Self-Management: What Have We Learned Over Time

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Self Management: Why Should We Care?

COACH study: Self Care

Assessed compliance in:
1) Sodium-restricted diet*
2) Fluid restriction*
3) Exercise*
4) Weight monitoring**
* scored mostly or always
** 3 x/week to daily

Cumulative survival

Time to primary endpoint***, days

- Overall non-compliant
- Overall compliant

HR 1.40 (1.08-1.82); P=0.01

Compliance measured 1 month after hospital discharge & followed for 18 months; 48% (N=830 patients)

***, all-cause death or HF rehospitalization

COACH study: Self-Care Adherence

Compliance with advice on weight monitoring, low sodium diet, fluid restriction and exercise

* * P < 0.01; ** P < 0.05

Van der Wal MH, et al. *Eur Heart J* 2010;31:1486-1493
Self Management (based on SCHFI) & Event-Free Survival Risk

<table>
<thead>
<tr>
<th>Factor</th>
<th>Adjusted HR (95% CI)</th>
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<tbody>
<tr>
<td>Age (y)</td>
<td>0.967 (.941, .995)</td>
</tr>
<tr>
<td>Depression</td>
<td>1.074 (1.04, 1.11)</td>
</tr>
<tr>
<td>β-Blocker</td>
<td>0.346 (.187, .641)</td>
</tr>
<tr>
<td>DASI Score</td>
<td>0.960 (.930, .991)</td>
</tr>
<tr>
<td>Symptom free</td>
<td>0.481 (.238, .971)</td>
</tr>
<tr>
<td>Above average SCM score</td>
<td>0.441 (.222, .877)</td>
</tr>
</tbody>
</table>

Behavioral Predictors of 30-Day Rehospitalization; N=729

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Univariate Regression</th>
<th>Multivariable Regression</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>OR</td>
<td>95% CI</td>
</tr>
<tr>
<td>Service decline/refusal</td>
<td>2.21</td>
<td>1.42-3.43</td>
</tr>
<tr>
<td>Nonadherence</td>
<td>1.99</td>
<td>1.28-3.10</td>
</tr>
<tr>
<td>Dementia</td>
<td>1.91</td>
<td>1.08-3.40</td>
</tr>
<tr>
<td>Depression</td>
<td>1.55</td>
<td>1.00-2.40</td>
</tr>
<tr>
<td>Missed appointment</td>
<td>1.99</td>
<td>1.28-3.09</td>
</tr>
</tbody>
</table>

Patient-Identified Factors of HF Hospitalization

- Interviews; Reasons for rehosp ≤ 6 months
  - 28 patients
    - 8 from community hospitals
    - 20 from academic centers

  5 themes:
  - Distressing symptoms
  - Unavoidable progression of illness
  - Influence of psychosocial factors
  - Good but imperfect self-care
  - Health system failures

No differences in themes between those admitted ≤ 30 days vs. > 30 days from their last admission

Naturalistic Decision-Making

- Conflict vs synergy with personal goals or family goals
- Decision characteristics
  - Uncertainty
  - Ambiguity
  - High/low stakes
  - Illness characteristics
  - Others’ involvement

Mental simulation of actions

Situational Awareness

Experiences or Illness beliefs
- Identity
- Cause
- Timeline
- Consequences
- Cure/Control

Self Care Decision

Patient Activation

- Patients who are “activated” (have skills, ability, and willingness to manage their own health and health care)
  - Experience better health outcomes at lower costs compared to less activated patients
- Patient activation measure: 13-items; values range from 38.6 to 53 (rescaled on a 0-100 point scale)
  - 4 levels (1, lowest; 4 highest); scores the degree to which someone sees himself or herself as a manager of his or her health and care
    - Active role is important → Confidence & knowledge to take action → Taking action → Staying the course under stress

Hibbard JH. *Health Services Res.* 2005;40(6);1918-1930.
Patient Activation in Heart Failure

- At Mayo Clinic in ADHF, 302 patients studied; mean age 77.3 yrs

Patients with lower activation were older, less educated; had lower patient satisfaction, and worse health literacy

Enhancing Patient Activation

- 84 patients w HF randomized to UC or Heart PACT Program then reassessed at 3- and 6-months

Enhancing Patient Activation

Who is in Charge?

