



The Role of Family Caregiving in Chronic Illness: Three Studies



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Poll question

What is your interest in the current topic?

- -Student, intern, resident
- -research
- -VA operations
- -VA or non-VA policy
- -clinical provider
- -case manager

Self-management is critical to chronic illness outcomes

- 80% of American adults have chronic illnesses, such as heart failure, diabetes, depression
- 68% of these have ≥ 2
- Managing chronic illnesses account for 75% of US healthcare costs
- Self-management recommendations enhance outcomes
 - Managing medications, Diet, Physical activity, Preventive care (e.g., flu shot), Seeking timely care

Caregivers: unsung heroes of self-management

- Caregiver involvement results in:
 - Better adherence to medications and lifestyle recommendations
 - Cohabitation allows for increased monitoring of patients
 - Shared activities e.g., preparing and eating meals together
 - Better care coordination with teams
 - Better outcomes upon discharge from hospital stay
 - Better well-being through emotional support

Who are FAMILY caregivers?

- ~50M Americans are caregivers
 - 2/3 women; ~40% significant others
- \$470 billion worth of unpaid services annually
- 43.5 million US adult have provided unpaid care in the prior 12 months
- Provide variety of assistance
 - Emotional support
 - Instrumental support (e.g., picking up medications)
 - Complex medical tasks (e.g., wound care)

Caregivers experience has received increasing attention

- Caregiver burden
 - Juggling multiple priorities
 - Patient's disability, deteriorating health
- Caregivers may experience positive uplifts through love and caring
- Growing attention being paid to interpersonal factors:
 - Interpersonal communication
 - Relationship quality

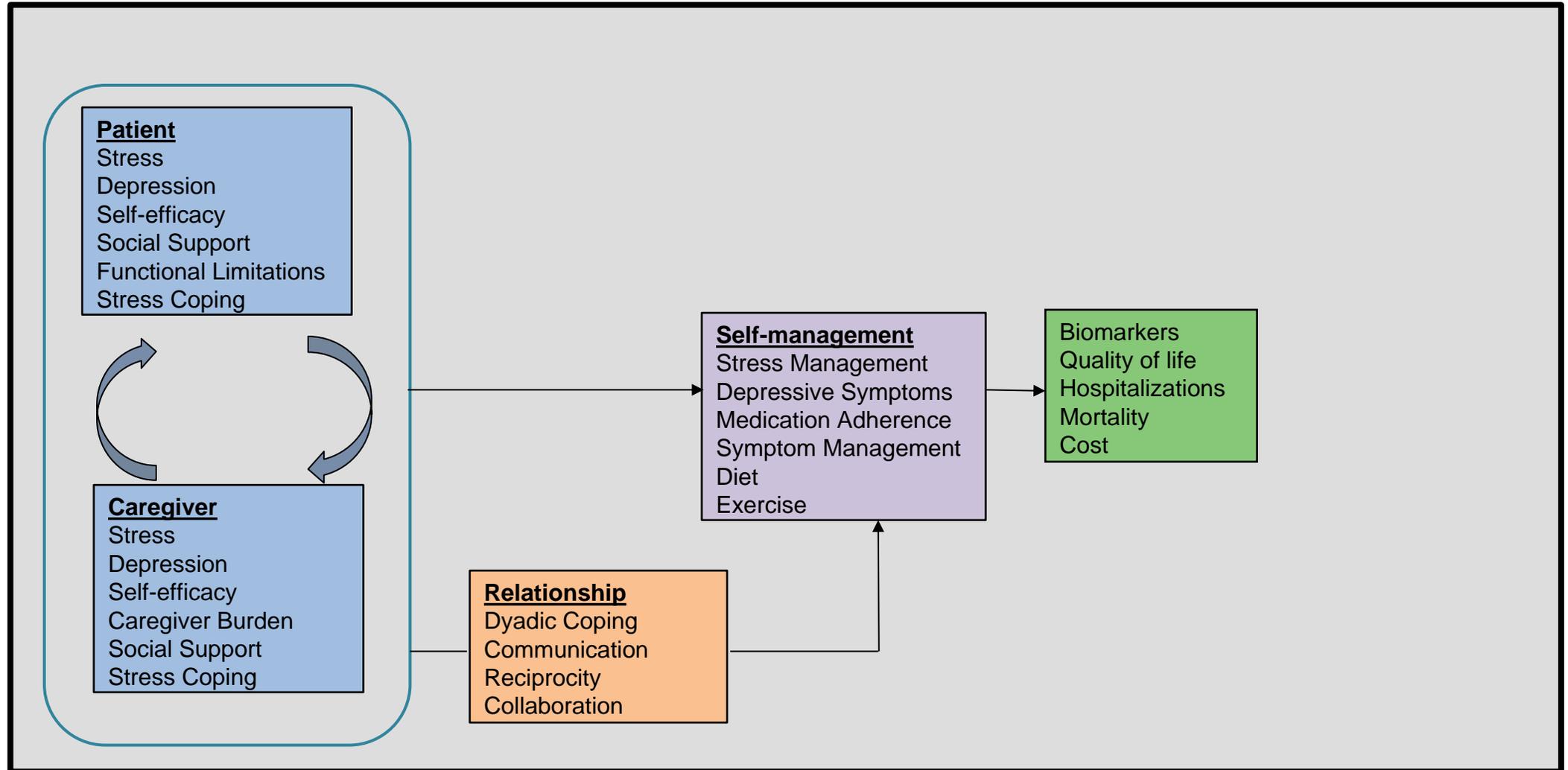
Self-management is difficult for dyads

- Most research is focused on patient barriers
 - Knowledge, communication, socioeconomic factors
 - Relationships with providers, family
- Barriers experienced by family caregivers are also important
 - Role strain, lack of social and professional support
- Few studies have simultaneously focused on barriers as perceived by patients, caregivers, and providers

