



Heart Failure and Pain Research Studies

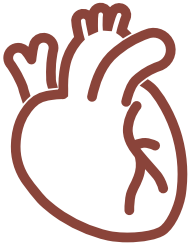
Shena Gazaway, PhD, RN

Rachel Wells, PhD, RN

Kayleigh Curry, MPH, MA, ALC

**UAB Integrative Center for Aging Research
Seminar Series**

Objectives



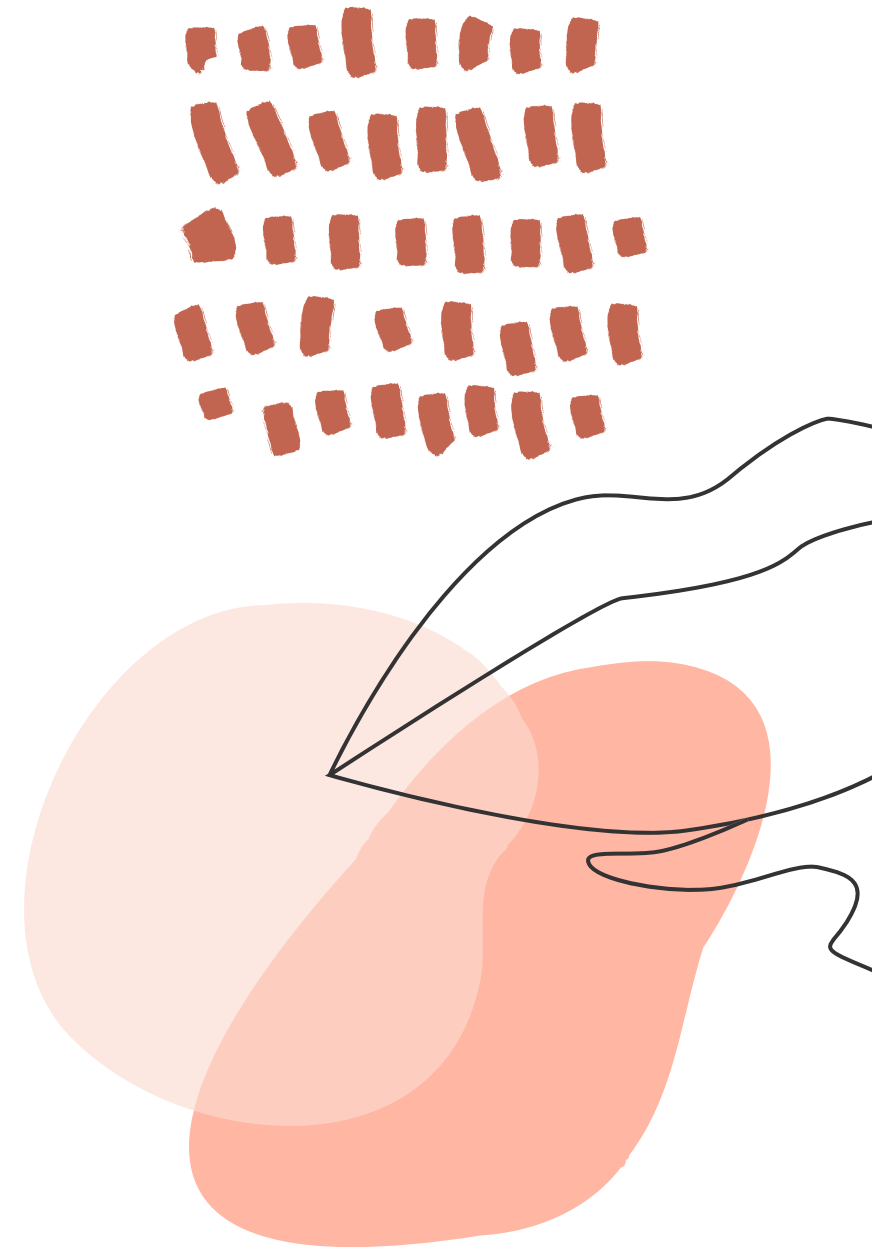
Describe the integrative interventions for PROJECT ADAPT

