The Heart Failure Patient as Partner in Care

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Disclosures

- None
Learning Objective

• Outline a patient-centered approach to involving heart failure (HF) patients and their families in the short- and long-term treatment plan
Heart Failure (HF) in the U.S. Today

Incidence of HF:
- ≥ age 65, 10/1,000
- ≥ age 80, ~12% of men and women have HF

Prevalence: 5.1 M US adults ≥ 20 years have HF
- By 2030, ↑6% (>8 M)
- Most at risk?
  - Black, obese, hypertensive (lifetime risk doubles for BP >160/90 mm Hg vs. BP <140/90 mm Hg)

- Annual total costs for HF estimated to increase from $31 billion in 2012 to $70 billion in 2030
- Costs are due to hospitalizations: 1 in 4 HF patients is readmitted to a hospital within 30 days and almost 50% are readmitted within 6 months.

HF Patients Face Challenges

- Older age
- Low income
- Live alone, socially isolated
- Poorly educated
- Depressed, anxious
- Few periods with minimal or no symptoms

- Functionally compromised
- Low energy
- Multiple comorbid conditions with overlapping symptoms
- Cognitive impairment is common and often subtle
HF Rarely Occurs Alone; Comorbid Conditions are Common

- Pulmonary disease (COPD, bronchiectasis, chronic respiratory failure, other lower respiratory disease, asthma)
- Osteoarthritis
- Thyroid Disease
- Alzheimer’s Disease/Dementia, Cognitive Impairment
- Chronic Renal Failure
- Osteoporosis
- Depression, Anxiety
- Diabetes Mellitus
- Hypertension
- Anemia
- Sleep-disordered Breathing
- Liver Dysfunction
- Skeletal Myopathy
ARS Question #1

Who provides most of the care to HF patients?

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>25%</td>
<td>1. Cardiologists</td>
</tr>
<tr>
<td>25%</td>
<td>2. Nurse practitioners</td>
</tr>
<tr>
<td>25%</td>
<td>3. General internists</td>
</tr>
<tr>
<td>25%</td>
<td>4. Patients</td>
</tr>
</tbody>
</table>
95% of Care for HF and other Chronic Illnesses is Performed by Patients, not Providers

Funnell & Anderson, 2000; Safford et al, 2005; Russell, Suh, & Safford, 2005
Each Condition has a Unique Set of Symptoms and Management Requirements

Each adds complexity for patients and providers

- “I can tell when my sugar is too high or too low... no problem, I can fix that, I don't even have to stick myself anymore... and I know the bones; they don’t work so well anymore... but I get tired easy... is that the heart or what is it?... I don't know... mostly I just wait to see if it passes or not”.
Different Instructions for Different Illnesses

- **Arthritis**: non-steroidal anti-inflammatory drug (NSAID) for pain (contraindicated in heart failure)
- **Asthma**: bronchodilator for shortness of breath (in heart failure, take an extra diuretic)
- **Irritable bowel disease**: Drink at least 8 cups of non-caffeinated fluids per day (contraindicated in heart failure)
- **Diabetes**: low glycemic index foods (in heart failure low sodium, in coronary artery disease low fat...
9.4. Other Multiple Comorbidities

Although there are additional and important comorbidities that afflict patients with HF as shown in Table 31, how best to generate specific recommendations remains uncertain, given the status of current evidence.
We must help patients become experts in their own self-care
What is Self-Care?

- A naturalistic decision-making process involving...
  - the choice of behaviors that maintain physiologic stability
    - (self-care maintenance)
  - the response to symptoms when they occur
    - (self-care management)

Riegel, Carlson, Moser, et al 2004
Self-Care of Heart Failure Model

Self-Care Maintenance

Symptom monitoring and treatment adherence

Self-Care Confidence

Self-Care Management

Symptom Recognition

Symptom Evaluation

Treatment Implementation

Treatment Evaluation

Riegel, Carlson, Moser, et al 2004
Self-Care Maintenance: those behaviors used by patients with a chronic illness to maintain physical and emotional stability.

Self-Care Monitoring: the process of observing oneself for changes in signs and symptoms.

Self-Care Management: the response to signs and symptoms when they occur.

