prior experience with healthcare technology and remote monitoring, and the hardest part of managing HF at home.

Data Collection

All interviews were conducted by a faculty member (JC) and a research coordinator assisted with audio control and

note-taking. All procedures were approved by the hospital-based institutional review board, and all participants provided verbal informed consent.

The interview focused on the following questions: (1) What do you know about how you should manage your heart failure? (2) Would you be interested in a helper giving you resources to help manage your food, salt, or water intake? (3) Are there other things that you can think of that would help you manage your heart failure better at home (such as food security, financial security, housing security, better knowledge of your heart condition, better access to doctors, better insurance, someone who could help support you better)?; (4) What do you think about using technology to help manage your heart failure? (5) What is the hardest thing about having heart failure? Semi-structured interviews occurred via phone at times designated by interviewees and lasted 20 to 40 min. All semi-structured interviews were audio-recorded and transcribed verbatim.

Data Analysis

We used a framework analysis to identify main themes along with verbatim transcription for coding and analyses. Interview transcripts were uploaded into Dedoose (software version 8.3.47b.exe, Los Angeles, CA, 3/5/2021). An analytic framework was developed based on the major domains of the patient interview guide (see Supplemental Material for coding themes). We identified 11 parent codes and 41 sub-parent codes and looked across those codes to see emergent themes. To help facilitate greater reliability, 2 coders (AA and JC) familiarized themselves with the raw data, independently identified key themes raised by respondents, and reapplied this thematic frame by rearranging the raw data into themes and relationships. Coders identified associations between themes, user characteristics, and outcomes. Each coder performed content analysis to capture themes associated with each patient interview. Researchers achieved intercoder reliability through an iterative process of comparing each level of coding of themes and codes while discussing discrepancies and comparing results to the raw data until the analysis was complete. This occurred during weekly meetings focused on data interpretation and discussion of emerging themes. On completion of the analysis, the coders reviewed the data and a third researcher (KD) with expertise in qualitative data discussed any discrepancies with the research team. Ultimately, the research team determined that data saturation had been achieved and the coders did not identify any additional codes outside of the existing analytic framework. These methods were completed with COREQ checklist standards in mind.¹⁸

In addition to patient interviews, research coordinators completed a structured medical record review using the electronic medical record. Researchers used a REDCap database to capture the data. Abstracted data included

demographic information, insurance status, education, history of experiencing homelessness, and major medical and psychiatric comorbidities including substance use disorder.

Rigor

The research team applied specific selection criteria and used a qualitative interview guide to standardize questions asked of participants. Research team members also asked probing questions for any unanticipated answers in order to accurately capture the participant's perspective. The research team tracked all coding decisions meticulously. While the perspectives gathered here from participants may not apply to those in rural or non-heart failure populations, the themes were collected from heart failure patients in an urban setting that may apply to other cohorts with similar characteristics. The small sample size facilitated in depth and authentic interviews reflective of the patient experience. While the nature of qualitative studies can make replication challenging, the research team focus was on gathering individual perspectives to add to the evidence-base for heart failure care.

Results

Researchers interviewed 27 patients with HF by phone between 12/2020 and 3/2021. Table 1 shows the demographics and characteristics of the study participants.

Our analysis of our qualitative coding for the patient interviews yielded 5 emergent themes that are described below and in Table 2.

Theme 1 (Knowledge): While patients with HF receive helpful instructions from their clinical team, they often struggle to follow the clinical care plan at home.

One of the most common themes described by patients was the challenge of managing medications, balancing salt and fluid intake, and eating a healthy diet. This was often expressed as a "struggle" to "stay on track" or "stick to things" or "follow rules." Patients knew what they were supposed to do but had difficulty with execution. One person said, "They are great with explaining the medication and diet part to me- it's very clear." With respect to fluid intake, another participant offered that "I know that one liter is my cut off - I am never supposed to go over that."

Theme 2 (Clinical Barriers): Patients think the toughest part about having HF is managing medications and diet.

Many patients stated that the toughest part about having HF is managing their diet. Participants described managing their diet as "the worst," the "most difficult" and "complicated." Fluid and salt management was a particular challenge: one patient stated, "I think it's difficult to determine

Table 1. Participant Characteristics.

