1) What is Heart Failure?
2) What is “Disease Management?”
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Heart Failure as a Clinical Syndrome

Egyptian physicians (1600 BC): the heart is over-flooded, bored, kneeling and unable to speak such that the flesh is tired as a result.

Hippocrates (467-377 BC): description of the clinical syndrome of heart failure, relating shortness of breath and sputum production to the failing heart.

Aretaeus of Cappadocia (150 BC): made connections between gravity and swelling.

Heart Failure as a Circulatory Disorder

Harvey (1628)
HEART FAILURE FROM ALTERED ARCHITECTURE

Giovanni Maria Lancisi (1745)

Regurgitation to Dilatation to Weakness

HEART FAILURE FROM ABNORMAL HEMODYNAMICS

Ernest Starling (1918)

↑ LVEDV volume ↑ cardiac output

HEART FAILURE AS A DISORDER OF BIOCHEMICAL ABNORMALITIES

Energy Starvation (1950s): Robert Olson - impaired energy consumption by contractile machinery

Depressed Contractility (1950s): Stanley Sarnoff - cardiac output not exclusively a function of LVEDV - contractility is critical.

Eugene Braunwald (1960) - contractility reduced in heart failure.

Neurohormonal Response (1983): Peter Harris - responses to exercise and hemorrhage are harmful in heart failure.

CONSENSUS (1986) - ACEI.
HEART FAILURE AND MALADAPTIVE HYPERTROPHY

Remolding (1985):

Reversion to fetal phenotype (1987).


HEART FAILURE, GENOMICS AND EPIGENETICS

First Molecular Cause of Familial Hypertrophy (1990):

Cytosine methylation implicated in familial cardiomyopathies (2005).

Genotype positive-phenotype negative cardiomyopathy (2011).


HEART FAILURE: WHERE ARE WE NOW?

Genetic
epigenetics
Clinical
syndrome
Maladaptive
hypertrophy
Disordered
fluid balance
Abnormal
hemodynamics
Altered
architecture
Circulatory
disorder
Biochemical
abnormalities

Katz
Circulation
HF
2008;
1:63-87.
HEART FAILURE: WHERE ARE WE NOW?

Still a clinical syndrome, wherein symptoms are integral, self-care is critical, and most patients get help with management.

OUTLINE:

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HEART FAILURE DISEASE MANAGEMENT TAXONOMY

Higher ranking if patient and caregiver are central to the intervention

Embedded continuous quality improvement process of following clinical guidelines and practice protocols, measuring outcomes, providing feedback to clinicians, and revising protocols as appropriate.
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PATIENT-CENTERED HEART FAILURE CARE

Patient-centered care: “providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.”

HFSA 2010 Guideline Executive Summary

Executive Summary: HFSA 2010 Comprehensive Heart Failure Practice Guideline

Patient-centered mentioned explicitly (Section 8):
- Symptom management
- Learning preferences
- Care preferences
- Time/quality trade offs
Patient-centered mentioned twice:
1. Citation of NQF work on care coordination.
2. Time will be required to learn from patient-centered research

Patient preferences mentioned with respect to end-of-life care.

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2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure

Patient-centered: Ø
Patient preferences:
- Regarding place of death only

---

2014: AHA Changed the “Patients’ Bill of Rights” to the “Patient Care Partnership”
- High quality hospital care.
- A clean and safe environment.
- Involvement in your care.
- Protection of your privacy.
- Help when leaving the hospital.
- Help with your billing claims.

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http://www.aha.org/content/00-10/pcp_english_030730.pdf
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OUTLINE:

WHAT IS HEART FAILURE SELF-CARE?

Self-Care of Heart Failure Model

Self-Care Confidence

WHAT IS HEART FAILURE SELF-CARE?

Riegel et al. (including Lee) Circulation 2009

Riegel, Lee, & Dickson Nature Cardiology Reviews 2011
WHAT IS HEART FAILURE SELF-CARE?

Maintenance – routing adherence and health preservation behaviors aimed toward preventing exacerbations
  • medication/dietary adherence, keeping scheduled appointments, exercise et al.

Monitoring – routine assessment of signs and symptoms of worsening heart failure.

Management – behaviors in response to symptoms
  • Self-management – self-initiated behaviors aimed toward ameliorating symptoms.

Consulting behaviors – contacting a provider

Confidence – self-efficacy related to self-care behaviors

WHAT IS HEART FAILURE SELF-CARE (DISAMBIGUATION)?
### What is Heart Failure Self-Care?