• **Patients are in control**
  – No matter what we as health professionals do or say, patients are in control of important self-management decisions
  – When patients leave the clinic or office, they can and do veto recommendations their healthcare provider makes

• **Shared decision making allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences**

## Strategies for Shared Decision Making

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient and Family</th>
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<tbody>
<tr>
<td>Diagnosis</td>
<td>Personal experience of illness</td>
</tr>
<tr>
<td>Pathology</td>
<td></td>
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<tr>
<td>Prognosis</td>
<td></td>
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<tr>
<td>Treatment</td>
<td></td>
</tr>
<tr>
<td>Treatment Outcome</td>
<td>Preferences</td>
</tr>
<tr>
<td>Risk/benefit associated with each outcome</td>
<td>Attitudes/feelings regarding risks</td>
</tr>
</tbody>
</table>

Patients are the most underutilized RESOURCE, and they have the most at stake!

http://www.informedmedicaldecisions.org/
Decision Aid Example

Heart Rhythm Problems: Should I Get an Implantable Cardioverter-Defibrillator (ICD)?

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

<table>
<thead>
<tr>
<th>1</th>
<th>Get the Facts</th>
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<tbody>
<tr>
<td>2</td>
<td>Compare Options</td>
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<tr>
<td>3</td>
<td>Your Feelings</td>
</tr>
<tr>
<td>4</td>
<td>Your Decision</td>
</tr>
<tr>
<td>5</td>
<td>Quiz Yourself</td>
</tr>
<tr>
<td>6</td>
<td>Your Summary</td>
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</tbody>
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Get the facts

Your options
- Get an ICD.
- Don't get an ICD.

Ottawa Hospital Research Institute: https://www.healthwise.net/cochranedecisionaid/Content/StdDocument.aspx?DOCHWID=abk4103
"There simply is no pill that can replace human connection. There is no pharmacy that can fill the need for compassionate interaction with others. There is no panacea. The answer to human suffering is both within us and between us."

—Dr. Joanne Cacciatore
Steps in Shared Decision Making

• Invite patient & family to participate
• Both parties share information
  – Clinician
    – Introduces concept of participation in decision making
    – Offers options & describes associated risks/benefits
  – Patient & family
    – Express preference/values
• In audiotaped single medical visits of 93 HF patients (36 w companion)
  – 32% more positive rapport-building statements ($p<0.01$) and almost 3x as many social rapport-building statements ($p<0.01$) from patients and companions in accompanied visits versus unaccompanied patient visits

What matters most: what are the priorities for the patient & family?

http://www.informedmedicaldecisions.org/
Caring for Patients with Heart Failure

Engagement in care assessed via qualitative interviews
- 60 patients, 22 caregivers, and 11 healthcare providers

• Key themes of *patients & caregivers*:
  1. Education on disease specifics
  2. Guidance to enhance quality of life
  3. Learning to cope with HF
  4. Future outlook and care decisions

• Themes of “greatest impact” by *healthcare providers*:
  1. Knowledge is powerful
  2. Adherence to treatment plan
  3. Compliance with medication

Patient Engagement Strategies

• Must be prepared to do MORE than just deliver intense, repeated education and reinforce post-discharge follow-up appointments
  • Flip the script and empower patients to care for themselves
  • MUST see the person behind the patient
Shared Decision Making

“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”
Self Care Management Strategies
TABLE DISCUSSIONS

• How can we enhance:
  – *Patient engagement* in HF self-care adherence (globally and for specific self-care themes)?
  – *Shared decision making* in our real world clinical settings?
  – Patient adherence to self-care strategies *when under distress or in difficult situations*?

• What strategies are needed to shift provider focus from teaching “what” self-care entails to “how” to practically carry it out?

• What would a “*home care for HF*” program look like (who, what, when, how...) if the goal was to enhance self-care adherence?

• What *tools/resources* are needed (or if already available, how would they need to be altered) to enhance self-care adherence?