Achieving Coordinated Identification,
Detection and Treatment of Heart Failure Summit

April 12th, Hyatt Regency Bethesda, MD

Self-Management: What Have We Learned Over Time

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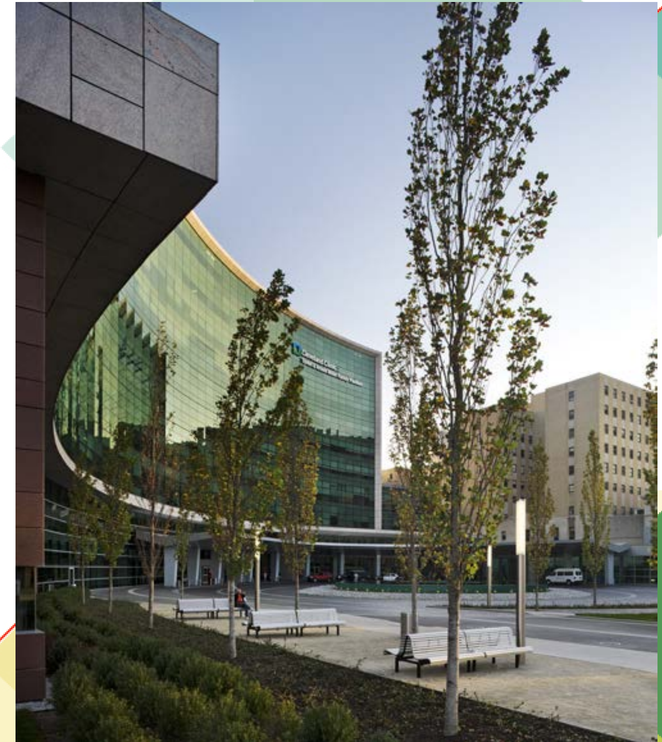

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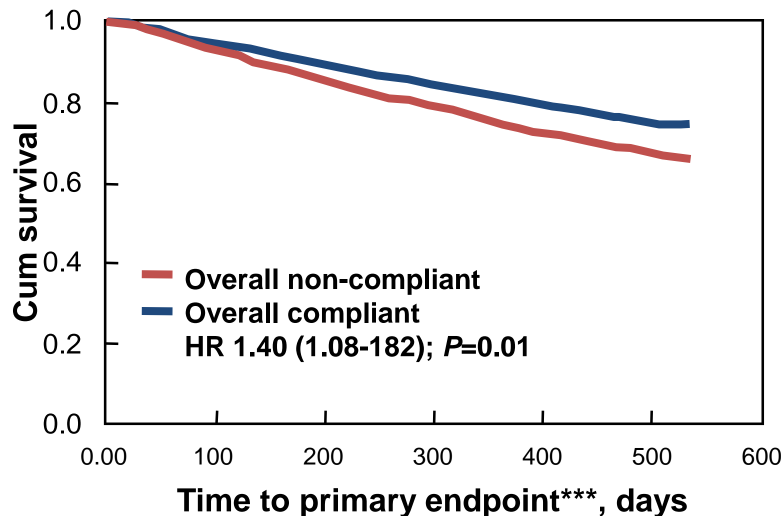
Self Management: Why Should We Care? COACH study: Self Care



Assessed compliance in:

1) Sodium-restricted diet*
2) Fluid restriction*
3) Exercise*
4) Weight monitoring**