- Heart Failure & Pain interference
- ADAPT Community Advisory Group



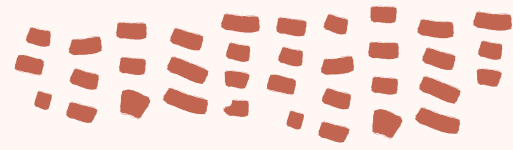
Describe the iterative interventions for PROJECT UPHOLDS

- Heart Failure & Quality of Life



Clinical Trials

- **Project ADAPT: Addressing Pain Through A Navigator-Led Palliative Care Optimized for Heart Failure**
- **Project UPHOLDS: An Optimization Pilot to Optimize An Early Palliative Care Intervention for Advanced Heart Failure**



Pain and Heart Failure

↑ Pain related to ↑ Anxiety, Sleeplessness, Depression, Hopelessness, Hospitalization

23-85% reported pain prevalence in HF;
top 3 symptom reported

Complex pain etiologies & heterogeneous

ADAPT HF Study *Innovation*

- **Formative Evaluation
Optimization Pilot Design**
- **Community-based lay navigator
coaches to deliver the
intervention**
- **Iterative, community-based
intervention development**
- **Exploring maintenance of effect**



ADAPT HF Study Team



Dr. Shena
Gazaway, PI



Dr. Rachel
Wells, PI



Dr. Deborah
Ejem, Co-I



Dr. Stephen
Clarkson, Co-I



Kayleigh Curry,
Project Manager



Margaret Armstrong,
Analyst

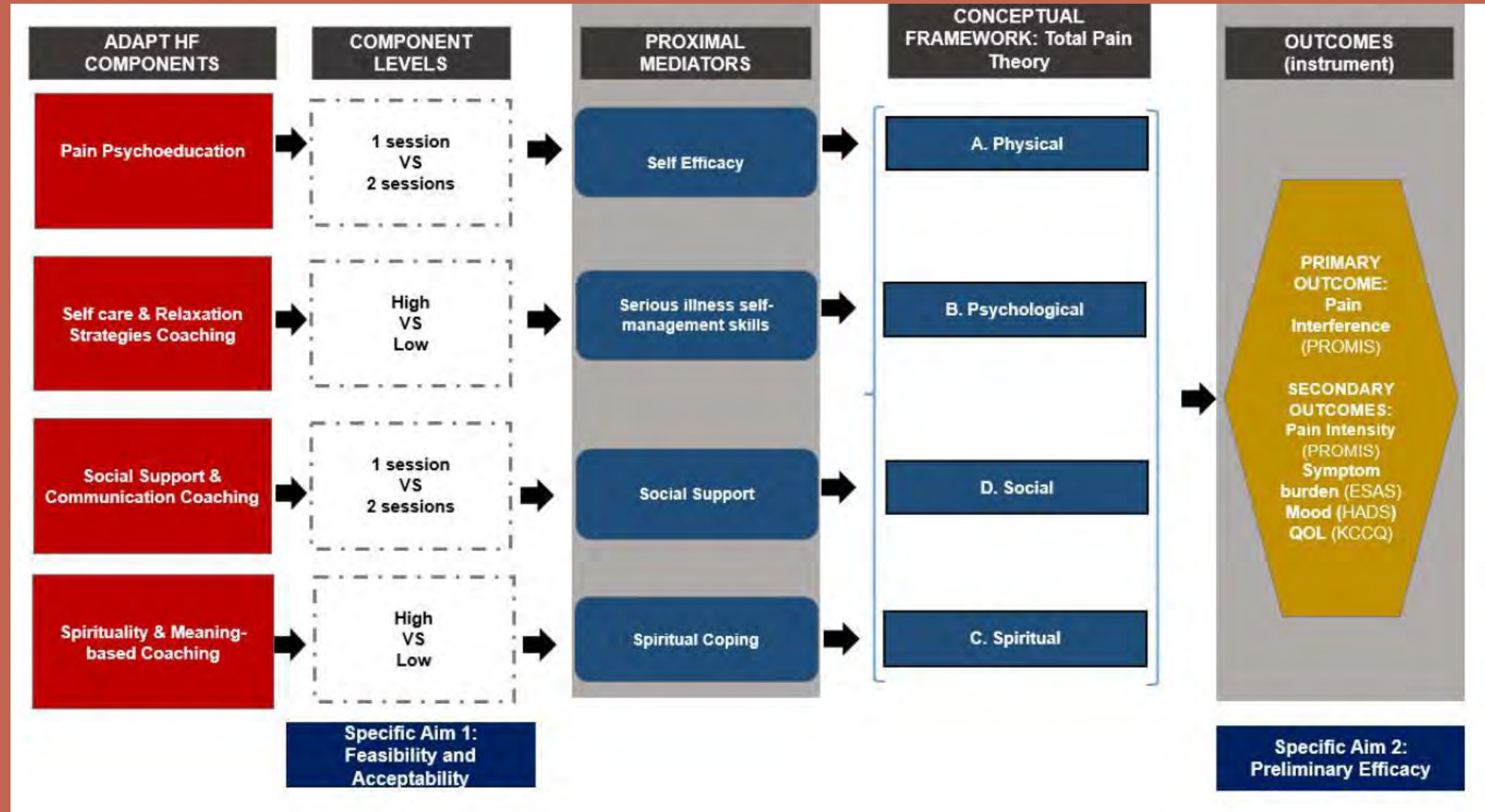


Dr. Raegan
Durant, Co-I



Dr. Marie
Bakitas, Co-I

ADAPT HF Conceptual Model



Proposed ADAPT HF Components

2⁴ factorial pilot

Condition	Pain Psychoeducation	Self-Care & Relaxation Techniques Coaching	Social Support & Communication Coaching	Spirituality & Meaning-based Coaching	n per condition
1	1 session	High	1 session	Low	n=2
2	1 session	High	1 session	High	n=2
3	1 session	High	2 sessions	Low	n=2
4	1 session	High	2 sessions	High	n=2
5	1 session	Low	1 session	Low	n=2
6	1 session	Low	1 session	High	n=2
7	1 session	Low	2 sessions	Low	n=2
8	1 session	Low	2 sessions	High	n=2
