Self-Care Behaviors of Women Living with Heart Failure:

A Mixed Methods Study

Susan Bartos PhD, RN, CCRN

Introduction

- Cardiovascular disease is the leading cause in global mortality
 - United States: 1/7 individuals
 - 1/5 develop Heart Failure

10 Leading Causes of Death by Age Group, United States - 2014

Rank	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+	Total
1	Congenital Anomalies 4,746	Unintentional Injury 1,216	Unintentional Injury 730	Unintentional Injury 750	Unintentional Injury 11,836	Unintentional Injury 17,357	Unintentional Injury 16,048	Malignant Neoplasms 44,834	Malignant Neoplasms 115,282	Heart Disease 489,722	Heart Disease 614,348
2	Short Gestation 4,173	Congenital Anomalies 399	Malignant Neoplasms 436	Suicide 425	Suicide 5,079	Suicide 6,569	Malignant Neoplasms 11,267	Heart Disease 34,791	Heart Disease 74,473	Malignant Neoplasms 413,885	Malignant Neoplasms 591,699
3	Maternal Pregnancy Comp. 1,574	Homicide 364	Congenital Anomalies 192	Malignant Neoplasms 416	Homicide 4,144	Homicide 4,159	Heart Disease 10,368	Unintentional Injury 20,610	Unintentional Injury 18,030	Chronic Low. Respiratory Disease 124,693	Chronic Low. Respiratory Disease 147,101
4	SIDS 1,545	Malignant Neoplasms 321	Homicide 123	Congenital Anomalies 156	Malignant Neoplasms 1,569	Malignant Neoplasms 3,624	Suicide 6,706	Suicide 8,767	Chronic Low. Respiratory Disease 16,492	Cerebro- vascular 113,308	Unintentional Injury 136,053
5	Unintentional Injury 1,161	Heart Disease 149	Heart Disease 69	Homicide 156	Heart Disease 953	Heart Disease 3,341	Homicide 2,588	Liver Disease 8,627	Diabetes Mellitus 13,342	Alzheimer's Disease 92,604	Cerebro- vascular 133,103
6	Placenta Cord. Membranes 965	Influenza & Pneumonia 109	Chronic Low. Respiratory Disease 68	Heart Disease 122	Congenital Anomalies 377	Liver Disease 725	Liver Disease 2,582	Diabetes Mellitus 6,062	Liver Disease 12,792	Diabetes Mellitus 54,161	Alzheimer's Disease 93,541
7	Bacterial Sepsis 544	Chronic Low Respiratory Disease 53	Influenza & Pneumonia 57	Chronic Low Respiratory Disease 71	Influenza & Pneumonia 199	Diabetes Mellitus 709	Diabetes Mellitus 1,999	Cerebro- vascular 5,349	Cerebro- vascular 11,727	Unintentional Injury 48,295	Diabetes Mellitus 76,488
8	Respiratory Distress 460	Septicemia 53	Cerebro- vascular 45	Cerebro- vascular 43	Diabetes Mellitus 181	HIV 583	Cerebro- vascular 1,745	Chronic Low. Respiratory Disease 4,402	Suicide 7,527	Influenza & Pneumonia 44,836	Influenza & Pneumonia 55,227
9	Circulatory System Disease 444	Benign Neoplasms 38	Benign Neoplasms 36	Influenza & Pneumonia 41	Chronic Low Respiratory Disease 178	Cerebro- vascular 579	HIV 1,174	Influenza & Pneumonia 2,731	Septicemia 5,709	Nephritis 39,957	Nephritis 48,146
10	Neonatal Hemorrhage 441	Perinatal Period 38	Septicemia 33	Benign Neoplasms 38	Cerebro- vascular 177	Influenza & Pneumonia 549	Influenza & Pneumonia 1,125	Septicemia 2,514	Influenza & Pneumonia 5,390	Septicemia 29,124	Suicide 42,773



Women and Heart Disease

- Nearly half (47%) of individuals diagnosed with heart failure are female.
 - Females are generally older at the time of first diagnosis, have higher rates of depression and a higher mortality rate than males (57.8% vs. 42.2%).
- Females are highly underrepresented in large scale clinical trials accounting for approximately 25% of study participants.