Sociobehavioral mechanisms underlying caregiving require further study

- Many questions remains unanswered:
 - How do patient-caregiver dyads collaborate and communicate around self-management?
 - How does relationship quality influence caregiver involvement?
 - What barriers do patients and caregivers experience as they navigate the healthcare system together?
- **Studies to enhance understanding how patients and caregivers collectively manage chronic illnesses are needed to develop effective strategies to enhance caregiver involvement in self-management, in a way that enhances both patient and caregiver well-being.**

Dyadic Health Behavior Change Model (Trivedi et. al., 2016)



Three studies

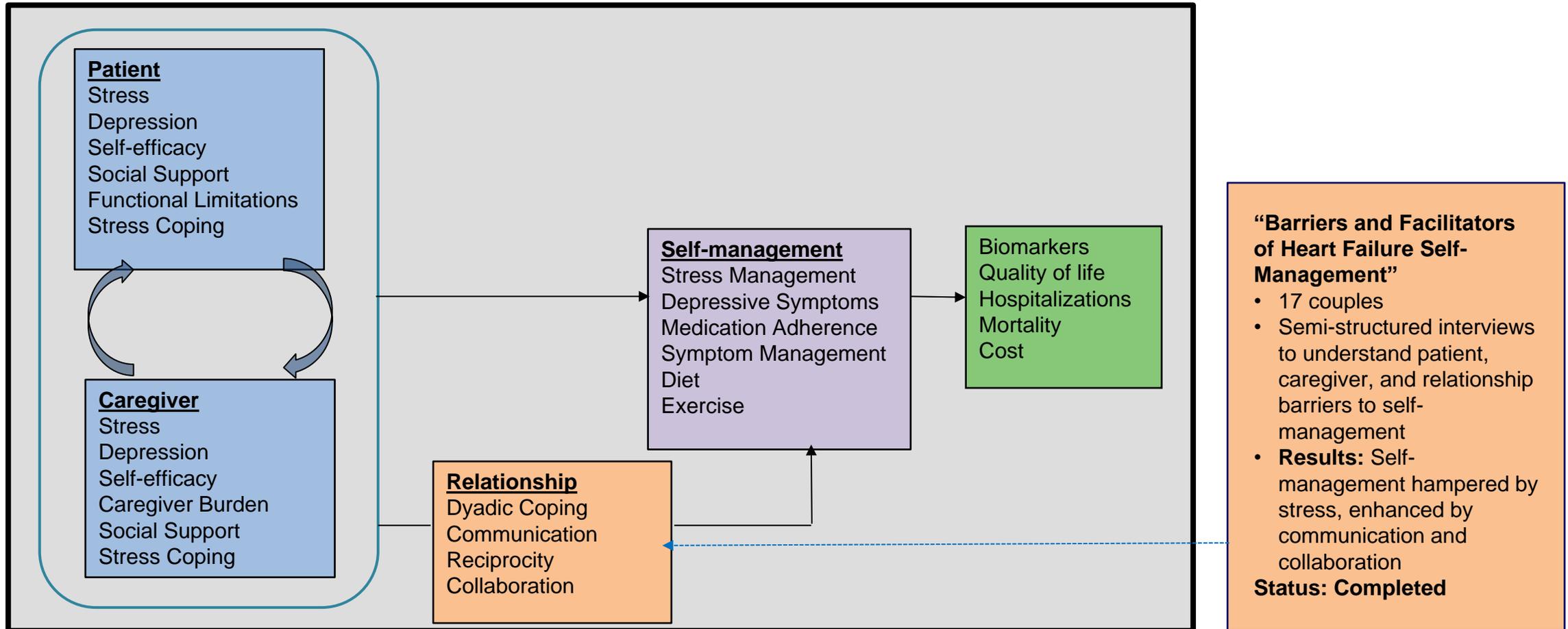
- Studies 1 and 2 focus on the barriers and facilitators experienced by patient-caregiver dyads in self-management of heart failure
- Study 1 also focuses on the barriers experienced by clinical providers, and examines the overlap between barriers reported by patients, partners, and providers
- Study 3 examines how patients with depression, their non-cohabitating caregivers, and cohabitating caregivers communicate and collaborate around managing depression

Study 1

Comparing the barriers and facilitators of heart failure management as perceived by patients, caregivers, and clinical providers

(Slightam et al., 2016 Presented at Annual Meeting of the Society of Behavioral Medicine; Trivedi et al under review)

Dyadic Health Behavior Change Model (Trivedi et. al., 2016)



Why Heart failure?