9	2 sessions	High	1 session	Low	n=2
10	2 sessions	High	1 session	High	n=2
11	2 sessions	High	2 sessions	Low	n=2
12	2 sessions	High	2 sessions	High	n=2
13	2 sessions	Low	1 session	Low	n=2
14	2 sessions	Low	1 session	High	n=2
15	2 sessions	Low	2 sessions	Low	n=2
16	2 sessions	Low	2 sessions	High	n=2

Inclusion/Exclusion Criteria

Inclusion Criteria

1. Age \geq 18
2. African American
3. NYH Classification of Heart Failure
4. English Speaking
5. Willing to participate

Exclusion Criteria

1. Age $<$ 18
2. Not African American
3. Ineligible HF classification
4. Self-reported severe mental illness
5. Dementia
6. Active Suicidal Ideation
7. Active substance abuse
8. Uncorrected hearing loss
9. Unable to respond in English
10. Non-cardiac terminal illness
11. Previous PC consultation
12. Clinician decline
13. Other

ADAPT HF Outcomes

- PROMIS Pain Interference (primary)
- PROMIS Pain Intensity
- Edmonton Symptom Assessment Scale
- Kansas City Cardiomyopathy Questionnaire- short form (Quality of life)
- Self-care of Heart Failure Index
- Multidimensional Scale of Perceived Social Support
- Patient Activation Measure- short form

- Baseline & 12-weeks

CAG-refined Recruitment Process & Materials



Community Advisory Group formation

- Final Composition
 - 5 members
 - 3 patients
 - 2 Caregivers
- Meetings
 - November 2023
 - Introductions, Study Overview, CAG Recruitment Flyer Review
 - Phone Call
 - Feedback Survey Instruments
 - March 2024
 - Introductions, Updates, Intervention Material Feedback
 - Fall 2024
 - Updates, Intervention Material Feedback

WELCOME AND HEARTFELT THANKS



Community Advisory Group – Your Role

The Advisory Group will consist of heart failure patients who identify as Black.