Riegel, Jaarsma, Strömberg, 2012
Specific Self-Care Behaviors

- Diet
- Exercise
- Sleep
- Medication taking
- Tobacco use
- Alcohol use
- Stress management

Self-care Monitoring
- Monitoring behaviors
- Symptom perception, recognition, attribution

Self-care Management
- Decision-making
- Behavior taken in response to signs/symptoms
- Ability to judge how well a response worked
ARS Question #2

Most patients with a chronic illness make thoughtful, careful, rationale decisions about these self-care behaviors.

<table>
<thead>
<tr>
<th></th>
<th>1. True</th>
<th>2. False</th>
</tr>
</thead>
<tbody>
<tr>
<td>50%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Naturalistic Decision-Making

Poor Self-Care Decisions

Patient Identified Factors

- Ran out of medication
- Lapses in low-salt diet
- Got sick (e.g., cold)
- Worry or stress
- Missed or skipped medication

How Can We Engage Patients and Families in Self-Care?
Engaging Patients and Families

What can we influence?

1. Medication adherence

2. Motivating engagement in healthy routines (e.g. diet and exercise patterns)

3. Engaging caregivers to contribute to self-care
A Union Official Told Reporters that the Train's Driver may have Fallen Asleep

Chicago Train Derailment March 2014
Conceptual Model of How Poor Sleep Influences HF Self-Care and Outcomes

Riegel & Weaver, 2009
Poor Medication Adherence in HF Patients

- Most investigators cite rates of medication nonadherence between 40% to 60%

Wu et al, 2008
Patient 5 - 57.6% Consistency

Patient 6 - 1.0% Consistency

Patient 7 - 0.1% Consistency

Patient 1 - 93.4% consistency

Patient 2 - 79.9% consistency

Patient 3 - 61.7% consistency

Patient 4 - 40.0% consistency

Riegel & Knafl 2013
Poor Medication Adherence was the Best Predictor of Hospitalization

Who are the patients with poor medication adherence?

- Three interaction risk factors for poor adherence were identified:
  - More comorbid conditions + more daily medicines
  - Older age + poorer sleep quality
  - Less experience with HF + poorer sleep quality

- Patients had 0-3 risk factors

- Odds for poor adherence increased by 2.6 times with a unit increase in the number of risk factors (OR=2.62, 95% CI 1.78-3.86, P<0.001)

Knafl & Riegel, under review
1. Polypharmacy

- Defined as the chronic use of 5 or more medications daily
  - Average 10/day (0-25 range)
  - 96% were taking a drug known to cause daytime sedation (0-7)
- Medication Reconciliation: the process of comparing a patient’s medication orders to all of the medications that the patient has been taking

Kripalani et al, 2007; Christensen & Lundh, Cochrane review, 2013; Graabaek & Kjeldsen, 2013
Medication Reconciliation in Acute Care

- Clinically significant unintentional discrepancies affect only a few patients
- These interventions are poorly standardized
- Medication reconciliation when bundled with other interventions (e.g., transitional care) may improve discharge coordination

Kwan et al 2013; Onder et al, 2013
2. Poor Sleep Quality

- **Defined**: insufficient total sleep time, delayed sleep onset, sleep fragmentation/disruptions/arousals, sleep inefficiency
- Poor sleep quality causes *death of brain cells* important for mood, thinking, attention, memory, and learning
- **Causes** of poor sleep quality in HF:
  - Age
  - Nocturia
  - Insomnia
  - Comorbid illnesses
  - Sedating medications
  - Sleep apnea

Krystal & Edinger, 2008; Lim & Dinges, 2010; Baddeley, 1986; Norman & Shallice, 1986
Sleep Apnea in HF

- 10% of the general population and >50% of HF patients
- Obstructive sleep apnea (OSA) most common in milder HF (NYHA I/II)
- Central sleep apnea (CSA) most common in more severe HF (NYHA III/IV)
- Sympathetic stimulation of HF → fewer complaints of sleepiness in HF patients

Flores, 2013; Kazimierczak et al, 2013
Poor sleep is common in our patients (and ourselves).

What should we do about it?

ARS Question # 3

1. The only evidence-based treatment available is CPAP for sleep apnea.

2. Exercise and relaxation have been shown to improve sleep quality.

3. It’s an irritant but not really important enough to focus on.
Interventions for Improving Sleep
Motivational Interviewing

To motivate engagement in healthy routines (e.g. diet and exercise patterns)
Illness is a Great Motivator
Motivational Interviewing

- Educating is effective for people who perceive a need to know or want to change
- Motivating is needed for those who do not see a problem or do not wish to change

“People are generally better persuaded by the reasons which they themselves have discovered than by those which have come into the minds of others”

Pascal’s Pansees, 17th Century
“A directive, client-centered approach for initiating behavior change by helping clients to explore and resolve ambivalence.”