- 6.5 Million Americans suffer from heart failure (HF)
 - #1 discharge diagnosis among Veterans
- Optimizing HF outcomes requires adherence to self-management recommendations
- Understanding and addressing barriers and facilitators to self-management is key to enhancing adherence

Objective

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

METHODS

- Participants recruited from VA Palo Alto HCS
- Patients had ≥ 1 HF (ICD-9 code 428.XX) contact in previous year
- Have a caregiver who is a cohabitating significant other
- Patients and caregivers were:
 - cognitively able to participate
 - not actively on hemodialysis or receiving cancer treatment
 - No paid caregiver

Methods

- Semi-structured interviews
- 17 patient-caregiver dyads
 - Self-management roles, barriers to managing HF, motivation
 - 30-45 min interviews with couples together, followed up with 1:1
 - 1:1 Interviews used to elicit information that couples might not feel comfortable sharing in the presence of the other person (Morgan et al., 2006)
- 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, barriers to managing HF

Methods

- Interviews conducted in person or over the telephone
- ~45 minutes together, followed by ~5 min individual interviews
- Transcribed using a professional transcription service
- Analyzed using thematic analyses methods per Braun and Clark (2006)
- Independently coded by two coders, and conflicts resolved through consensus
- Analyses were conducted using Atlas.ti

Theme 1: Lack of Knowledge was a key Barrier to Self-management

- **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.”

- **Patients and significant others were interested in classes or groups that would teach them more about how to manage HF at home**

“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)

Theme 2: Communication between providers and the patient/caregiver dyad is necessary to optimize HF care, but barriers remain

- **Providers reported a communication gap with patients 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.”

- **Patients 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.”

- **Significant others had difficulty obtaining necessary information**

“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.

Theme 3: A Strong Affectionate Relationship within Couples Enhanced Self-management, while Stress Hampered It

- **Participants 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.” (patient)

“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” (caregiver)

Study 2

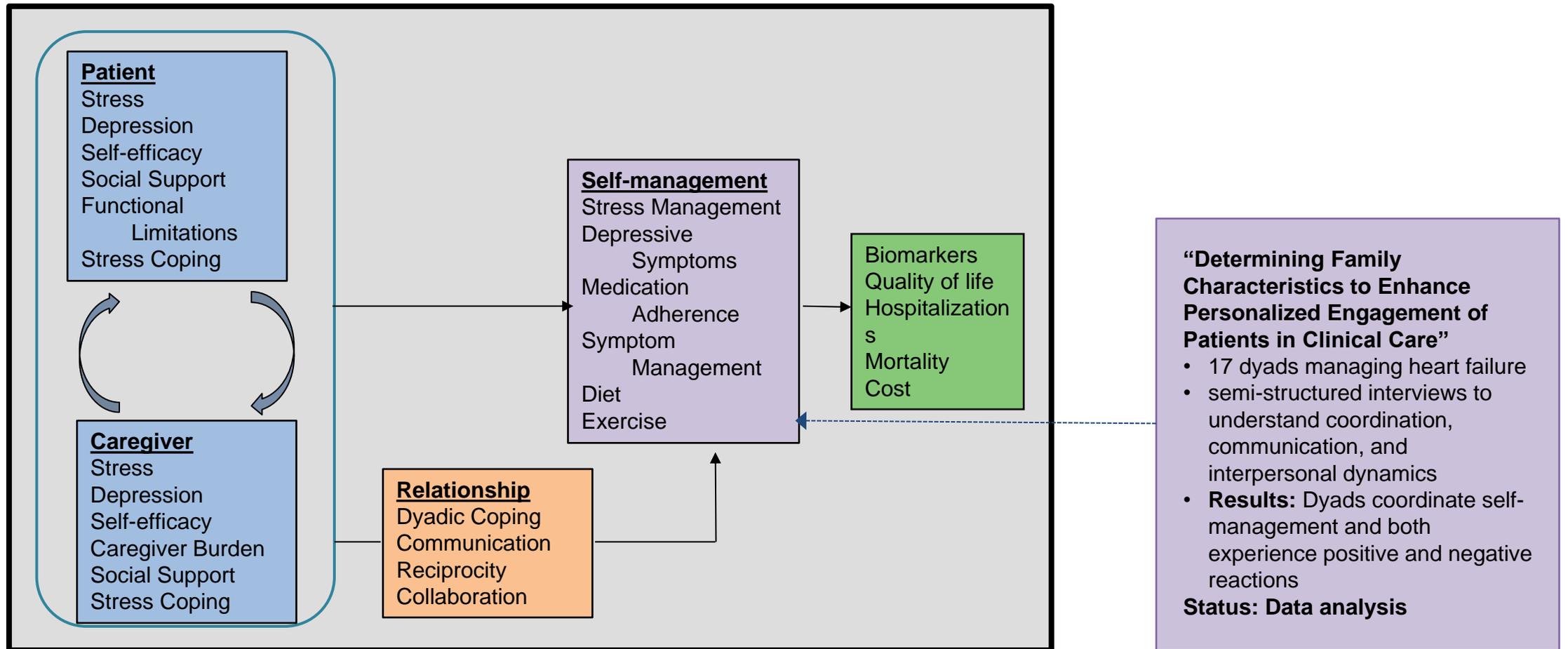
**Determining Family Characteristics to Enhance
Personalized Engagement of Patients in Clinical Care**

**(Work completed for Juliah Kim's Masters Thesis;
Manuscript under preparation)**

OBJECTIVE

To characterize how patient-caregiver dyads engage with each other and the medical community around managing health and illness

Dyadic Health Behavior Change Model (Trivedi et. al., 2016)



Patient-caregiver dyads go beyond couples

- Much of the research around dyadic interactions comes from couples research
 - However, family caregivers may be children, in-laws, and even friends
 - Differ in experience of burden as well as positive effects
- If not a significant other, caregivers may be living separately
 - May have different roles than significant others
 - May have a different connection with providers than significant others

Methods

- 17 dyads managing HF recruited from Stanford Heart Failure Clinics
- Caregivers defined as anyone identified by patient as being an important contributor for managing HF
- Semi-structured interview with HF patient and their caregiver
 - Daily challenges, caregiver roles, modes of communication
- 30 min-1 hour interviews with dyads, followed up with 1:1 (~5 min)

Theme 1: Health beliefs of patients and Caregivers shaped their experience of illness.