Those who begin serving will continue to help us identify others who may be willing to serve until we are full – max 8 individuals.

There will be 6 meetings over the grant period, these will occur in person and over Zoom.


The goal is for you to share your experiences dealing with heart failure and pain, give us your honest feedback on the look and feel of study materials, and help us make sure the work addresses a need.

Members of the advisory group will be paid for your time each meeting you will receive \$50.

Sending to you next week

- Tentative Intervention toolkit
 - When you review once you receive
 - Take notes – be honest
 - Make an appointment with Kayleigh
 - Give us your feedback
- Surveys
 - Please take these for fun, time yourself – don't rush
 - Give us feedback – length of time, ease of read and understanding when you talk with Kayleigh
- Share the opportunity to serve on board with others you know, who you think are a great fit
 - Share their names with Kayleigh or share Kayleigh's contact with them (take a flyer or 10 ☺)

CAG-refined Recruitment Process & Materials



Thank you for participating in ADAPT-HF.

Your time and effort on this survey will help us develop programs to help Black adults living with heart failure. Please fill out this survey within 2 weeks of receiving it and send it back in the self-addressed, stamped envelope provided.

Again, thank you!

BASELINE

Study Staff Only

Screening ID _____

REDCap ID _____

Date Entered into REDCap ____/____/____ Initials ____

5

The next series of questions ask about your use of the internet and access to technology. These responses will help us understand how people with heart failure access information and what types of devices you have available.

19. Do you ever go on-line to access the Internet or World Wide Web (www.)?

- ☐ No (GO TO Healthcare Resource Question 1 on next page (page 6))
- ☐ Yes

If yes, how often do you access the Internet through each of the following?

	Daily	Sometimes	Never
19a. Computer at home...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19b. Computer at work...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19c. Computer in a public place (e.g., library, community center, <u>other</u>)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19d. On a mobile device (e.g., cell phone, smart phone, <u>tablet</u>)...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Please indicate if you have any of the following. (Select ALL that apply)

- ☐ Desktop or laptop computer
- ☐ Tablet computer (e.g., iPad, Samsung Galaxy, Motorola Xoom, or Kindle Fire)
- ☐ Smartphone (e.g., iPhone, Android, or Google phone)
- ☐ Basic cell phone only
- ☐ I do not have any of the above

Please continue to next page





As shown in this figure, how you think and respond to pain can impact how you experience pain in the future. Coping with pain in life, especially coping with chronic pain, is a complex process.

Making the Most of The 3 P's and ADAPT HF



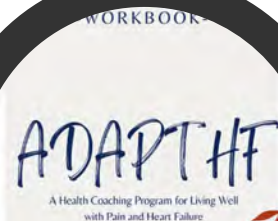
Participate: 80% of success is showing up. People have busy schedules. But people who get the most out of this program are present for their appointments. They are engaged, uncensored, unfiltered, and talk openly about what's on their minds.



Prepare: Take time to read and think about the material in this toolkit before your appointment with your coach. If you can't read ahead of time, that's okay too.



Practice what you learn: It is one thing to learn something—it's another thing to put it to use. You will learn a lot more by practicing something than you ever will just by reading about it.



CAG-refined Intervention Toolkit

Improving my pain reflection plan

What would happen if I didn't reach this goal?

» _____

» _____

» _____

On a scale of 1 to 10, with 1 being "not confident" and 10 being "highly confident," how confident are you that you will reach your goal?