<table>
<thead>
<tr>
<th>Major self-care activity</th>
<th>Activities required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Becoming knowledgeable about heart failure</td>
<td>• Knowing that one has heart failure and what the condition is (and what it is not)</td>
</tr>
<tr>
<td></td>
<td>• Determining how to get appropriate information at an understandable level</td>
</tr>
<tr>
<td></td>
<td>• Understanding the links between self-care activities and symptoms</td>
</tr>
<tr>
<td></td>
<td>• Understanding the meaning of escalating symptoms</td>
</tr>
<tr>
<td></td>
<td>• Understanding the requirements for self-care</td>
</tr>
<tr>
<td>Adhering to medication and diet recommendations</td>
<td>• Taking medications as prescribed and usually chronically; remembering on a daily basis; knowing what to do if forgot a dose</td>
</tr>
<tr>
<td></td>
<td>• Distinguishing between side effects, adverse effects, and normal effects</td>
</tr>
<tr>
<td></td>
<td>• Knowing not to stop medications without discussing with care provider</td>
</tr>
<tr>
<td></td>
<td>• Bearing the potential financial burden of multiple medications</td>
</tr>
<tr>
<td></td>
<td>• Dealing with polypharmacy</td>
</tr>
<tr>
<td></td>
<td>• Learning how to monitor sodium intake, choose lower-sodium foods</td>
</tr>
<tr>
<td></td>
<td>• Learning how to follow a heart healthy diet</td>
</tr>
<tr>
<td>Getting exercise</td>
<td>• Understanding how much, how often, what type</td>
</tr>
<tr>
<td></td>
<td>• Determining how to start if never exercised or are sedentary</td>
</tr>
<tr>
<td></td>
<td>• Overcoming fears of activity if have injured self in past</td>
</tr>
<tr>
<td></td>
<td>• Determining how to deal with symptoms with activity</td>
</tr>
<tr>
<td>Taking preventative actions such as stopping smoking, limiting alcohol intake, receiving immunizations</td>
<td>• Understanding what preventative actions to take and when to take them</td>
</tr>
<tr>
<td></td>
<td>• Developing the motivation and soliciting appropriate support to stop smoking</td>
</tr>
<tr>
<td></td>
<td>• Developing the motivation and soliciting appropriate support to limit alcohol intake appropriately</td>
</tr>
<tr>
<td>Managing comorbidities</td>
<td>• Managing demands for multiple, sometimes competing, diets and other self-care activities</td>
</tr>
<tr>
<td></td>
<td>• Distinguishing among symptoms</td>
</tr>
<tr>
<td></td>
<td>• Understanding differing self-care needs</td>
</tr>
<tr>
<td>Navigating the health care system</td>
<td>• Managing transitions in care</td>
</tr>
<tr>
<td></td>
<td>• Managing recommendations and sometimes conflicting advice from multiple care providers</td>
</tr>
<tr>
<td></td>
<td>• Dealing with lack of communication among multiple providers</td>
</tr>
<tr>
<td></td>
<td>• Understanding when to contact who of many providers</td>
</tr>
</tbody>
</table>
Interventions focused on improving self-care reduce HF (44%-56% relative risk reduction) and all-cause hospitalizations (27%-41% relative risk reduction).


Lee et al. Heart & Lung 2011

Better self-care management:
- Lower levels of heart stress and inflammation
WHAT IS HEART FAILURE SELF-CARE?

Trajectories of heart failure self-care and changes in quality of life

Christopher K Lee, Junsung O Moon, Shinobu O Hara, JH M Baker, Kathleen N. Stotts and Barbara King

Lee et al., European Journal of Cardiovascular Nursing 2015

OUTLINE:

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CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:

• Healthcare providers often involve and rely upon informal caregivers to help patients monitor, appraise and manage symptoms
• Heart failure caregiving is associated with:
• Knowledge Divide (Patients or Caregivers)
• Heart failure couples that take a collaborative approach to self-care may have better outcomes (Quinn C et al. JCH 2010;25:142-148; Retrum JH et al. JCN 2013;28:129-136; Sasser M et al. ECH 2009;8:97-104).
Living with a spouse or other family member improved patient adherence to low sodium diet only when the spouse or family member also followed the low sodium diet.

These results suggest that interventions aimed at improving low sodium diet adherence should target patient and family member dyads to encourage family members to follow the low sodium diet with patients.

**CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:**

Heart failure family-based education: a systematic review

Family-based education (among other things):
- Improves knowledge in patients and caregivers,
- Reduces caregiver burden, but
- Does not improve perceived control among caregivers.

**CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:**

Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study

**Caregiving/Family Contributions to Care:**

Greater Gap in Contributions →

22.4% of dyads: novice and complementary
56.4% of dyads: inconsistent and compensatory
21.2% of dyads: expert and collaborative


CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:

A Dyadic Approach to Managing Heart Failure With Confidence

Karen S. Lyons, PhD, Escole Vellone, PhD, RN, Christopher S. Lee, PhD, RN, FAHA, FAAN;
Antonella Cucchiaro, PhD, RN, Julie T. Biddiss, BSN, RN, Fabio D’Agostino, PhD, RN;
Shirin O. Hsien, MPH, RN, Rosaria Alvaro, MDx, RN, Raul Juarez-Velez, PhD, RN;
Barbara Riegel, PhD, RN, FAHA, FAAN

What’s New and Important

- Most HF care dyads reported moderate levels of confidence that fall short of recommended guidelines for self-care.
- Patient-, caregiver-, and dyadic-level factors all played important roles in understanding dyadic confidence to self-care and understanding the relational aspect of HF.
- Taking a dyadic perspective to HF practice will allow clinicians to recognize care dyads with low levels of collaboration and communication and caregivers who may be experiencing high levels of depressive symptoms and strain.


CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:

Recommendations for Family Members:

- Watch for changes in HF symptoms and help patients monitor for these changes. Help HF patients practice the decision-making skills needed to plan what to do when symptoms occur.
- Watch for changes in cognition, depression, and anxiety that can occur with chronic HF. Patients may not notice these changes.

Riegel et al. (including Lee). Circulation 2009.

CAREGIVING/FAMILY CONTRIBUTIONS TO CARE:

Lee, C.S., Lyons, K.S., et al. OHSU IN-STEP study

(Images of graphs and charts are present but not described in detail.)
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FAMILY PARTNERSHIPS:

A Trial of Family Partnership and Education Interventions in Heart Failure

SANDRA B. DUNBAR, RN, DNS, FAAN; PATRICIA C. CLARK, RN, MS, FAAN; CAROLYN M. HEIGL, RN, MS, CCRN, PHN; JANET J. FREIDSON, MD; CINDY DASHIFF, CRT, MS; NANCIE KASLOW, PhD; JAMES DASHIFF, PhD; ANDREW SMITH, PhD

Goal: evaluate the efficacy of family education and partnership interventions on dietary sodium intake and medication adherence.

Usual Care (UC) Participants in the UC group received an informational brochure Taking Control of Your Heart Failure (HFSA) and usual care from their health care providers.

Patient-Family Education (PFE) dyads participated in a 1st educational session delivered by a research nurse (HF overview, symptoms of fluid overload, rationale for and ways to modify dietary NA intake, cues to take medications regularly and maintain refills, and other self-management activities). 2nd 2-hour (RN and dietitian), selection of low NA foods, meal planning, and adapting recipes.
**Family Partnerships:**

**Family Partnership (FPI)**
- PFE intervention plus two, 2-hour small group FPI sessions (RN) brief discussion of dietary and medication education with patient and family members.
- Break-out patient and family member sessions were held on living with HF or a family member with HF, principles of autonomy and supportive communication, HF self-care scenarios with role playing of responses based on autonomy supportive approaches (e.g. decrease criticism, give motivating messages, increase family problem-solving etc.).
- Coordinated written materials about family partnership and autonomy supportive communication, a family focused brochure (Tips for Family and Friends, HFSA).
- Scripted booster telephone call during which information about the patient’s 4M dietary NA results were reviewed with reinforcement of efforts to reduce dietary NA.

**Family Partnerships:**

- Family partnership and patient family member interventions reduced urinary sodium.
- Greater efforts to study and incorporate family-focused education and support interventions into heart failure care are warranted.

**Family Partnerships:**

Model of family context and heart failure self-care.
**Family Partnerships:**

The family partnership intervention group significantly improved confidence and motivation at four months, whereas patient-family education group and usual care did not change.

**Dunbar, S.B. et al. Heart & Lung [Epub ahead of print]**

- **Family Partnerships:**

  Family partnership and education interventions to reduce dietary sodium by patients with heart failure differ by family functioning

  Sandra B. Dunbar, PhD, RN, FPCNA, FAHA, FAAN, Patricia C. Clark, PhD, RN, FAHA, FAAN, Kelly D. Stamp, PhD, ANP-C, RN, FAHA, Carolyn M. Reilly, RN, PhD, Rebecca A. Gary, RN, PhD, FAHA, FAAN, Melinda Hieatt, PhD, Nadine Kaskow, PhD

  The Family Assessment Device Questionnaire (FAD) measures the overall health and dynamics of the family group and the patterns of communication among family members.

  Global Family Function Scale used to split dyads into Good vs. Poor family function.

  Participants with poor family functioning had higher levels of Na intake at baseline than those with good family functioning.

  Family partnership intervention works in poorly functioning families.

**Dunbar, S.B. et al. Heart & Lung [Epub ahead of print]**
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WHAT REMAINS?

1) How do family partnerships influence patient-, caregiver- and dyadic-level factors other than adherence (and Na++)?
   - Symptoms/other patient-reported outcomes/other aspects of self-care
   - Clinical outcomes
   - Economic outcomes
   - Strain and relationship quality
   - Communication
   - Concealment/protective buffering

WHAT REMAINS?

2) Can family partnerships be tailored to the type of dyad?
   - 22.4% of dyads: novice and complementary
     - Predominantly older patients and their adult child caregivers
     - Poorest relationship quality
   - 56.4% of dyads: inconsistent and compensatory
     - Caregivers reported greater contributions in all domains
     - More patients had hospitalizations in the past year
     - Worst caregiver burden
   - 21.2% of dyads: expert and collaborative
     - Worst patient quality of life and the greatest limitations (sickest patients)
     - Best relationships quality
     - Caregiver strain was lowest
3) Are family partnerships efficacious at all phases of the heart failure trajectory?

SUMMARY:

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Many thanks!
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