

# PATIENT PERCEPTIONS OF WORSENING HEART FAILURE SYMPTOMS: AN EXPLORATORY ANALYSIS

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*ThinkofYourHeartFirst - TYHF*



# BACKGROUND

- ♥ Annually in the U.S.:
  - ~ 1-million HF hospitalizations
  - ~ 6.5-million hospital days
  - > 11-million physician visits
  - > \$40-billion
- ♥ Hospitalizations:
  - Unplanned occur disproportionately
  - ~ 1 in 4 persons are readmitted within  
30 days of hospital discharge
  - Independent risk factor for death



# Symptom Management Issues

- ♥ Inconsistent HF self-care research findings
- ♥ Wide range of symptoms, perceptions & attributions
  - treatment side effects
  - co-morbidities
  - overlapping & unresolved symptoms
  - aging processes
  - symptoms wax and wane over time
  - low somatic awareness
  - variation in symptom responses



# PURPOSE

To explore symptom perceptions and self-care behaviors leading up to hospitalization for acute decompensated heart failure.



# METHODS

- ♥ Cross-sectional design
- ♥ 60 patients hospitalized for acute decompensated heart failure (ADHF)
- ♥ Large, urban Midwestern university medical center
- ♥ Semi-structured interviews were conducted using the Day Reconstruction Method (Kahneman et al., 2004) to enhance recall of retrospective symptom experiences.



# Interview Questionnaire Domains

- ♥ Symptoms experienced
- ♥ Symptom interpretation & attributions
- ♥ Symptom relief self-care behaviors
- ♥ Symptom evaluation lay consultations
- ♥ Symptom reporting to health care providers
- ♥ Symptom reporting response by health care providers

## Demographic summaries of study sample (N=60).

Variable	n	%	Variable	n	%
Gender			Marital Status		
Male	33	55.0	Married	29	48.3
Female	27	45.0	Not Married	31	51.7
Age (Years)			Children age <18 years (n=59)		
20 - 55	18	30.0	Yes	12	20.0
56 - 89	42	70.0	No	47	78.3
Race			Employed (n=56)		
White	33	55.0	Yes	8	13.3
Black	25	41.7	No	48	80.0
Multi-racial	2	3.3	Income Adequacy (n=56)		
Hispanic/Latino/Spanish			Inadequate	31	51.7
Yes	4	6.7	Adequate	25	41.7
No	56	93.3	Health Insurance (n=54)		
Education (n=59)			Private	11	18.3
High School or Less	26	43.3	Public/Other	43	71.7
College	33	55.0			

# Symptoms Experienced

- ♥ On average, patients experienced  $3.77 \pm 1.67$  (range=0-8) symptoms before hospitalization
- ♥ Shortness of breath, swelling, fatigue
- ♥ Symptoms did not significantly vary by
  - Hospital length of stay
  - Length of time diagnosed with HF
  - Previous hospitalization for ADHF



### Symptoms experienced prior to HF hospitalization (N=60).

Variable†	n	%
Dyspnea	42	70.0
Orthopnea	32	53.3
Fatigue or feeling tired	31	51.7
Paroxysmal nocturnal dyspnea	20	33.3
Swelling of ankles, hands, feet	17	28.3
Feeling anxious	12	20.0
Chest pain or discomfort	12	20.0
Excessive weight gain due to edema	9	15.0
Upset stomach (nausea, vomiting, indigestion)	7	11.7
Feeling bloated	5	8.3
Exercise Intolerance	4	6.7
Loss of appetite (cachexia symptom)	4	6.7
Unusual or unexplained increase in coughing	4	6.7
Having to wake up and use the bathroom at night	4	6.7
Palpitations or feeling irregular heartbeat	3	5.0
Sweating	2	3.3
Dizziness	2	3.3
Weight loss	1	1.7
† Multiple Responses Possible		

# Symptom Attributions

- ♥ 37 (61.7%) patients experienced early warning signs of evolving symptoms
  - Only 6 (10%) patients attributed these to their heart.
- ♥ 25 (41.7%) patients attributed symptoms to:
  - Diet: 18.3%
  - Medications: 13.3%
  - Weight: 6.7%
  - Sleep: 5%
  - Exercise: 3.3%
- ♥ Patients who had lived with HF under 5 years were less likely to consider changes to medication as a cause of symptoms than those diagnosed more than 5 years ago ( $p=.048$ )




# Self-care Strategies for Symptom Relief

- ♥ 26 (43.3%) patients engaged in self-care strategies to relieve symptoms
  - Self-medication was most common strategy
- ♥ Self-medications: Lasix, Nitroglycerin, prescription analgesics, Metformin, Aspirin, Oxygen, and prescription breathing treatments.
- ♥ Less commonly, raising the head of the bed, resting, walking, and diet changes were attempted to relieve symptoms.



# Symptom Evaluation Lay Consultations

- ♥ 47 (78.3%) patients said they talked to others about their symptoms before hospitalization
  - ♥ 43 (91.5%) lay consultations were face-to-face as symptoms occurred.
- ♥ Most often, patients discussed symptoms with spouse/life partner (55.3%) or adult children (23.4%).



# Lay Consultant Symptom Attributions

- ♥ Symptom attributions were given by 24 (51%) lay consultants.
- ♥ Lay consultants attributed patients' symptoms to their heart (70.8%), respiratory disorders (37.5%), or diabetes (33.3%).



# Lay Consultant Symptom Advice

- ♥ 39 (83%) lay consultants gave patients advice on what to do for symptoms;
  - 15 lay consultants gave advice, but did not offer any symptom attributions.
- ♥ Most often, lay consultants advised patients to seek professional care for symptoms.
- ♥ 30 (76.9%) patients took the advice given by others, with over 80% of patients seeking care within 1 day.
  - 20% delayed from 2 to more than 5 days.

# Timeliness of Symptom Reporting & Health Care Provider (HCP) Response

HCP Contact to ED	HCP Contact to Clinic	Clinic to ED
1 – 6 hours: 10 Pts.	10 Minutes: 1 Pt.	Within 20 Minutes: 1 Pt.
1 – >14 Days: 8 Pts.	2 Hours: 1 Pt.	Within 2 Hours: 5 Pts.
	1 – 3 Days: 7 Pts.	Within 6 Hours: 1 Pt.
	1 Week: 1 Pt.	With $\geq$ 20 Hours: 2 Pts.
	5 Weeks: 1 Pt.	



# DISCUSSION

- ♥ Patients tended to experience typical HF symptoms.
- ♥ While nearly  $2/3$  of the patients had early warning signs, few attributed these signals to their heart, and efforts focused on thinking of their heart first are needed.
- ♥ Patients who had lived with HF longer might have undergone more prescriptive medication changes or self-adjustments.





# DISCUSSION

- ♥ Nearly half of the patients engaged in self-care strategies to relieve symptoms before seeking professional treatment.
  - Further study needed on self-care strategies used for symptom relief
- ♥ Most lay consultants advised patients to seek professional care, even in the absence of symptom attributions, stressing the importance of care giver involvement in HF self-care.