My name is Kayleigh and I am a Project ADAPT HF supportive care coach. I will be there to help you step by step through this process. I look forward to our time together, and if you have any questions, please see feel to reach out at any time.

Kind regards,

Kayleigh

Coach Name: Kayleigh Curry

Contact Information:
705-996-0107

Kayleigh obtained her Masters in Clinical Mental Health Counseling and Public Health. She has served as a supportive care coach for the ADAPT HF program.



Improving my pain reflection plan

In approaching or thinking about pain, one thing I want to get better at is?

» _____

» _____

» _____

Why does getting better at this goal matter?

CAG-refined Feedback

ADAPT HF toolkit CAG Review Form

General Impression	1. Style
	2. Photos
	3. Representation of relevant HF concerns
Layout	1. look and feel of the toolkit (materials inside – pens, highlight, post its, hole punch, notepad)
	2. Section dividers (do the divisions make sense)
	3. Order that the material is presented in
	4. Do you like the cases that are presented based on real life stories?
	5. Tell me your thoughts about the space for self-reflection throughout the toolkit, are there enough, too, much, does having the notebook – give you the additional space to write that you want?

Follow	If you were doing the program alone could you complete the activities with no help?
	Were there sections that were hard to follow?
	Were there any pages where the words or reading did not make sense that you want us to review now because you marked them?
Appropriate	Do you think this toolkit as it will help someone with pain and heart failure? Why?
Resources	Are there any resources (local, national, online) that you have used that you think we should add?

Community-Based Palliative Care Coaching with Navigators



Study Timeline

Table. 1 Study Timeline						
Activity	Pre-award	Year (December 2023-November 2024)				Extended
	(6/1/23-11/30/23)	Q1 12/1/23-2/29/24	Q2 3/31/24-5/31/24	Q3 6/1/24-8/31/24	Q4 9/1/24-11/31/24	
IRB approval, protocol/tracking system development						
Finalize ADAPT HF intervention components with Community Advisory Group (CAG) <i>Funding supports time/effort compensation (Initial pre-award support through ICAR Seed funding)</i>						
Hire research coordinator <i>Funding supports salary (Initial pre-award support through ICAR Seed Funding)</i>						
Hire & train lay navigators <i>Funding supports salary (ICAR Seed Funding 1st 3 months)</i>						
Quarterly CAG meetings <i>Funding supports materials and supplies needed for meetings</i>						
Rita & Alex Hillman Foundation workshops, updates, & reports						
Recruitment/Enrollment (32 patient participants) <i>Funding supports participant incentives</i>		4	20	32		

What is Project UPHOLDS?



Goal is to increase patients' serious illness self-management skills and self efficacy to improve QoL

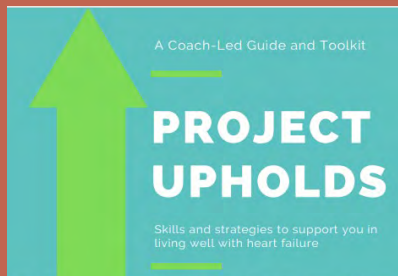


Older adults with advanced heart failure

Palliative care coach-led



Phone + In-person interaction



4-9 coaching sessions using UPHOLDS Toolkit (20-30 minutes)

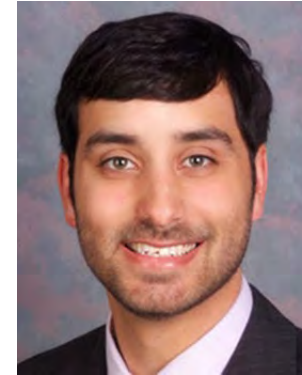
UPHOLDS Study Team



Dr. Shena
Gazaway, PI



Dr. Rachel
Wells, PI



Dr. Stephen
Clarkson, Co-I



Kayleigh Curry,
Project
Manager/Coach



Margaret Armstrong,
Data Analyst



Alicia Cole,
Coach

2⁴ full factorial optimization trial design

Purpose

Test feasibility, acceptability, and preliminary efficacy of components of the UPHOLDS (Utilizing Palliative Care for Heart Failure Optimized using Lay Navigators to Decrease Suffering) intervention for patients with advanced heart failure.