- Patients and caregivers expressed acceptance of the limitations they would face and willingness to deal with the challenges of heart failure.

*“You got to figure you’re going to die sometime. You got to learn how to accept things in life.”
(patient)*

- Resilience shaped people’s lived experience of illness

“We just live through it [illness]. We don’t let it hinder us from doing things... I bounce back and they can’t believe that I’m sick. So that’s been our thing: keep going.” (patient)

Theme 2: Emotional effects of heart failure characterize the experience of illness

- Positive emotional effects: optimism and satisfaction in life.

“Because you have two paths to go down, so you have to pick which one. And so I choose to be uplifting and optimistic.” (caregiver)

- Negative emotional effects: stress, depression, and caregiver burden.

“It was a very big deal and scary that you [the patient] got a defibrillator. So obviously there was a lot of sadness and anger and frustration that I had because I wasn’t in control over any of this... It took a long time, years to accept that this is what it is.” (caregiver)

Theme 3: Quality of patient-Caregiver relationships reflected the experience of illness

- Patients and caregivers were motivated by love, gratitude, and empathy.

“I didn’t want to nag him anymore. I was tired of nagging him... I realized that I was wasting more time instead of enjoying the time that I had with him... I think what helped is remembering how much I loved him.”

- Motivation was also based on responsibility and a sense of duty.

“Because I’m the oldest, so I feel that’s my job... it’s our job to take care of him because he took care of us.”

summary of studies 1 and 2

- Both patients and caregivers experienced the stress of managing HF
- Providers, patients and caregivers highlighted the role of communication, education, and social support as critical to successful HF management
- Caregivers may be motivated by love, empathy, or sense of responsibility
- Enhancing caregiver involvement may benefit patients, and caregivers alike
- Providers may benefit from strategies to effectively engage family caregivers