*, scored *mostly* or *always*

**, 3 x/week to daily

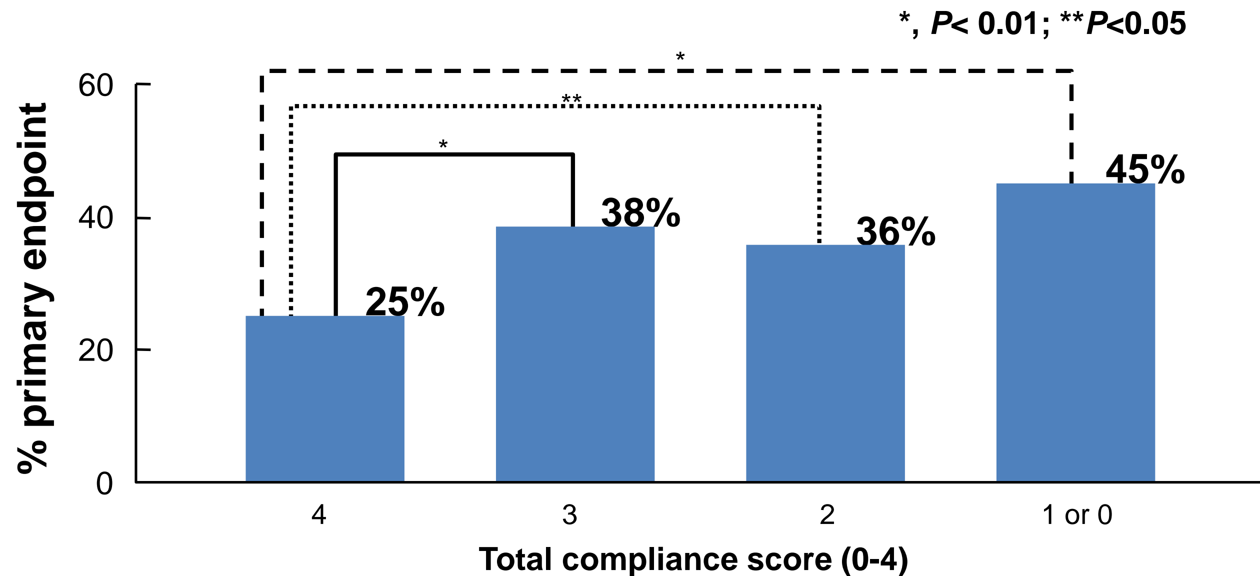
Compliance measured 1 month after hospital discharge & followed for 18 months; 48% (N=830 patients)

***, all-cause death or HF rehospitalization

Van der Wal MH, et al. *Eur Heart J* 2010;31:1486-1493.

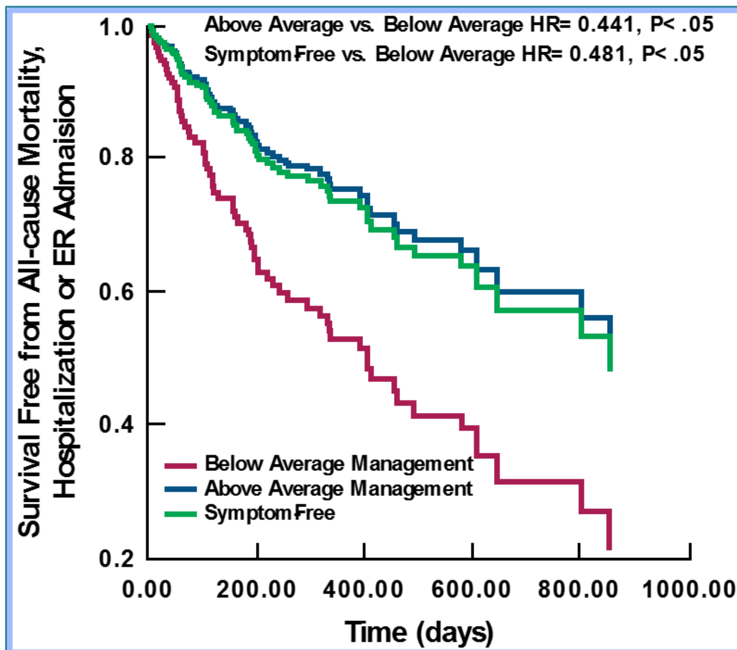
COACH study: Self-Care Adherence

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



Van der Wal MH, et al. *Eur Heart J* 2010;31:1486-1493

Self Management (based on SCHFI) & Event-Free Survival Risk



Factor	Adjusted HR (95% CI)
Age (y)	.967 (.941, .995)
Depression	1.074 (1.04, 1.11)
β-Blocker	.346 (.187, .641)
DASI Score	.960 (.930, .991)
Symptom free	.481 (.238, .971)
Above average SCM score	.441 (.222, .877)

Lee C, et al. *Heart & Lung*. 2011;40:12-20.

Behavioral Predictors of 30-Day Rehospitalization; N=729

Predictor	Univariate Regression			Multivariable Regression		
	OR	95% CI	*P*	OR	95% CI	*P*
Service decline/refusal	2.21	1.42-3.43	0.0004	1.75	1.07-2.87	0.03
Nonadherence	1.99	1.28-3.10	0.002	1.72	1.07-2.76	0.03
Dementia	1.91	1.08-3.40	0.03	1.51	0.81-2.81	0.19
Depression	1.55	1.00-2.40	0.05	1.14	0.68-1.91	0.62
Missed appointment	1.99	1.28-3.09	0.002	1.73	1.06-2.80	0.03

Watson AJ, et al. *Psychosomatics* 2011;52:319-327.