Design

2⁴ full factorial design testing feasibility and acceptability of improving quality of life for heart failure patients using these components: 1) palliative care psychoeducation coaching (4 vs. 8 sessions); 2) financial coaching (yes vs. no); 3) monthly follow-up (1 call vs. 4 calls) and 5) outpatient palliative care clinic visit (yes vs no)

Inclusion/Exclusion Criteria

Inclusion Criteria

1. Age ≥ 50
2. African American
3. NYH Classification of Heart Failure
4. English Speaking
5. Recent Hospitalization (6 months)
6. Willing to participate
7. Telephone access

Exclusion Criteria

1. Age < 50
2. Not African American
3. Ineligible HF classification
4. No recent hospitalization
5. Self-reported severe mental illness
6. Dementia
7. Active Suicidal Ideation
8. Active substance abuse
9. Uncorrected hearing loss
10. Unable to respond in English
11. Non-cardiac terminal illness
12. Previous PC consultation
13. Clinician decline

There are 4 main components to UPHOLDS

COMPONENT 1: Palliative Care Psychoeducation

Basic psychoeducation – 4 sessions

Content:

- 1) Coping with serious illness
- 2) Self-care principles and strategies
- 3) Symptom management principles and skills
- 4) Value elicitation

Advanced psychoeducation – 8 sessions

Content:

- 1) Same as above plus:
- 2) Illness/prognosis understanding
- 3) Managing advanced therapeutics
- 4) Principles of social support effectiveness theory
- 5) Serious illness conversations
- 6) Basics of healthcare decision making

There are 4 main components to UPHOLDS

COMPONENT 2:

Financial Coaching

Content:

- 1) Normalizing financial distress
- 2) Strategies to address financial strain
- 3) Review resources within the community

COMPONENT 3:

Palliative Care Consultation

Objectives:

- 1) Connect/build rapport with specialty palliative care team
- 2) Proactively address symptoms/areas of suffering identified during coaching sessions

**There are 4
main
components
to UPHOLDS**

COMPONENT 4:

Follow up calls

One Monthly Follow-up Call vs. 4 Monthly Follow-Up Calls

- 1) Ask about how last month has been and new challenges in living with advanced heart failure
- 2) Reinforce prior session content
- 3) Follow up on prior action plans and provide action support