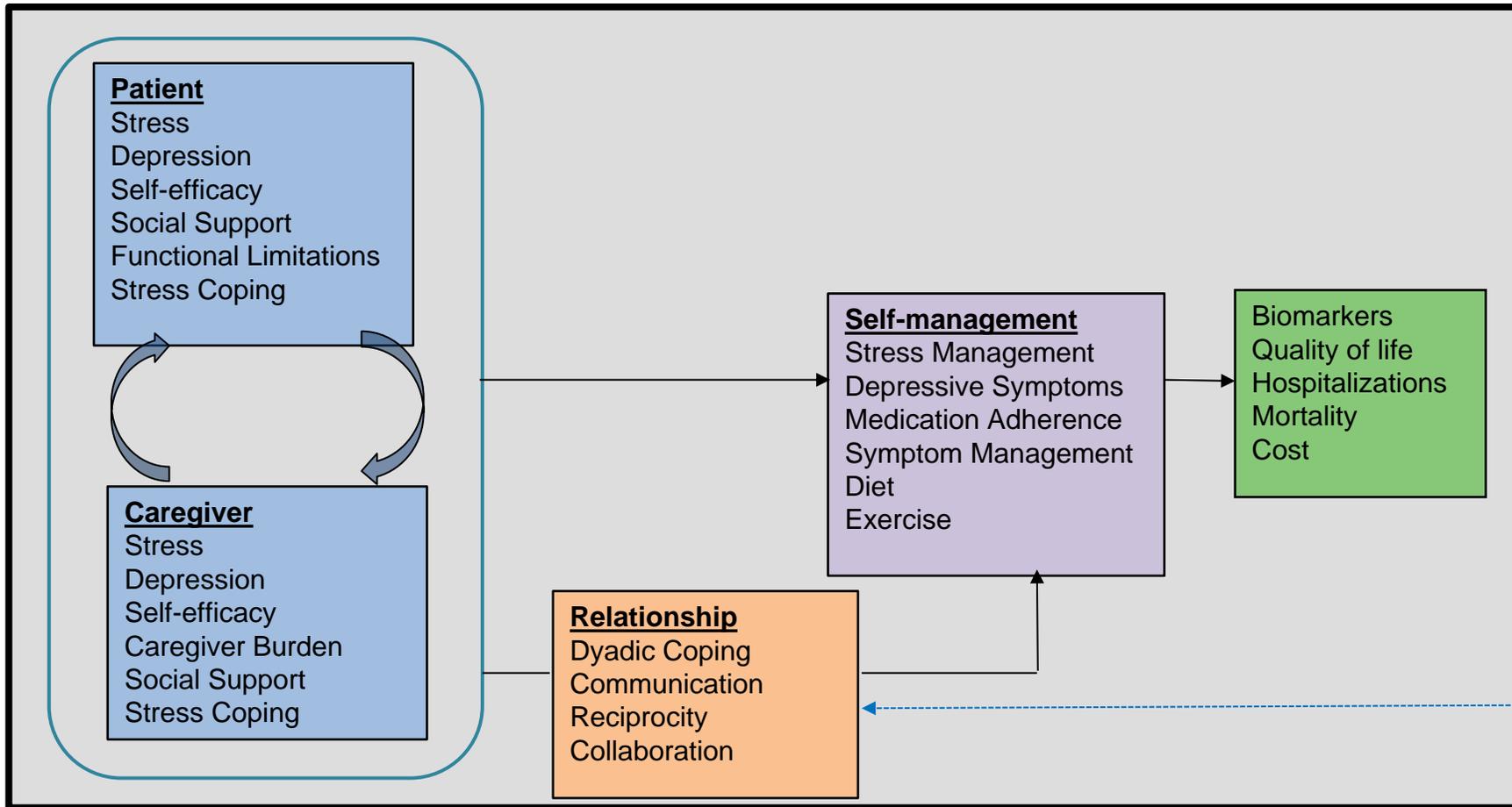
Study 3

Relationship closeness between patient and caregivers improves coordination of clinical depression

Risbud R.D. et al (2017). Presented at Annual Meeting of the Society of Behavioral Medicine

objective

To understand the characteristics of communication, collaboration, and relationship quality that underlie the interactions among depressed patients, an in-home caregiver, and an out-of-home caregiver (CarePartner)



“Telemonitoring Enhanced Support for Depression of Self Management”

- 39 depressed patients, cohabitating caregivers, and CarePartners
- **Results:** Relationship closeness between patient and caregivers improves self-management of depression

Status: Manuscript preparation

methods

- Depressed patients, CarePartners, and in-home caregivers
- Patients and CarePartners had completed participation in an intervention that used mobile health technology to enhance self-management of depression (PI: Aikens and Piette)
- 30-45 minute semi-structured interviews, individually completed over the phone
- Interviews asked about care coordination, communication, relationships, challenges, care tasks, and overall self-management
- Similar analytic strategies as previous two studies

RESULTS

Table 1: Sociodemographic Characteristics

	All	Patients	CarePartners	In-home Caregivers
N	39	18	14	7
Women, N (%)	23 (67%)	12 (67%)	13 (93%)	3 (43%)
Age, M (SD)	49.8 (16)	46.9 (16.8)	56.1 (14)	44.4 (15.7)
White, non-Hispanic, N (%)	35 (89.7%)	16 (88.9%)	12 (85.7%)	7 (100%)
Income < \$30,000, N (%)	-	13 (72.2%)	-	-
High School or GED, N (%)	-	5 (27.7%)	-	-
PHQ, M (SD)	-	10 (4.8)	3.6 (3.76)	7 (2.8)

Theme 1: Relationship Closeness was Important for Communication Around Depression

“We can talk about this stuff anywhere from a few minutes to a few hours. And usually we always end up gaining insight on things. We kind of like bouncing ideas off of each other, personal growth stuff. ..We always feel pretty good after our talks... And just already having a good relationship foundation has helped I think. “ (In-home caregiver)

Theme 2: Having a Support Person Improved Understanding of Depression

“Because she's knowledgeable and she has a good handle on what depression is all about, where my husband and his family have never really had to deal with that, so it's a little bit harder for him to understand. And I just don't open up to people about that kind of stuff, so she was the person that was, I felt, close enough and knowledgeable enough to help me work through it because she had done it before we started the program.” (Patient)

Theme 3: The CarePartner Program Facilitated Communication by making roles explicit

“Before the program, we knew there was issues and you try and say something but you had to be careful because you didn't want to offend or step on toes or you didn't want to over assert yourself. But once he said that, yeah, he wanted some help with it, then it was kind of like, “Okay, you said you want some help with it, so we're going to help you with it. You don't have to feel bad about saying something.” (CarePartner)

Summary: Study 3

- Relationship closeness influenced people's perception of their depression management, communication, and knowledge.
- Through role assignment, the CarePartner program provided a platform for caregivers to be more active in their care roles by removing barriers of privacy concerns and uncertainty about how to help.
- Patients who had close relationships with their CarePartner or in-home caregiver felt that they benefited from the intervention, but not patients who did not report close relationships.