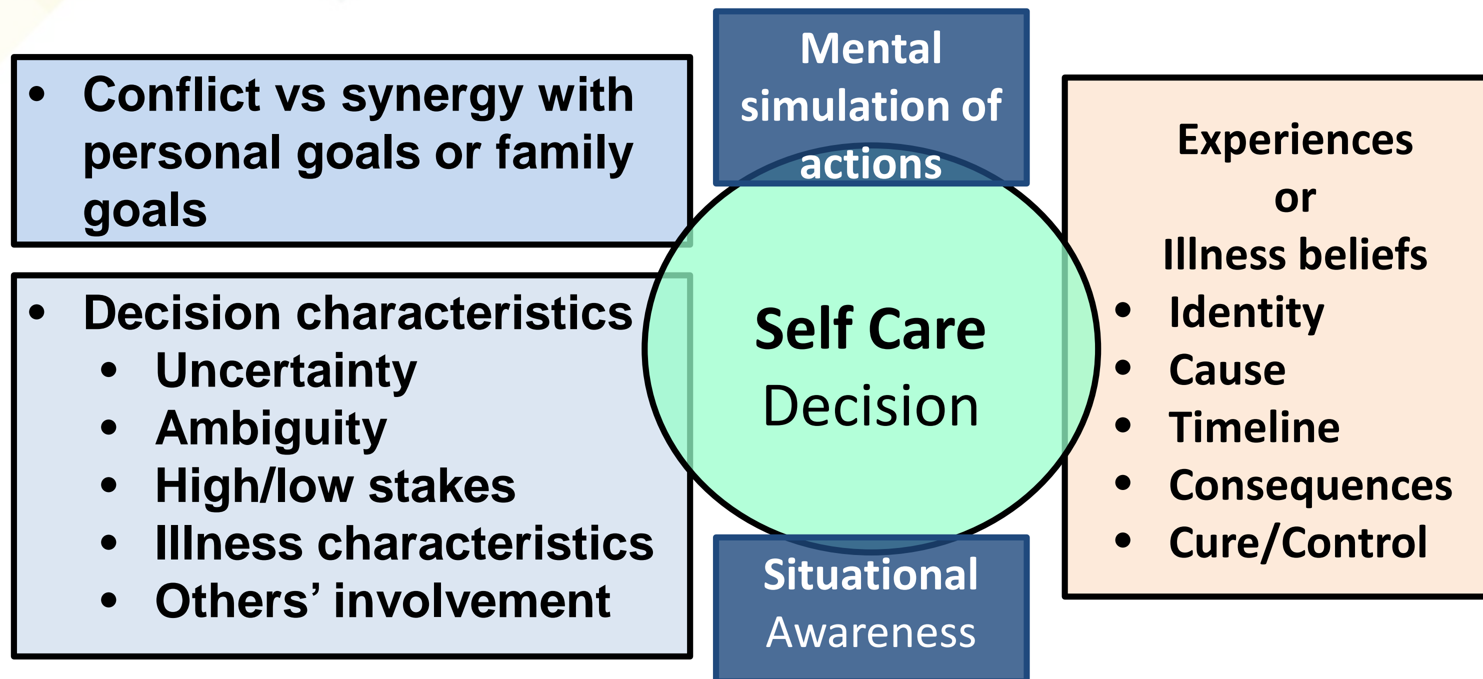
Patient-Identified Factors of HF Hospitalization

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

Retrum et al. *Circ Cardiovasc Qual Outcomes* 2013;6:171-7.

Naturalistic Decision-Making



Moser et al. *Age Ageing*. 2013;42:626-32.