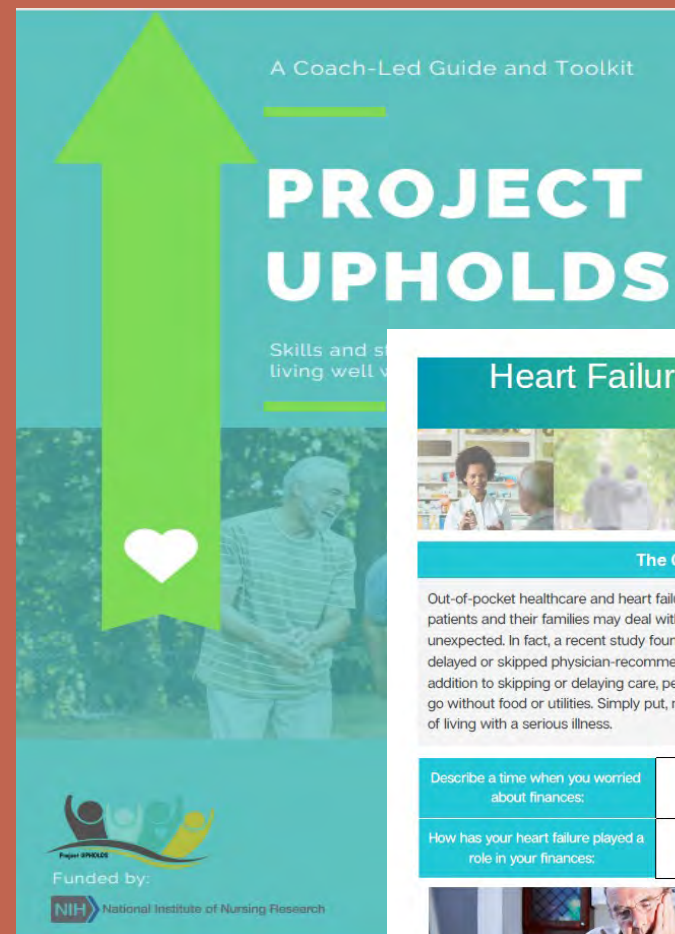
2⁴ factorial trial design

Condition	Specialty Palliative Care Consultation (Yes vs No)	PC Coaching (4 Sessions vs 8 sessions)	Financial Coaching (Yes vs. No)	Monthly Follow- up calls (1 call vs. 4 calls)	<i>n</i> per condition
Aqua	Yes	4 sessions	Y	1 call	n=4
Blue	Yes	4 sessions	Y	4 calls	n=4
Coral	Yes	4 sessions	N	1 call	n=4
Denim	Yes	4 sessions	N	4 calls	n=4
Emerald	Yes	8 sessions	Y	1 call	n=4
Fuchsia	Yes	8 sessions	Y	4 calls	n=4
Gold	Yes	8 sessions	N	1 call	n=4
Harlequin	Yes	8 sessions	N	4 calls	n=4
Indigo	No	4 sessions	Y	1 call	n=4
Jade	No	4 sessions	Y	4 calls	n=4
Khaki	No	4 sessions	N	1 call	n=4
Lime	No	4 sessions	N	4 calls	n=4
Maroon	No	8 sessions	Y	1 call	n=4
Navy	No	8 sessions	Y	4 calls	n=4
Orange	No	8 sessions	N	1 call	n=4
Pink	No	8 sessions	N	4 calls	n=4

There are 16
different
UPHOLDS
“packages”

<div><div>AQUA</div><div>Condition Aqua of Project UPHOLDS</div><div></div><div>Project UPHOLDS</div><div><table><tr><td># of Weekly Coaching Sessions:</td><td>5 sessions (4 psychoeducation, 1 financial coaching)</td></tr><tr><td># of Monthly Calls:</td><td>3 call</td></tr><tr><td>Outpatient PC Visit:</td><td>Yes</td></tr></table></div></div>	# of Weekly Coaching Sessions:	5 sessions (4 psychoeducation, 1 financial coaching)	# of Monthly Calls:	3 call	Outpatient PC Visit:	Yes	<div><div>BLUE</div><div>Condition Blue of Project UPHOLDS</div><div></div><div>Project UPHOLDS</div><div><table><tr><td># of Weekly Coaching Sessions:</td><td>5 sessions (4 psychoeducation, 1 financial coaching)</td></tr><tr><td># of Monthly Calls:</td><td>4 calls</td></tr><tr><td>Outpatient PC Visit:</td><td>Yes</td></tr></table></div></div>	# of Weekly Coaching Sessions:	5 sessions (4 psychoeducation, 1 financial coaching)	# of Monthly Calls:	4 calls	Outpatient PC Visit:	Yes	<div><div>CORAL</div><div>Condition Coral of Project UPHOLDS</div><div></div><div>Project UPHOLDS</div><div><table><tr><td># of Weekly Coaching Sessions:</td><td>4 sessions (4 psychoeducation)</td></tr><tr><td># of Monthly Calls:</td><td>3 call</td></tr><tr><td>Outpatient PC Visit:</td><td>Yes</td></tr></table></div></div>	# of Weekly Coaching Sessions:	4 sessions (4 psychoeducation)	# of Monthly Calls:	3 call	Outpatient PC Visit:	Yes	<div><div>DENIM</div><div>Condition Denim of Project UPHOLDS</div><div></div><div>Project UPHOLDS</div><div><table><tr><td># of Weekly Coaching Sessions:</td><td>8 sessions (8 psychoeducation)</td></tr><tr><td># of Monthly Calls:</td><td>4 calls</td></tr><tr><td>Outpatient PC Visit:</td><td>No</td></tr></table></div></div>	# of Weekly Coaching Sessions:	8 sessions (8 psychoeducation)	# of Monthly Calls:	4 calls	Outpatient PC Visit:	No
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The UPHOLDS Toolkit