Dissonance between values and behavior

Ambivalence about change is normal

Motivation for change is malleable and relational

Natural motivation for growth

Motivational Interviewing

Miller, 1996
“Dancing, not wrestling”
First Motivational Interviewing Study

- Enrolled 15 HF patients in hospital
  - Typically female, Caucasian, high school educated, living alone, NYHA II

Data collected at baseline and 3 months

Quantitative analysis of individual change scores

Proportion of patients who improved with the intervention

71.4% had evidence of improved self-care after 3 months of intervention

Qualitative analysis of taped intervention sessions

Mechanism of intervention effectiveness

Advanced practice nurse visited patients in their homes 3.0 ± 1.5 times

Riegel et al, JCN 2006
Mechanism of Intervention Effectiveness

Communication
- Reflective listening
- Expressing empathy

Making it fit
- Acknowledging cultural beliefs
- Overcoming barriers and constraints
- Negotiating a plan of action

Bridging the setting transition
- Providing information
- Building skills
- Activating support resources

Riegel et al, JCN 2006
Motivational Interviewing Tailored Intervention: MITI-HF

Randomization 2:1 using minimization balancing NYHA and gender

**Intervention**
Participants received patient education materials while in the hospital and a behaviorally based, motivational interviewing tailored program at home and by phone for 90 days from a HF specialist nurse

**Usual Care**
Participants received patient education materials while in the hospital and usual care after discharge from the hospital

**Study outcomes at baseline and 90-days**
Self care: Self Care of Heart Failure Index [primary]

Quality of life: Kansas City Cardiomyopathy Questionnaire

Symptom burden: HF Somatic Perception Scale
## MITI-HF: Baseline Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>Overall (N=67)</th>
<th>Control (N=26)</th>
<th>Intervention (N=41)</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>62 (13.4)</td>
<td>63 (12.6)</td>
<td>60 (13.9)</td>
<td>0.397</td>
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<tr>
<td>Female Gender</td>
<td>20 (29.9)</td>
<td>5 (19.3)</td>
<td>15 (36.6)</td>
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<tr>
<td>Race</td>
<td></td>
<td></td>
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<td>0.128</td>
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<tr>
<td>Black</td>
<td>36 (53.7)</td>
<td>17 (65.4)</td>
<td>19 (46.3)</td>
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<tr>
<td>White</td>
<td>31 (46.3)</td>
<td>9 (34.6)</td>
<td>22 (53.7)</td>
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<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td>0.233</td>
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<tr>
<td>&lt;High School</td>
<td>42 (62.7)</td>
<td>14 (53.9)</td>
<td>28 (68.3)</td>
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<tr>
<td>College/Grad School</td>
<td>25 (37.3)</td>
<td>12 (46.2)</td>
<td>13 (31.7)</td>
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<tr>
<td>Ischemic HF Etiology</td>
<td>20 (29.9)</td>
<td>9 (34.6)</td>
<td>11 (26.8)</td>
<td>0.299</td>
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<tr>
<td>Total comorbidities</td>
<td>6 (2.9)</td>
<td>6 (3.6)</td>
<td>6 (2.4)</td>
<td>0.564</td>
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<tr>
<td>NYHA Functional Class</td>
<td></td>
<td></td>
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<td>0.125</td>
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<tr>
<td>Class I/II</td>
<td>11 (16.4)</td>
<td>2 (7.7)</td>
<td>9 (22.0)</td>
<td></td>
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<tr>
<td>Class III/IV</td>
<td>56 (83.6)</td>
<td>24 (92.3)</td>
<td>32 (78.1)</td>
<td></td>
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</table>
MITI-HF: Preliminary Results

Both groups improved but after adjusting for group differences, the MI group improved more, $P=0.02$.
Activities Contributed by Caregivers

Caregiver’s contribution to heart failure (HF) patient’s self-care

Direct (hands on) activities
- Measurements, Tasks

Indirect (hands off) activities
- System navigators
- Interpersonal skills

Buck et al, 2013
Recurring theme: “searching for support”

- Need of support from friends, family, formal services and health professionals and need to be adequately prepared for the disease
- Caregivers complained about knowledge deficits regarding the disease and its management and did not know the importance of behavioral management strategies such as *weight monitoring, physical activity, salt and fluid restriction*
- … even after 18 months of caregiving!