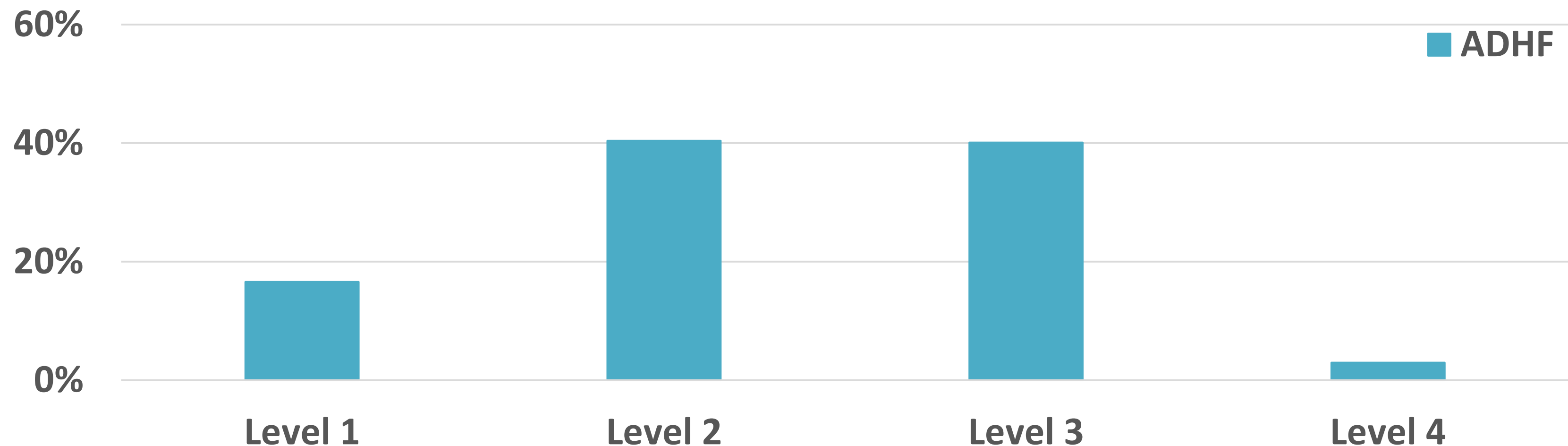
Patient Activation

- 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

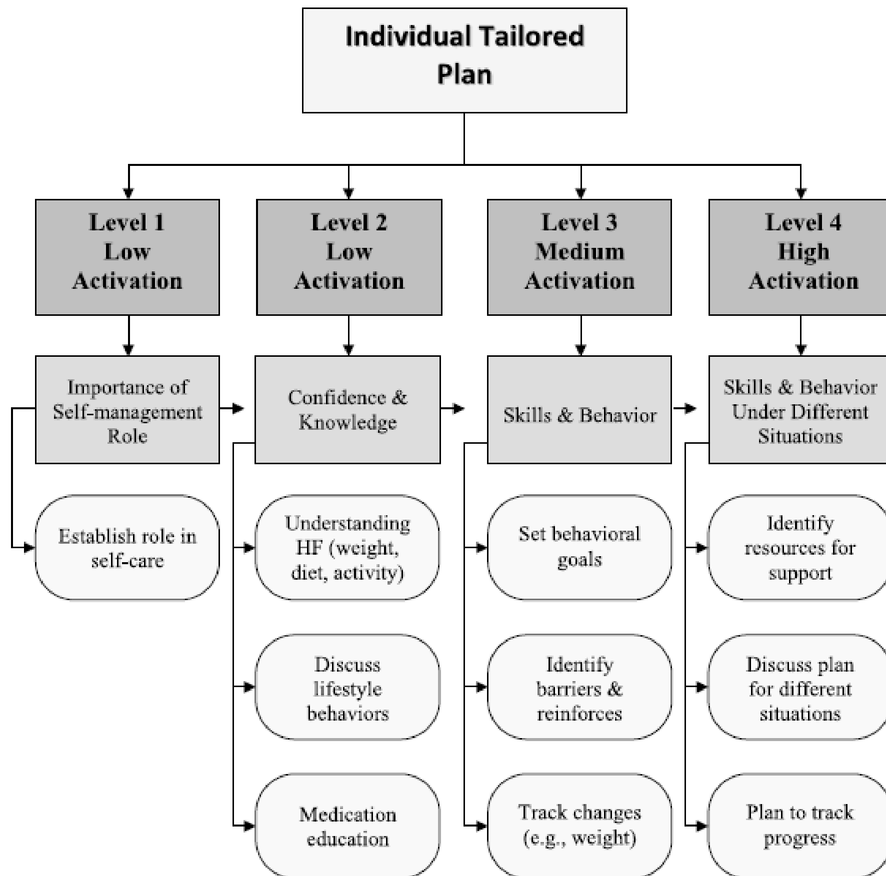
- At Mayo Clinic in ADHF, 302 patients studied; mean age 77.3 yrs



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

Dunlay SM et al. *J Cardiovasc Nurs*. 2016 Sep 13. ePub.