Heart Failure and Finances

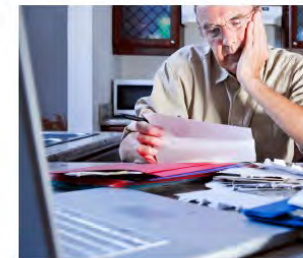


The Cost of Heart Failure

Out-of-pocket healthcare and heart failure costs patients and their families may deal with high out-of-pocket costs. In fact, a recent study found that 43% of patients delayed or skipped physician-recommended tests in addition to skipping or delaying care, people may go without food or utilities. Simply put, many people struggle with the cost of living with a serious illness.

Describe a time when you worried about finances:

How has your heart failure played a role in your finances:



Session Reflections

Self-care is an intentional act that may need planning. What are some self-care activities you can plan for the following week?

When you have completed self-care activities in the past, how have they helped with your heart failure?

Making the Most of Your Supportive Care Clinic Visit



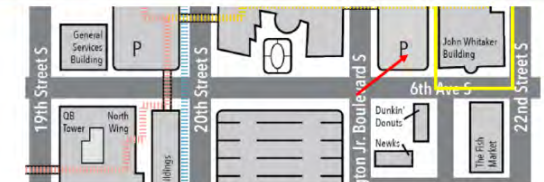
What to Expect

The UAB Center for Palliative and Supportive Care uses a comprehensive approach when caring for patients with serious illness. They focus on the [whole patient](#), addressing the physical, emotional, social, and spiritual suffering of disease. An [interdisciplinary team](#) including physicians, nurses, physical therapists, psychologists, counselors, massage therapists, social workers, and others are committed to supporting patients and their families through the stress of serious illness.

At your first visit, you will meet with either a doctor or nurse practitioner who specializes in palliative care. They will ask you about your experience with heart failure and any other health concerns you may have. Like other clinic visits, they will look and listen to your body and may order bloodwork or other tests. At the end of your appointment, [together you will make a plan](#) that addresses your needs and concerns.

My appointment is scheduled for (day/time):

My visit location is (the Whitaker Clinic at UAB Hospital or telehealth):



Measures

Measure	Baseline	Week 12	Week 24
Feasibility (intervention component & measure completion rate)			X
Acceptability (interviews)			X
*Quality of life (Kansas City Cardiomyopathy Questionnaire-12)	X	X	X
Mood (Hospital Anxiety and Depression Scale)	X	X	X
Financial Distress (Comprehensive score for financial toxicity)	X	X	X
Self-management (Self-care of Heart Failure Index)	X	X	X
Symptom burden (Edmonton Symptom Assessment Scale)	X	X	X
Self-efficacy (PROMIS General Self-efficacy measure- Short Form)	X	X	X
Financial Well-Being Scale	X	X	X

- Measures to be collected at baseline, 12 weeks, and 24 weeks. Acceptability interviews are conducted at 24 weeks.

Palliative care coaches receive advanced training as UPHOLDS Coaches

- 50-60 hours of structured didactic and skills training curriculum
- Enhanced preparation areas: lay navigation, coaching and action planning, motivational interviewing, heart failure and palliative care fundamentals
- Simulated practice with debrief
- Ongoing weekly oversight by palliative care and heart failure clinicians

Questions & answers