Self-Care and Chronic Disease

- Self-care behaviors are at the foundation of heart failure management.
 - Decreases hospitalization rates and improves overall quality of life.
- Self-Care is effected by physiological and psychological factors

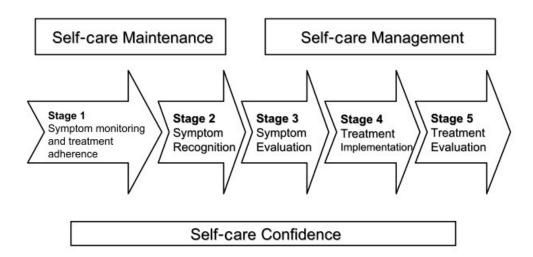
Physiological	Psychological		
Cognitive impairment	Depression		
Functional status	Anxiety		
Co-morbid conditions	Social Support		
Polypharmacy	Emotional Distress*		
Fatigue*	Previous negative experiences*		

*Greater effect on females

Theoretical Framework: Situation Specific Theory of Heart Failure Self-Care

• Aims to link clinical practice, research, and theory

Self-Care of Heart Failure Model



Theoretical Framework: Situation Specific Theory of Heart Failure Self-Care

• Aims to link clinical practice, research, and theory



Naturalistic Decision Making (NDM)

Self-Care of Heart Failure Index (SCHFI)

- 3 subscales: Maintenance, Management, Confidence
 - 22 item, Likert style questionnaire.
 - Coefficients for each subscale:
 - Maintenance: 0.55
 - Management: 0.59
 - Confidence: 0.82
 - Confirmatory factor analysis (2009)
 - Structural equation modeling (2013)
 - Tested in multiple countries including: Italy, Brazil, Taiwan
 - Translated into multiple languages including: Spanish, Dutch, Portuguese, Japanese, Persian, Slovakian, Lithuanian, Albanian, and French.

SCHFI - Maintenance Scale

Listed below are common instructions given to persons with heart failure. How routinely do you do the following?

	Never or rarely	Sometimes	Frequently	Always or daily
1. Weigh yourself?	1	2	3	4
2. Check your ankles for swelling?	1	2	3	4
Try to avoid getting sick (e.g., flu shot, avoid ill people)?	1	2	3	4
4. Do some physical activity?	1	2	3	4
5. Keep doctor or nurse appointments?	1	2	3	4
6. Eat a low salt diet?	1	2	3	4
7. Exercise for 30 minutes?	1	2	3	4
8. Forget to take one of your medicines?	1	2	3	4
Ask for low salt items when eating out or visiting others?	1	2	3	4
10. Use a system (pill box, reminders) to help you remember your medicines?	1	2	3	4

SCHFI - Confidence Scale

In general, how confident are you that you can:

	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself <u>free of heart failure</u> <u>symptoms?</u>	1	2	3	4
18. Follow the treatment advice you have been given?	1	2	3	4
19. <u>Evaluate the importance</u> of your symptoms?	1	2	3	4
20. <u>Recognize changes</u> in your health if they occur?	1	2	3	4
21. <u>Do something</u> that will relieve your symptoms?	1	2	3	4
22. Evaluate how well a remedy works?	1	2	3	4

Purpose of the Study

- This study aimed to explore and identify new factors affecting women with heart failure, therefore, a mixed methods approach to encompass both quantitative and qualitative data was warranted.
- The primary aim of the study was to <u>identify key differences</u> in women who displayed an *adequate* (≥ 70) level of heart failure self-care maintenance behaviors as compared with women who scored *inadequately* (≤ 69) on the Self-Care of Heart Failure Index (SCHFI) version 6.2.

Research Questions

Quantitative

- What is the distribution of self-care maintenance scores in women with heart failure?
- Is there a relationship between adequate and inadequate scores of heart failure self-care maintenance and adequate and inadequate scores in heart failure self-care confidence?

Qualitative

- What are the different factors that can be identified which facilitate or impede heart failure self-care behaviors in women scoring adequately and inadequately on the SCHFI?
- What are the motivating factors that influence heart failure self-care behaviors in women who score adequately and inadequately on the SCHFI?