Discussion

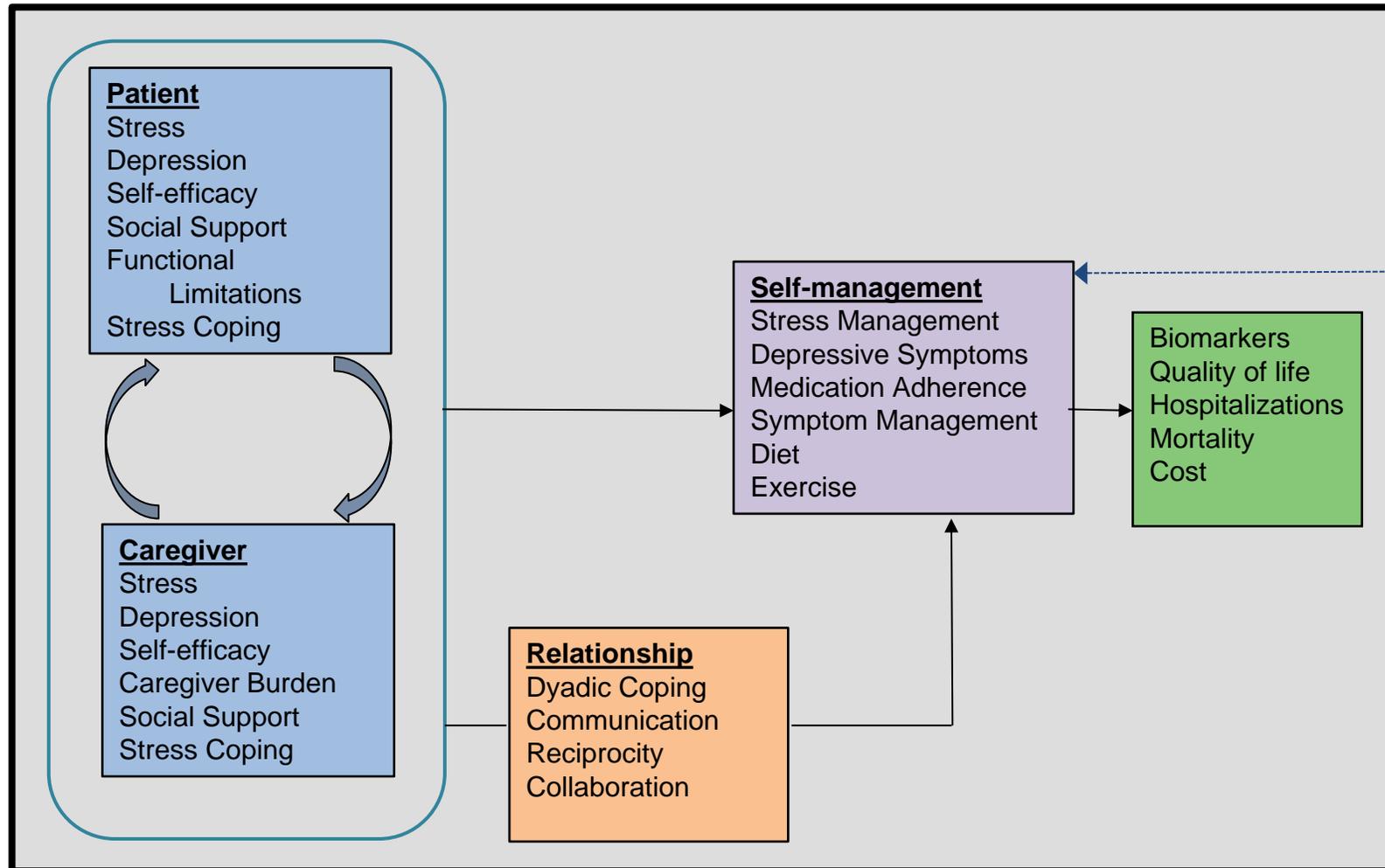
- Patients manage their chronic illnesses embedded in complex social relationships
- Providers experience similar barriers as experienced by the dyads, suggesting the need for a caregiver-friendly healthcare system
- Closeness of the relationship and effective communication between patients, their caregivers, and the healthcare providers are crucial to enhancing self-management
 - Interventions that enhance communication and relationship closeness may improve illness outcomes as well as well-being in patients and caregivers.
 - Since most self-management programs serve the needs of patients only, interventions are needed that address dyads

One such Intervention...

A Couples' Based Self-Management Program for Heart Failure: Results of a Feasibility Study (Trivedi et al., 2016)

Objective

To develop and pilot a dyadic self-management program for patients and caregivers, called SUCCEED



“SUCCEED: Self-management Using Collaborative Coping EnhancEment in Diseases”
 Pilot Study: Trivedi et al. (2016)
 R01 submitted to test efficacy
 Developing web-SUCCEED
Status: Ongoing

Development of SUCCEED

- Components derived from or based on Chronic Disease Self-management Program, VA National Caregiver Training Program, Couples Coping Enhancement Training
- Stakeholder input from patients and caregivers through VA Palo Alto Veteran and Family Council
- Education experts to evaluate reading and comprehension levels
- Iteratively developed based on feedback from patients, caregivers, providers, and facilitators

METHODS

- **Step 1: Identify Intervention Targets**

Identify intervention targets and components using conceptual model + results of patient, caregiver, and provider interviews