Kang, Li, Nolan, 2011
Validity and Reliability of the Caregiver Contribution to Self-care of Heart Failure Index

Ercole Vellone, RN, MSN; Barbara Riegel, RN, DNSc, FAHA, FAAN; Antonello Cocchieri, RN, MSN; Claudio Barbaranelli, PhD; Fabio D’Agostino, RN, MSN; Dale Glaser, PhD; Gennaro Rocco, RN, MSN; Rosaria Alvaro, RN, MSN

Background: Caregivers make an important contribution to the self-care of patients with heart failure (HF), but few instruments are available to measure this contribution. Objective: The objective of this study was to test the psychometric properties of the Caregiver Contribution to Self-care of Heart Failure Index (CC-SCHFI), an instrument derived from the Self-care of Heart Failure Index version 6.2. The CC-SCHFI measures the contribution of caregivers to the self-care maintenance and self-care management of HF patients, as well as their confidence in their ability to contribute to the patients' HF self-care. Methods: A cross-sectional design was used to study 291 Italian caregivers whose HF patients were cared for in 17 cardiovascular centers across Italy. Caregivers completed the CC-SCHFI and...
Caregiver Contributions to Self-Care Maintenance

(1) Weigh Daily
(2) Check ankles for swelling
(3) Try to avoid getting sick (get a...
(4) Do some physical activity
(5) Keep doctor or nurse...
(6) Eat a low-salt diet
(7) Exercise for 30 minutes
(8) Remember to take medicines
(9) Ask for a low-salt items when...
(10) Use a system (pill-box,...

Never or rarely  □ Sometimes  □ Frequently  □ Always or daily

Vellone et al under review
Caregiver Contributions to Self-Care Management

(11) If the person you care for had trouble breathing or…

- I did not recognize it
- Not quickly
- Somewhat Quickly
- Quickly
- Very Quickly

(12) Reduce salt in the diet

(13) Reduce fluid intake

(14) Take an extra...

(15) Call your doctor or…

- Never or rarely
- Sometimes
- Frequently
- Always or daily

Vellone et al under review
ARS Question # 4

Which of the following is the major issue that caregivers are struggling with?

1. Monitoring and treatment of fluid retention
2. Medication adherence
3. Communication with providers
4. When to adjust diet and fluid intake
Without symptom monitoring and early response...
Caregiver Contributions to Self-Care Confidence

(17) Prevent HF symptoms?
(18) Follow the treatment advice?
(19) Evaluate the importance of HF symptoms?
(20) Recognize health changes in the person you care for?
(21) Do something that relieves HF symptoms?
(22) Evaluate how well a remedy works?

Vellone et al under review
Confidence was the *Major Factor* Predicting Caregivers’ Contributions to HF Patients’ Self-care

Vellone et al under review
How Can We Improve Caregiver (and Patient) Self-Care Confidence?

Simplify the treatment regimen
- Complexity decreases confidence in the ability to perform self-care

Patient education
- Prior clinical trials with caregivers have shown that education can improve caregivers’ confidence and consequently outcomes in patients and caregivers
- Patient education probably improves confidence even more than knowledge

Self-Efficacy: Confidence in the Ability to Perform a Specific Task & Achieve a Desired Result

Vicarious experience
- Facilitate exchange of experiences between caregivers contributing highly to patient’s self-care with those who are not contributing well

Verbal persuasion
- Convincing caregivers of their ability to cope with the caregiving demand

Emotional arousal
- Empathy in the relationship between the caregiver and the provider

Bandura, 1977
Summarizing Effective Ways of Engaging Patients and Families

1. Focus on medication adherence
   - Simplify the regimen
   - Promote sleep to help patients think better

2. Use motivational interviewing
   - Effective in improving routine self-care behaviors (e.g. diet and exercise)

3. Engage caregivers to improve patient self-care
   - Simplify the treatment regimen
   - Educate to improve confidence
Self-care is not about self-indulgence, it’s about self-preservation.

—Audrey Lorde

EmpowerLounge.com