



# The Experience of Illness Control and Hospital Readmission In Adults with Chronic Heart Failure

Stephanie Turrise, PhD, RN, BC, APRN, CNE<sup>1</sup>, Nina Hadley, BSN, RN<sup>2</sup>, Denise Phillips-Kuhn, MSN, RN, ACM<sup>2</sup> & Barbara J. Lutz, PhD, RN, FAAN<sup>1</sup>

<sup>1</sup>University of North Carolina-Wilmington, School of Nursing,

<sup>2</sup>New Hanover Regional Medical Center



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# Introduction

## Heart failure (HF)

- progressive, chronic condition
- significant public health problem
- affects 6.5 million Americans (Benjamin et al., 2017).
- little improvement in hospital readmissions among these patients (Curtis et al., 2008)
  - nearly 25% of Medicare patients readmitted within 30 days (Dharmarajan et al., 2013).



# Introduction

## Managing HF

- Requires adherence to complex treatment regimens
  - dietary changes
  - medications
  - symptom monitoring
- However, exactly how individuals define illness control, and in what way hospital readmission affects their perceptions of illness control are not known.



# Introduction

- Counterintuitive findings about illness management
- Limited knowledge about
  - Patient perceptions of illness control
  - Impact of hospital readmission on perceptions of illness control



# Theoretical Frameworks

- Corbin and Strauss' Chronic Illness Trajectory Model (1991, 1998)
- Leventhal's Common Sense Model of Self-Regulation (1980, 2003, 2010).



# Purpose

The study aims were to:

1. Explore experiences of chronic HF patients in managing and controlling their HF
2. Understand the impact of hospital readmission on perceptions of illness control



# Methods: Sampling & Recruitment

- Recruitment site IRB approved the study
- Purposive sampling;
- Inclusion criteria:
  - adults greater than 18
  - experienced a hospital readmission for HF within 60 days of an index hospitalization also for HF
  - speak and understand English
  - were being discharged to home





# Methods: Setting & Sample

- 11 participants
- Recruited from a large Level II trauma center in SE North Carolina
- Living in 6 counties (5 of which are considered rural);
- Semi-Structured Interviews
  - B/T June 2015 and February 2016.
  - 1 participant lost to follow-up after discharge
  - 10 participants were interviewed in their homes



# Methods: Data collection and Analysis

- Semi-structured interviews
  - conducted by PI and one other team member
- Two interviews included significant others at the request of the participant
- Interviews
  - audio recorded,
  - transcribed verbatim
  - Verified for accuracy
- ATLAS.ti® data management software facilitated data coding and analysis



# Methods: Analysis

- Applied thematic analysis (Guest, MacQueen and Namey 2012)
- Transcripts were open coded individually by 3 members of the research team
- Discussion about the codes and themes took place; discrepancies were resolved



# Results

## Participants

- Age range: 53 - > 90 years
- 2 females & 8 males
- 4 White, 5 Black/African American, & 1 Other
- 2 to 20 different types of RXs
- Time of HF diagnosis: 2 months and 10 years
- 1 participant did not have insurance
- 2 participants had less than a high school education
- Income less than \$25,000 per year: 60% (n=6)



# Results: Aim 1

## Experience of chronic HF patients illness control and illness management

Themes	Sub-themes
Strategies for controlling HF	<ul style="list-style-type: none"><li>• Managing dietary intake &amp; medications</li><li>• Self advocacy</li><li>• Monitoring symptoms</li><li>• Social support</li></ul>
Barriers to controlling HF	<ul style="list-style-type: none"><li>• Systems issues</li><li>• Provider relationships</li><li>• Knowledge deficits</li><li>• Personal characteristics</li></ul>



## Results: Strategies for Controlling HF

Sub-Theme	Quotes
Managing dietary intake	<ul style="list-style-type: none"><li>• The nutritionist came in. She gave me a list to read, and she talked to me about a diet and she’s like, “I made you a diet, you know, to go by.” Then I took her diet and put my own little twist in it, and, you know...”</li><li>• “Mm-hmm. I used to love cup noodles. Cuz it’s quick, pour the water. Didn’t realize all the sodium is in it. Did away with it. Salt, did away with it. Um, started grilling more. Once I found out what was really a lot of the stuff that, you know, would create the problem and help build the fluid. So, I stopped doing it.”</li><li>• Oh, yeah. Very important. It’s very, very important. And I’ve learned from self-experience diet. Especially, you know, being black for the simple reason we season our food heavy. Our mama did, our grandma did, our great-grandma did. I mean it’s just a—it’s just a thing that you grow”</li></ul>
Managing medications	<ul style="list-style-type: none"><li>• Uh, I’m making sure to take my medicine. And I’m trying to take it at the same time every morning, every—”</li><li>• “I said I’m—I’m not taking it. And I missed the day, a day and a half and felt better. Uh, then I thought. I said, nah, I got this—I got to take it cuz I don’t want the fluid back on me, so I went back to taking it”</li></ul>