Mixed Methods

• In what ways do the interview data that investigate self-care in women with heart failure help to explain the quantitative results about self-care maintenance and the influence of self-care confidence in both those scoring adequately and inadequately as reported on the SCHFI?

Significance and Novelty

Significance

- Self-care maintenance is at the foundation of self-care.
- Little is known about self-care maintenance independent of other aspects of heart failure self-care.
- Women are historically underrepresented in research studies
- Self-care maintenance is a precursor to symptom perception and self-care management.

Novelty

- First study to exclusively focus on heart failure self-care maintenance in women using a convergent mixed methods design.
- Previous studies have included both genders and included all aspects of heart failure self-care.
- Lower percentage of women than men.

Review of the Literature

- Databases searched: CINAHL, PubMed, PsycINFO, Cochrane, and ProQuest.
- Years: 1990 August 2016
 - Emphasis placed on the years 2011 2016.
- Key words: heart failure, women, female, gender differences, quantitative, qualitative, mixed methods, and self-care.

Heart Failure Self-Care: Notable Quantitative Studies

- Typologies of Heart Failure (Riegel et al., 2011)
 - Novice low self-care confidence
 - Experts- High self-care confidence
 - <u>Inconsistent</u> Few limitations in activity with high levels of confidence
- Social support influences heart failure self-care behaviors (Cené, 2013; Graven et al., 2015)
- Women tend to have lower self-care maintenance scores than men and a gender specific approach to improving heart failure self-care is needed (Stamp, 2014).

Heart Failure Self-Care: Notable Qualitative Studies

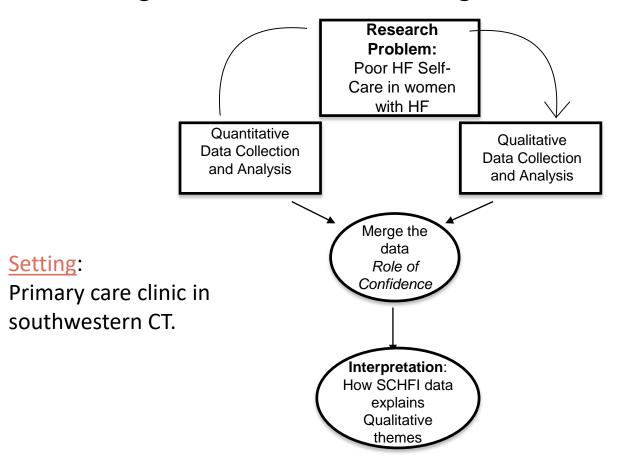
- Gender influences heart failure self-care through overwhelming physical limitations, changes to social and gender roles, and the importance of social support (Thomas & Clark, 2011).
- Women tend to seek guidance and advice from family, friends, and health care providers (Riegel, et al., 2010).
- Involvement of caregivers, financial capacity, and lifestyle changes also influence heart failure self-care (Strachan, et al., 2014).
 - Women tend to support others, rather than be supported.

Heart Failure Self-Care: Notable Mixed Methods Studies

- Expertise in heart failure: poor, good, or expert (Riegel, et al., 2007).
 - Classification based on qualitative interviews
 - Experts showed evidence of being "active" in their self-care behaviors.
- "Inconsistent" classification emerged (2008): range of attitudes and skills but lacked self-care confidence.
- Individuals with heart failure assume an active or passive role in their self-care behaviors (Dickson, et al., 2011).

Methods

• Convergent, mixed methods design (Creswell, 2015).