Gender	N = 27
Female gender, N (%)	10 (37.0)
Age, years, mean (SD)	76.1 (9.79)
Race/ethnicity, N (%)	
Hispanic/Latino	0 (0.0)
White	22 (81.5)
Black	4 (14.8)
Asian	0 (0.0)
Native American	1 (3.7)
Primary insurance, N (%)	
Medicare	20 (74.1)
Medicaid/MassHealth	2 (7.4)
Commercial/private	5 (18.5)
Heart failure ejection fraction (EF)	
EF < 40%	3 (11.1)
EF ≥ 40%	24 (88.9)
Co-morbid disease N (%)	
Atrial fibrillation	19 (70.4)
Hypertension	14 (51.9)
Chronic kidney disease	13 (48.1)
NSTEMI	12 (44.4)
Diabetes mellitus type II	9 (33.3)
COPD	6 (22.2)
Cardiac valvular disease (stenosis/regurgitation)	6 (22.2)

the amount of salt that you're actually taking in- it's impossible," and another said, "It's rough right now but I'm doing everything I can." Some participants also specifically focused on medication in addition to other components that were the toughest part of their care. A patient remarked that ". . . maintaining a good lifestyle with the medications is the most difficult," and another emphasized that "because I was not on the right medication, nothing was working. . . It's all about the medications." Other participants stated that while there wasn't a single thing that was the toughest part of having HF, the challenge really was managing all the individual pieces at the same time: "It's not one thing but it's just the whole shebang."

Theme 3 (SDOH barriers): Many patients with HF face challenging barriers related to social determinants of health that make it difficult for patients to put their health first.

About half the patients felt very confident that they had financial means to care for themselves at home while the other half expressed how financial hardship made it difficult to follow their care plan. One patient mentioned how insurance plays a role: "I'm supposed to pay doctors \$20 every time I have a visit. . . Sometimes I can't pay right away, and I put off going to the doctor for that reason."

The cost of medications was also a barrier: ". . . just for one medication was \$47 for the bottle, and there wasn't even that many pills there. . . that's a lot of money and I just wasn't able to get it refilled as often as I should have." Financial challenges also limited healthy food choices: "It's not healthy food they give you at the food pantry. A lot of it is canned food that you don't know anything about. And full of salt."

Theme 4 (Home-based support): Patients with HF see home-based support as an essential part of staying healthy.

Most patients felt strongly that in-person home support was critical to being able to take care of themselves. A few patients had this support from family: "My daughter and I look at every medication-and there isn't a medication that comes in here that isn't researched. I couldn't make it without her." Other patients got support from home nursing: "The home nurses are really good . . . That's why I get on as well as I do- otherwise I'd be no good to anyone." Most patients, whether they had pre-existing home-based support or not, were interested in having additional in-person home support: ". . . right now it certainly feels like I'm stranded at sea here on the daily thing. . . I could use more support." Another respondent stated, "The home health nurse [helps] - but it's still tough to know what's what. . . if they had a person I could talk to more about things, I would use them."

Theme 5 (Remote support): While many patients use minimal or no digital platform interventions to help them manage their HF, most would be willing to try it.

Half of the patients said that they had some prior experience with technology to help them manage their HF. Of the participants with a history of using technology that connected them to their care team, most had a positive experience. "When I initially got out of hospital, they gave me this machine that had a monitor for your oxygen level and your blood pressure . . . it kept me kind of in check. But after a while, they took it away . . . [which] makes it tough." A few patients had a number of devices that they used for daily remote monitoring due to their own personal interest with no connection to their care teams. One patient said, "I got a Fitbit on one wrist, I got an Apple Watch on the other wrist. . . and I've got another watch that will control my phone if I'm driving. . . but my doctor doesn't deal with any of them."

Of the participants without a prior history of using technology to manage their health, many agreed that they would be willing to do so: "I mean if somebody wants me to use an app for my heart, I'll do it, but I don't have one as of yet." Other participants expressed some hesitancy in using technology. "It took . . . a lot of practice to even be able to

Table 2. Major Themes Associated With Illustrative Quotes.

