



Patient, caregiver, and providers' perceptions of barriers to heart failure care

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Background

- ▶ Heart failure (HF) is a growing public health problem
- ▶ Optimizing HF outcomes requires adherence to several self-management recommendations
 - ▶ Family caregivers are integral to HF self-care
- ▶ Understanding and addressing barriers and facilitators to self-management is key to enhancing adherence



Background

- ▶ Most research is focused on patient barriers
 - ▶ Knowledge, communication, socioeconomic factors¹
 - ▶ Relationships with providers, family⁵
- ▶ Barriers experienced by family caregivers is also important
 - ▶ Role strain, lack of social and professional support²⁻⁴
- ▶ Very few studies have focused on barriers as experienced by patients, caregivers, and providers

1. McEntee, 2009

2-4. Luttik, 2007; Luttik 2007b; Aldred, 2005; Burke, 2014

5. Skaperdas, 2014

Objective

To characterize barriers and facilitators of HF self-management as perceived by patients, spousal caregivers, and clinical providers



Methods

- ▶ Semi structured interviews with couples and providers

 - ▶ 17 couples managing HF
 - Topics included:
 - Experience with HF
 - Specific self-management roles of patients (PT) and spousal caregivers (CG)
 - Barriers to managing HF together or individually
 - 30-45 min interviews with couples together, followed up with 1:1 (~5 min)
 - Individual interviews were designed to elicit information that couples might not feel comfortable sharing in the presence of the other person

 - ▶ 13 providers from the VA Palo Alto Health Care System
 - ▶ 3 cardiologists, 3 internists, 5 nurse practitioners, 1 nurse, 1 social worker
 - ▶ Topics: Gaps in self-management, role of family caregivers in self-management
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Methods

▶ Data Analyses:

- ▶ Interviews transcribed using a professional transcription service
- ▶ Analyzed using rapid qualitative analyses methods
- ▶ Inductive and deductive coding techniques utilized



Results

	Provider	Patient (PT)	Caregiver (CG)
Communication	✓	✓	✓
Education/Knowledge	✓	✓	✓
Social Support	✓	✓	✓
Care Fragmentation	✓	✓	
Stress/ Stress Management		✓	✓
Relationship Quality		✓	✓



Results: Communication

- ▶ Providers reported a communication gap with PTs about care plans

“The nurse may be calling them on the phone and we might tell them to bring in their meds. They oftentimes will be unclear on what... They'll say the white pill over the phone, or they even bring it in, and then they're matched up in the computer, and trying to figure out what was the plan. So, that can oftentimes be very confusing.”

- ▶ PTs struggled to feel understood by their providers

“I told (my doctor) that I've had trouble with my breathing... She didn't understand what I was trying to tell her, you know? I got kind of frustrated with her, but I didn't say anything. I said, “Yeah, yeah, okay.”

- ▶ CGs had trouble with both understanding the patients needs and difficulty communicating with providers on behalf of the patient

“It seems like I get very little information. If he's actually having some kind of procedure and I'm in the waiting room, it's very seldom that a doctor will come out to talk to me.”



Results: Education and Knowledge

- ▶ Providers identified a lack of appropriate education materials

“Certainly, education is very, very important. There are plenty of times that I’ve told a person, I thought they understood...Then they came back to the nurses station wanting to talk to me because they weren’t sure.”

- ▶ PTs and CGs were interested in classes or groups that would teach them more about how to manage HF at home

“[By charting vitals] the doctors get a view of the patient, what the patient’s doing, all the way through the time that they’re not seeing them.” (PT)

“It’s hard for me to say he’s having a heart attack or it isn’t. I don’t know. He was just very uncomfortable. He had pain, but I cannot say that he was deadly ill. And I wish I could have a little bit clearer signs of, you know, what’s happening and what do I do now?” (CG)



Results: Social Support

- ▶ All three identified the important role of social support in managing HF

“I would say the most well has been when there’s an active family member involved,...We do embrace the family member to take part and be strong with them” (Nurse)

“Well, I think whoever you're going to try to help, I was going to say, they need the cooperation of both parties to be the most effective. Because it’s pretty traumatic when you come home—And when I came home from the hospital, I was really in bad shape.” (PT)

“That's why I think, more wives should be involved in their husband’s healthcare as far as even going into an appointment just to make sure that everybody knows what's happening with the person” (CG)



Results: Care Fragmentation

- ▶ Providers identified fragmentation during transitions

“the inpatient to outpatient transition, there can still be a gap, despite having all these resources....the patient themselves physically have to make that link.”

- ▶ PTs perceived fragmentation with multiple providers, and between VA and non-VA providers

“Well, every time I go in there, there’s a different person. So, they don’t know.” (PT)



Results: Stress/Stress Management

- ▶ Stress was a barrier to self-management for couples

“It’s hard to focus. Really is, yeah... And I find, when that is, that usually I gain weight and it takes a few days to get it back off again... I’ve got to go take a nap; I’ve got to lay down. I’ve got to just stop.” (PT)

“[Stress] probably makes me less sympathetic to him and his problems...I really just kind of want to walk away.” (CG)

- ▶ Effective stress management was a facilitator

“Meditate, try to just keep from coming uncorked at everyone.” (PT)

“You know, just breathe, take a walk, meditate and I'm totally into all that stuff because it is very helpful.”(CG)



Results: Relationship Quality

► Interpersonal conflict hindered collaboration within couples

“Like I say, a lot of times I just get frustrated because I can’t do things. I get frustrated with her because she seems to nag me so much.” (PT)

“When he eats stuff he’s not supposed to eat and which we all do, but since he’s got a problem, he should be a little more careful. And that's about our only conflict about his health is some of his eating habits.”(CG)



Results: Relationship Quality

▶ Strong relationship and love enhanced self-management

“I am very, very thankful [my wife] is so understandable and so cooperative and so taking care of me that it gives me the willingness to do things that I would ordinarily not do because I want to do it to please her.” (PT)

“Every time he opens his eyes in the morning, and he gets up and says, “I love you,” that’s a challenge; and that’s the silver lining.” (CG)



Conclusions

- ▶ Providers, patients and spousal caregivers highlighted the role of communication, education, and social support as critical to successful HF management
- ▶ Tools and interventions to enhance communication and collaboration may enhance the relationship between patients and their spousal caregivers, between couples and providers, and may enhance self-management
- ▶ Such programs may also focus on stress management and interpersonal relationships



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