Study Procedures for Data Collection

- Data collection occurred from January 2015 to April 2016.
 - Informed consent
 - SCHFI
 - Demographic Survey
 - Qualitative Interview (Audio Recorded)
 - Participants scoring \geq 70 were considered "Adequate"
 - Participants scoring \le 69 were considered "Inadequate"
- Data were collected either in person (n=11) or via telephone (n=20).
 - All consenting participants completed the SCHFI and Demographics survey
 - 24 participants completed the qualitative interview

Study Procedures for Data Analysis

- Quantitative:
 - Descriptive statistics means, standard deviations
 - Correlations
 - Quadratic Regression
- Qualitative:
 - Content analysis (Krippendorf, 2013)
- Mixed Methods:
 - Side-by-side comparison of quantitative and qualitative data

Results - Quantitative

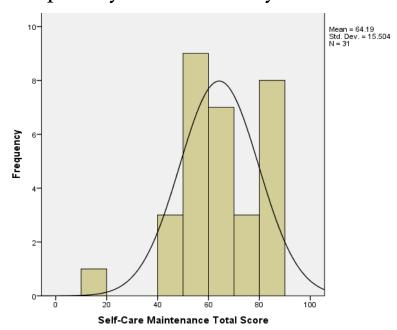
- N = 31
 - Adequate (n = 11)
 - Inadequate (n = 20)
 - Mean age = 57.9
 - Sample was predominantly:
 - Black (77%)
 - Unwed (86%)
 - Had a high school level education (74%)
 - Lived with someone else (68%)
 - Unemployed (77%)

Split Demographic Profile

	Adequate (≥ 70) (N)	Inadequate (≤ 69) (N)	P- value
Age	57.7	58.1	.58
Years with HF	5.3	5.4	.66
Race – Black	8	14	
Unemployed	10	14	
Unwed	8	13	
HS education	8	15	
Co-Habitant	6	15	

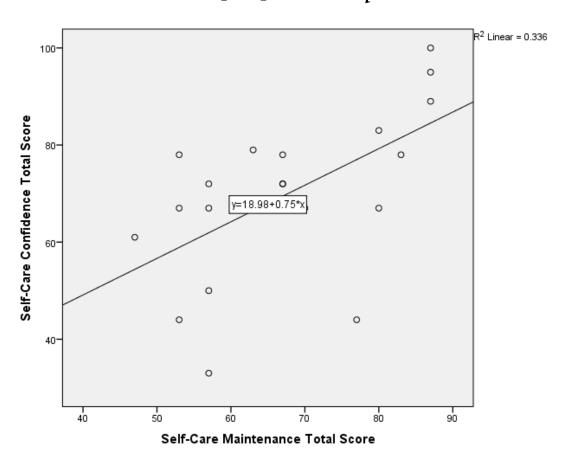
Research Question One

- Means, percentages, and standard deviations
 - Mean value for the self-care maintenance score was 61.1 (± 15.5) with a range of 17-87.
 - The majority of the participants in this study (70%, n = 22) scored inadequately as defined by the SCHFI.



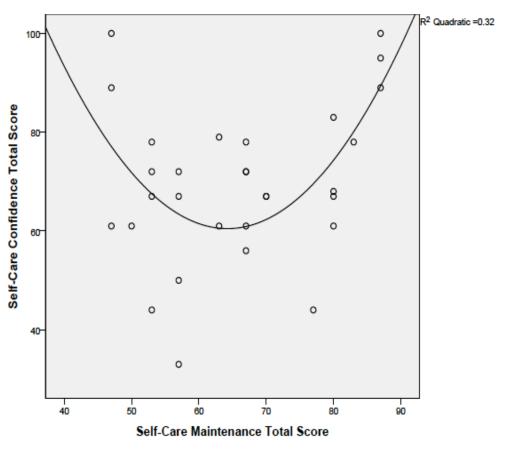
Research Question Two

• <u>Pearson's correlation</u>: r [29] = .19, p = .30



Research Question Two

• Quadratic Regression: $R^2 = 32\%$, F = 6.4, df = 2, 27, p = .005



Research Question Three

Factors that *facilitate* heart failure self-care maintenance behaviors:

Everyday and Always: The importance of routine and compliancy

"So what do you want to know? I take my medicine. I keep my appointments. My health is very important to me. I walk every day. I do my exercises. I eat properly. Right? I follow my diet and I see the doctor. I don't know what else. That pretty much covers everything. [80].

Strong Connections: Relationships with the Health Care Provider

"The visiting nurse helps me a lot. She puts my medicine in the box, seven days."

[63]

In Tune: The certainty of heart failure self-care behaviors

"We're making these habits. She [the participant] is very in tune with herself and her body with recognizing the warning signs." [67].