Themes	Quotes
Knowledge: <i>While patients with heart failure receive helpful instructions from their clinical team, they often struggle to follow the clinical care plan at home.</i>	<p>“Well, they tell me everything but I’m not doing a great job because I do have to go out and celebrate from time to time- you know birthdays and such. I know I’m not supposed to but I’ve got to celebrate sometime. I don’t take my meds those days because I know I know not to mix them with alcohol.”</p> <p>“I know what I’m supposed to do. Although I cheat. I mean you have to a cheat every now and then because it’s just too difficult. I mean I like vegetables but give me a break. No salt and all that stuff.”</p>
Clinical Barriers: <i>Patients with heart failure think the toughest part about having this condition is managing medications and diet.</i>	<p>“Oh yes, the diet is the worst. Yeah and I mean, I’m basically pretty good, but sometimes I do go away from what they say. And right now, I’m off. I feel like I need some help getting back on track.”</p> <p>“Yeah, I think maintaining a good lifestyle with the medications is probably the-yeah, that’s the most difficult.”</p> <p>“There are so many things and I can’t follow the rules all the time. No one can- it’s just too much but I try not to get discouraged.”</p>
SDOH-related barriers: <i>Some patients with heart failure face challenging barriers related to social determinants of health that make it difficult for patients to put their health first.</i>	<p>“No- I’m good. Everything is taken care of for my housing, and my insurance covers all of my medication.”</p> <p>“Do you know how hard it is to exist on what I have to live on? After rent I only have \$200 a month to spend. It’s really stressful.”</p>
Human support: <i>Patients with heart failure see in-person support as an essential part of staying healthy.</i>	<p>“First of all, I used to have a nurse and other people that would come in and check on me but that was right after I was in the hospital. Well, I don’t know how long it lasted. I don’t know. It was great and I wish I could have something like that now.”</p> <p>“The company that supplies my homemaker tries to get someone out here to check on me – but it doesn’t feel like they’ve been checking up on me enough. Every little bit helps but people don’t get how hard it is to stay on top of things.”</p>
Digital support: <i>While many patients use minimal or no digital platform interventions to help them manage their heart failure, most would be willing to try it.</i>	<p>“I have worn a heart monitor in the past for a few weeks and the information went straight to my doctor – all I had to do was keep it on which was easy. There was nothing to it.”</p> <p>“I haven’t done anything like that but I might be interested in some kind of app on my phone for my weight and blood pressure. The fact is that with the internet and these new phones there are so many options.”</p>

connect with my computer on the Zoom thing for virtual care. I am open to trying things, but it needs to be easy to use.” Another participant said, “I have a smart phone . . . but you have to get the hang of it and I don’t want to have to struggle too hard to learn about some new technology.” Other respondents were clear that while they were not eager to use technology for their health, they would consider something that would make management of their cardiac condition easier. One patient offered “Don’t misunderstand me. I don’t welcome it. I don’t like it, but if it’s going to help me, I’ll take it and use it.” Another respondent stated, “Well it’s . . . nothing I’ve ever done before but it sounds like something that would be helpful – I’ll try anything that can help me.”

Discussion

Results of this qualitative study suggest that despite receiving clear care plan instructions, patients struggle to adhere

to clinical care plans at home with regard to medications, diet, and fluid management. Specific challenges include financial barriers and having enough support at home. Most patients were willing to participate in interventions inclusive of remote monitoring, even if they did not have a history of prior use.

Our study builds on research focused on the perceptions of patients with HF and the use of home-based support and remote monitoring to enhance care at home. We identified a number of expected findings. Even though patients were pleased with the clinical care that they received from their clinic teams,^{19,20} participants reported a number of financial barriers and unmet social needs that limited their ability to follow care plans at home. Although financial barriers have been reported to varying degrees in prior studies,²¹⁻²⁴ many of these studies rest on what has been termed non-compliance as a primary reasons for lack of adherence in HF patients.^{25,26} Our findings support movement away from patient behavior as a pure etiology, and toward the specific

barriers to implementation that patients face (eg, limited finances, and access to food consistent with recommended diet, sodium, and fluid intake).^{23,24} Patients also emphasized the importance of home-based social support, which is echoed throughout the literature.²⁷

Unexpected findings were also identified. Participants stated that they received very clear instructions from their care teams (eg, sodium and fluid intake, diet, and activity). However, historically, there have been mixed outcomes with prior studies identifying gaps in knowledge regarding care team instructions,^{28,29} and few studies demonstrate high levels of patient knowledge.³⁰ Surprisingly, while up to one quarter of our participants had in-person home support engaged at the time of the interview, the majority of participants expressed needs for additional home-based support for day-to-day navigation and management of medications and diet. We were unable to find qualitative studies assessing needs for additional home-based support among those already receiving some form of care at home. The fact that both those who had and did not have pre-existing home-based support expressed needs for additional in-home assistance speaks to the importance of this domain. Several participants mentioned previous experiences with navigators or community health workers as valuable home-based support for medications, diet, or closing gaps in care related to unmet social needs. The evidence for CHW care is demonstrated in studies among chronic disease and cardiovascular populations.¹⁰⁻¹³