## Results: Strategies for Controlling HF

Sub-Theme	Quotes
Self Advocacy	<p>“Yeah. Cuz I keep telling him, you know, I have lymphedema, and I keep telling him it wasn’t the lymphedema, and that’s what the hospital was telling me, “Oh, it’s your lymphedema.” And I’m like, “No. I know my body. I know how I’ve had lymphedema goin’-goin’ on nine years.” I know how it felt in nine years, and all of a sudden six months of change. I know the difference, you know?”</p> <p>“Like I said, be proactive. Uh, learn all about your disease you can. You know, educate yourself. Ask the tough questions. You know, if you don’t think the doctor is doing like he wanted to or was supposed to or think he should do, ask him why. Don’t be—I used to be scared to ask the doctor anything, but now I’m not. Now I’m not ‘cuz if you don’t, I mean, how you gonna find out?”</p>
Social support	<p>“because, uh, if you don’t step up to the plate and look after your—your—your partner or whoever, your family member, you can’t expect other people to want to step up to the plate and do it for you.”</p> <p>“But that’s one reason I think—I thank God for our family—the unit because you can pull off of each other’s strength”</p>



## Results: Barriers to Controlling HF

Sub-Theme	Quotes
Systems issues	<p>“.....was when just about—well, I’d say time to, just before time to go to leave was all these different medicine. No one had a grip on what medicines that I was on. I mean, it was a mess.”</p> <p>“I believe in going to the doctor, trying to find out what was wrong. And I felt like, okay, after two times in the hospital, uh, and I’m still feeling the same way, I’m still sick, I’m still tired, and, you know, I’m like, you know, this-this is crazy. You know, what do I do? You know? I’m not getting better.”</p>
Provider relationships	<p>“Really, uh, to me, it seemed like doctors work at their own pace, how they want to do things. But to me, it seemed like I needed another paracentesis before I come out to make me a lot better. But they didn’t agree.”</p> <p>“And, uh, my GP is with this group.....- the factory. The only reason I’m staying there is because I like the doctor”</p>





## Results: Barriers to Controlling HF

Sub-Theme	Quotes
Provider relationships	<p>“And doctor came and the nur—doctor came in and said, uh, what was my, um, pain? Well, I told him it was about eight. And I don’t know what a bonehead marked zero, so they came in there. Everybody—all of them got together and they sent me home. See what I’m sayin’? I told ‘em, I said I-I don’t think I need to go home, but I couldn’t hardly walk. See what I’m sayin’? I could hardly walk. And really, it was swollen like that in my-my scrotum, my scrotum was swelled up.”</p> <p>“There was a little young girl there trying to tell me that I need to sleep with my breathing machine. So I got, uh, CPAP. They tried to tell me I need to sleep with it. ....uh—I know my body. I knew when sleep apnea is—sleep apnea don’t bother me as far as going to sleep. It’s just when I gets up I’m rested when I got the machine on. I’m well rested. But if I don’t wear it I’m still tired. And I told her that. She said, “No, you got to sleep—you put it on then you can sleep.” When you can’t breathe—I mean, I put the machine on cuz I said, “Well, I’ll force that air.” I put it on and it cut my air off, .....And, um, I was telling that young doctor there, she was a little young girl about 24 or 25. I called her Doogie Howser. I don’t know. But she kept telling me that and—and um, I knew there was something wrong. And she kept telling me that, and I shouldn’t have done it, but she just made me, I cussed her out all the way out the building.”</p>



## Results: Barriers to Controlling HF

Sub-Themes	Quotes
Knowledge deficits	<p>“Um, I was kinda short of breath. Became short of breath, and got tired real quick, and when I—when I got up there to do things. I didn’t really know I had it until I started swellin’ and I-I went to the hospital.”</p> <p>“Oh, I—I think it’s gone. There’s always a possibility it can come back. Uh, I don’t know what caused the water build-up. Nobody explained that to me.”</p> <p>“But, uh, I’m—I’m really, uh, back to normal. I don’t know what brought it on. Uh, no one gave me an explanation of how I filled up with water, but it happened about, maybe five years ago, it was just I was up at my daughter’s in New York, and I had the same thing with breathing. And I went to her doctor, and he put me on a water pill.”</p>
Personal characteristics	<p>“Now, they did mention my smokin’, although let me tell you somethin’. I’m 72 years old. I don’t intend to change a thing at my age now and I don’t.”</p> <p>“And I don’t know. A lot of times, I tell my wife, I tell my children, ‘I’m too old and stubborn to really change.’ And that stuck with me, too. I’m just too old fashioned. I don’t wanna learn most anything unless I want to. You know, there ain’t nobody gonna just make me do something. But—and it ain’t that way. It ain’t.”</p>



# Discussion

- All participants noted the importance of medication, diet and symptom monitoring to the control of their illness; however not all realized that this would be a lifetime commitment and that there is not a “fix” for their HF.
- Additionally, what they were told and how they interpreted the information varied.
- While individuals realized the importance of medications and diet to controlling their illness, there were barriers to being adherent.
- There appears to be an underlying element of experience or time living with HF that relates to their knowledge and control of it that is being further explored and analyzed.



# Implications and Next Steps

- Clinicians need to recognize where the individual is in their understanding of HF
- Standardized instructions for HF patients provided in multiple formats
- Support available to them beyond their hospitalization and provider
- Address the barriers

# My Colleagues



# Questions?



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