- **Step 2: Develop SUCCEED**

a. *Identify components*

b. *Ensure 6th grade reading level*

c. *Obtain feedback from Veteran and Family Council*

- **Step 3: Pilot Test SUCCEED**

Obtain data related to feasibility and acceptability

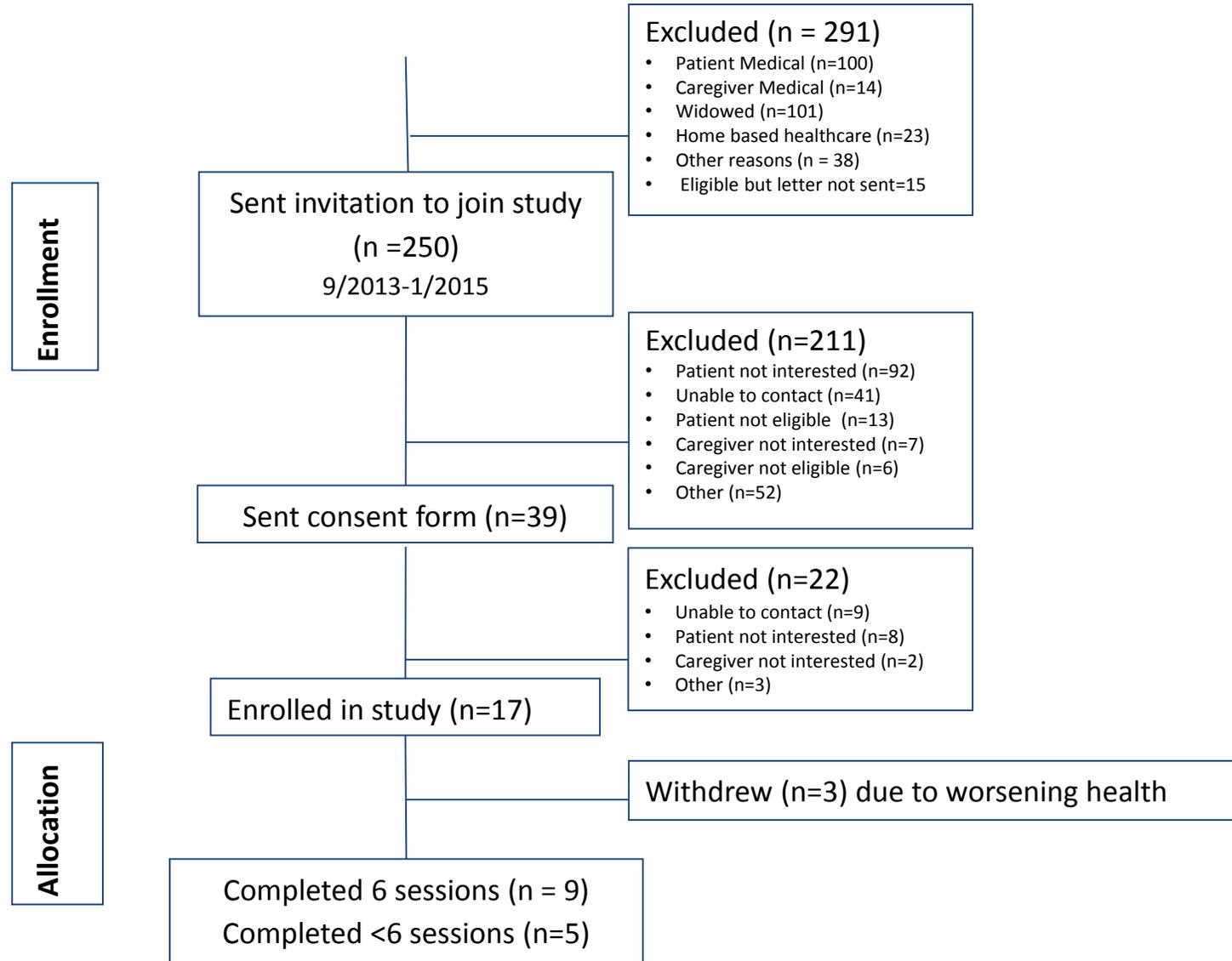
SUCCEED: Self-management Using Caregivers' Coping EnhancEment in Disease

- 6 sessions delivered in-person or over the telephone
- 45-60 minutes
- Delivered by Masters' level facilitator
- Sessions:
 - Session 1: Skills to Manage HF and Making Action Plans
 - Session 2 & 3: Skills to Manage Negative Emotions
 - Session 4 & 5: Skills to Manage Interpersonal Relationships and Relationship Stress
 - Session 6: Building a Fulfilling Life & Maintaining Behavior Change
 - Homework: Action Plan

Feasibility & Acceptability

- Feasibility Measures: Recruitment and retention
- Acceptability Measures: Participant feedback
 - Brief feedback after each session obtained via a 5-item Likert scale
 - Rating was anonymous to minimize social desirability bias
- Surveys: SF12, Minnesota Living with HF Questionnaire, Self-care for Heart Failure Index, PHQ9, Dyadic Coping Inventory, Chronic Illness Communication Scale, Caregiver Reaction Assessment