A number of participants acknowledged burdensome efforts to manage all aspects of their care at home (diet, medications, weight, blood pressure, etc.), rather than a single element, as the most difficult part of having HF. This finding, while not seen explicitly asked in the literature, may relate to patient perceptions of a lack of control with HF home management that has been described in other research studies.^{17,29} The inability to identify a single factor as the most challenging part of having HF also suggests that solutions for patients with HF should be comprehensive and address a broad range of clinical and social complexity.

In addition, this study found that most participants, regardless of age, financial constraints, or prior use of remote monitoring, were willing to use digital platform-based or remote monitoring interventions. This finding contrasts with themes found in prior qualitative studies emphasizing barriers to remote monitoring use as connected to financial constraints,²⁸ a prior history of technology use,³¹ or age-related limitations.³² This outcome suggests that implementing technology-based strategies to improve HF home management may be feasible. Additionally, most participants placed high value on the ease of use of any digital platform in order to aid efficiency and adherence which is another area where home-based staff like navigators or community health workers can support patients. These staff can act as anchors for clinical

teams during the implementation phase of remote monitoring for logistics like internet connectivity, device capture, and basic use instructions.

This study applied specific selection criteria and outreach to patients who had a known diagnosis of heart failure and were receiving care from primary care and cardiology clinicians within a single hospital system. Our goal was to reach a cohort of patients typically served in this care setting. The participant experiences in this study are representative of patients who are typically served by our care system, and are eligible for a future evidence-based interventions designed to improve heart failure outcomes. We recognize that other patient populations based in different regions and care settings may have alternative experiences and face different barriers to care than what was captured here.

Despite this, our findings highlight important opportunities to help address challenges faced by patients with HF and underline the need for solutions that address the comprehensive nature of HF management at home.³³⁻³⁵ Remote monitoring to help guide patients in clinical management along with home-based support to assist patients in implementing care plans and closing gaps related to unmet social needs are important components in maintaining HF health at home. Interventions inclusive of both remote monitoring and home-based care could help move patients closer to optimized home management by bolstering the strong clinical care team support identified by the patients interviewed here.

Limitations

This study has a number of limitations. The perspectives of the participants from a single institution may not be representative of HF patients in other settings. Also, the infrastructure of clinical care teams and resources available for care delivery may be different in other places. It is also possible that patients with strong views on HF management at home were more likely to agree to be interviewed. While there is significant institution-wide ethnic diversity amongst patients, the setting is not as racially diverse as other health care centers. Even so, we believe that this qualitative approach generated useful descriptors that can help change practice. Participant interviews occurred during the COVID-19 pandemic which may have introduced sampling bias with certain patients isolating in their homes being more available for participation than others who were unable to be contacted because they were working in-person or living in another temporary residence.

Conclusion

Patients with HF reported a number of financial and support-based challenges to managing their care at home. The majority of patients (whether familiar with digital platforms

or not) were willing to use a tech-based intervention and also reported needs for additional in-person home support. These findings may be helpful for HF and primary care teams involved in management of HF in outpatient settings. Further research is needed to understand how a single intervention combining home-based care in combination with remote monitoring could impact clinical outcomes for HF patients.

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Author Contributions

All authors contributed to the manuscript conception and design. JC wrote the initial manuscript and performed the analysis. AT and KD completed extensive revisions. All authors read and approved the final manuscript.

Availability of Data and Materials (Data Transparency)

Any data requests will be reviewed and carefully considered after publication.

Declaration of Conflicting Interests

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Ethics Approval and Consent to Participate

All participants provided verbal informed consent prior to the study. All methods were carried out in accordance with guidelines and regulations outlined by the hospital-affiliated Institutional Review Board. This study has received ethical clearance from the hospital-affiliated Institutional Review Board (protocol number 2018P002014) on August 10, 2020.

Consent for Publication

Consent was obtained.

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Supplemental Material

Supplemental material for this article is available online.

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