Research Question Three

Factors that *impede* heart failure self-care maintenance behaviors:

"I don't seem to have a problem" - Denial and Misunderstanding

"I don't seem to have a problem." [47]

"My ankles swell sometimes...I don't know why that happens." [47]

<u>It's very frustrating." – Changes to Lifestyle</u>

"As being a very active person in the past, I used to walk, I used to run, I used to ski and it's very frustrating not being able to do anything." [83]

"I'm juggling a lot right now." – Managing Co-Morbidities

"I'm juggling a lot right now." [67]

"I got diabetes too and I'm trying to correct that." [87]

Research Question Four

"I want more time with them" - The influence of friends and family

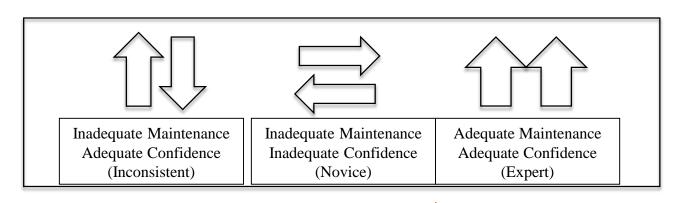
"My son...I just try to do what I need to do, you know, so that I can live longer and be here for him, you know. He's only 20, so, you know, I want to see him get married."

"I'm not ready."

"I'm not ready to give up! I get by, slowly and maybe not like I used to, but I get by."

"Life in general keeps me going...My motivation? I just want to be alive."

Research Question Five



"I've been dealing with it for 14 years now so I'm pretty strong." [57]

"Well, I take my medicine like I'm supposed to,"[57] "I try to not drink sodas but I guess soda is better than nothing. Is it?" [67] "My husband, he has high blood pressure, so he has to watch what he's doing too. We've been doing this for some years." [83]

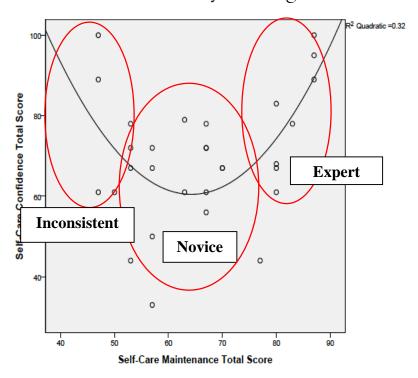
Discussion

Typologies of Heart Failure (Riegel et al., 2011)

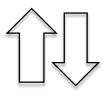
Novice – Low self-care confidence

Experts- High self-care confidence

<u>Inconsistent</u> – Few limitations in activity with high levels of confidence



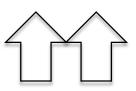
Active and Passive Typologies



Inadequate Maintenance Adequate Confidence (Inconsistent)



Inadequate Maintenance Inadequate Confidence (Novice)



Adequate Maintenance Adequate Confidence (Expert)

"I've been dealing with it for 14 years now so I'm pretty strong." [57]

"Well, I take my medicine like I'm supposed to,"[57]

"I try to not drink sodas but I guess soda is better than nothing. Is it?" [67] "My husband, he has high blood pressure, so he has to watch what he's doing too. We've been doing this for some years." [83]

Passive

Active

Typology Characteristics

	Inconsistent $(N = 5)$	Novice (N = 18)	Expert (N = 8)
Age (mean)	60	57.2	57.9
Years with HF (mean)	3	6.5	4.4

	Inconsistent (N = 5)	Novice (N = 18)	Expert (N = 8)	
Race				
White	3	3	3	
Black	1	15	5	

Implications

Education: Importance of gender specific needs and interventions.

Practice: Nurses as a health promoter for both in and outpatient settings.

Research: RCTs, large sample sizes, deeper understanding of typologies of heart failure and individual patient characteristics.

Policy: Reducing healthcare costs associated with HF hospitalizations.

Conclusion

- Use of the Mixed Methods designed allowed for a deeper understanding of the quantitative SCHFI score.
- Layering of previously discovered typologies and patient characteristics.
- Understanding both positive and negative influences on heart failure self-care.

Thank you!