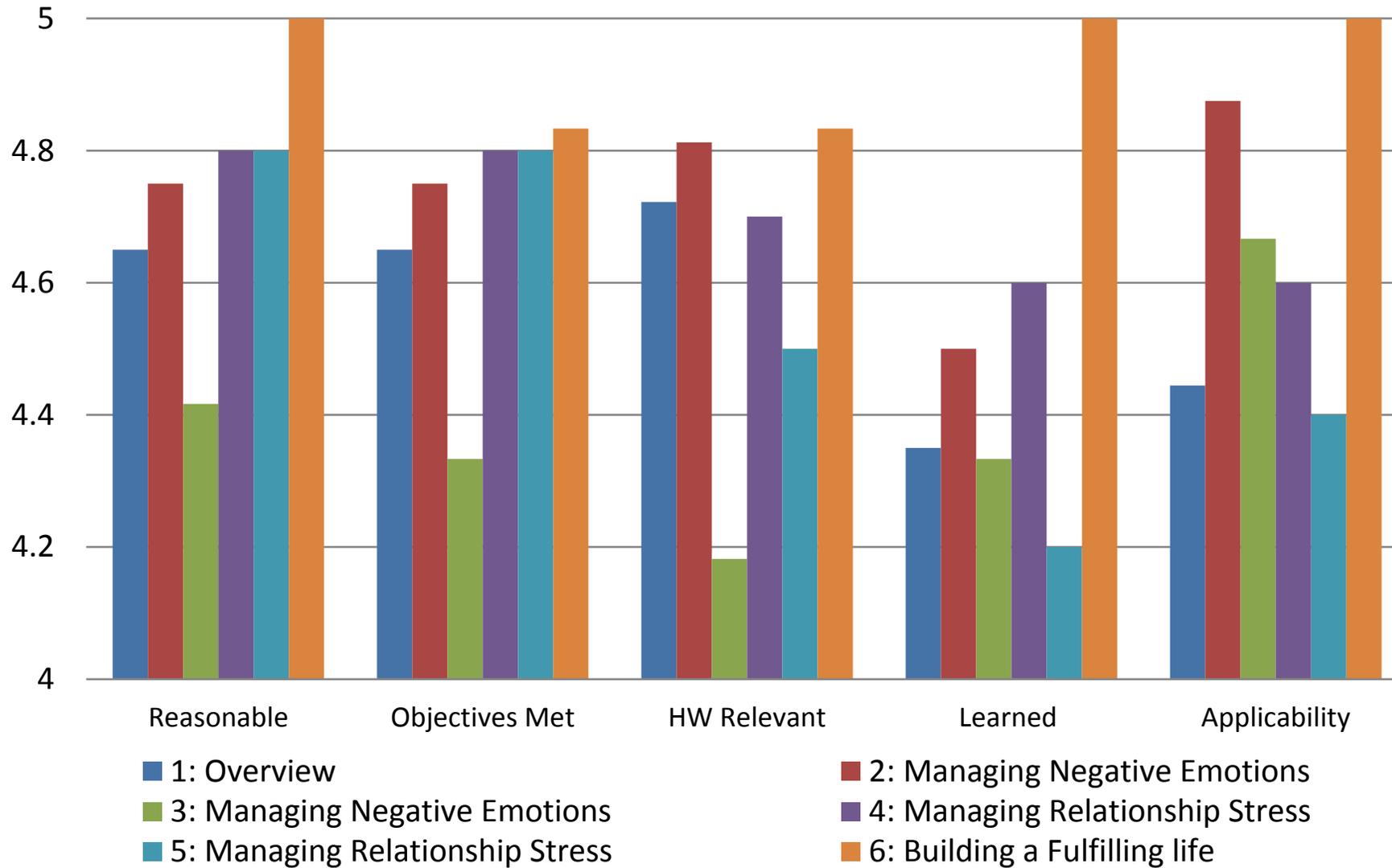
PILOT RESULTS



Feasibility

- Iteratively refined recruitment strategies
 - Initially used opt-in letters, changed to opt-out letters
 - Edited invitation letter to clarify study description and purpose, and to better address the role of caregiver
 - Trained an additional facilitator
- Changes improved recruitment from 3.8% to 5.4%
- Changes improved rate of recruitment
 - Initial 7 couples: 6 months
 - Next 10 couples: <3 months

RESULTS: Acceptability



SURVEYS

Survey	Construct	Patient		Caregiver	
		Pre	Post	Pre	Post
Minnesota Living with HF Questionnaire	HF-specific QoL	50.85(12.1)	56.14(10.6)		
SF-12	General QoL				
<i>Physical Component</i>		39.3(2.75)	33.5(1.8)	46.2(4.2)	39.43(3.4)
<i>Mental Component</i>		45.6(2.9)	34.3(3.9)	39.78(3)	33.3(3)
Self-care of Heart Failure Index	Self-care				
<i>Maintenance</i>		71.65(3.5)	74.2(3.3)		
<i>Management</i>		57.8(7.3)	61.4(7.5)		
<i>Confidence</i>		63.3(6.2)	69.5(3.8)		
PHQ9	Depression	11.14(2.5)	11(2.7)	5.57(1.6)	4.7(1.9)
Dyadic Coping Inventory	Relationship Quality	140.4(6.9)	142.9(6.22)	141.9(8.4)	136.3(4.9)
Chronic Illness Communication Scale	Communication	14.5(1.2)	15.75(1.11)	15.63(1.3)	14.4(1.4)
Caregiver Reaction Assessment	Caregiver Experience			65.1(3.36)	67(4.3)

SUMMARY

- SUCCEED developed based on a strong theoretical foundation, and refined based on feedback from content experts and key stakeholders
 - Limitation: small study, efficacy data needed
- Results of pilot study has implications for improving self-management among patient-caregiver dyads
 - Refined the recruitment process
 - Understand the FTEE necessary to conduct an RCT
 - Encouraging results regarding acceptability and feasibility

Future directions

- Interventions:
 - RCT to test the efficacy of the program (R01 submitted)
 - Adapting SUCCEED to the web (VA HSR&D Pilot Grant Funded)
- Observational studies to understand the sociobehavioral and biobehavioral mechanisms within patients and caregivers that determine self-management
- Understand cultural and ethnic differences in caregiving
 - e.g., Individual vs Collective cultures, multigenerational families, LGBTQ families, racial/ethnic differences

QUESTIONS/COMMENTS?

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