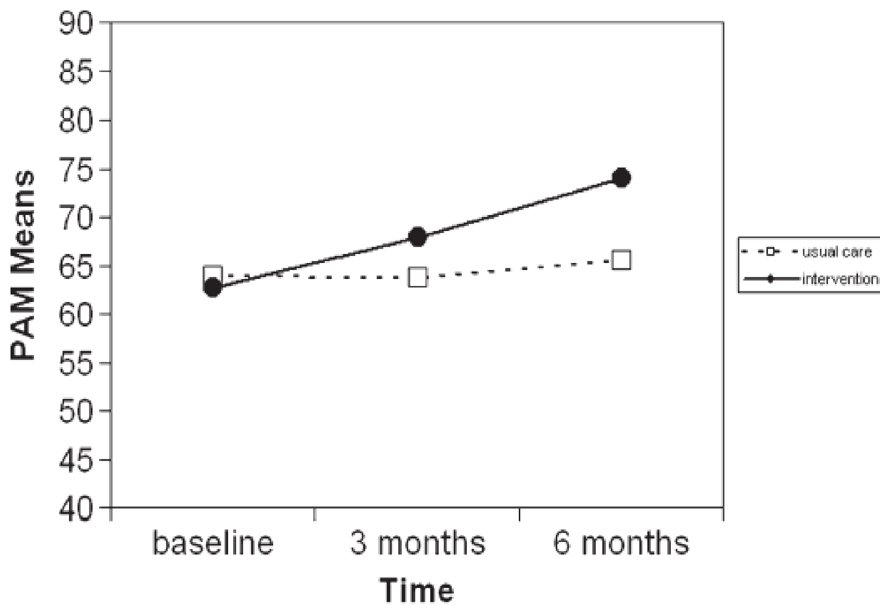
Enhancing Patient Activation

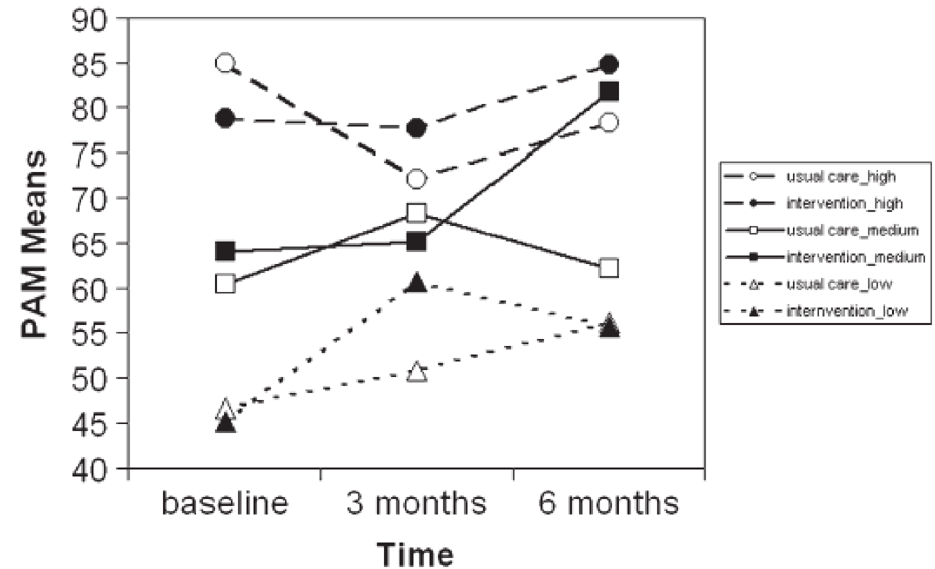


- **84 patients w HF randomized to UC or Heart PACT Program then reassessed at 3- and 6-months**

Shively et al. *J Cardiovasc Nurs*. 2013;28(1):20-34.

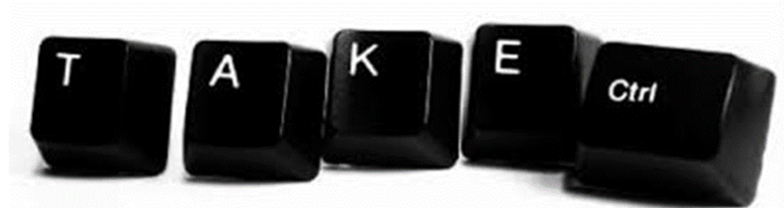
Enhancing Patient Activation





Shively et al. *J Cardiovasc Nurs*. 2013;28(1):20-34.

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**

Glasgow RE, Anderson RM. *Diabetes Care*. 1999;22(12):2090-2.

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Strategies for Shared Decision Making

Clinician	Patient and Family
Diagnosis	Personal experience of illness
Pathology	
Pr	
Tre	
Tre Outcome	Preferences
Risk/benefit associated with each outcome	Attitudes/feelings regarding risks

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

http://www.informedmedicaldecisions.org/

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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.

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

1 Get the Facts	2 Compare Options	3 Your Feelings	4 Your Decision	5 Quiz Yourself	6 Your Summary

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

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Supporters

It Takes A Village

"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

shinystarlight.tumblr.com

Steps in Shared Decision Making

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

- 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

http://www.informedmedicaldecisions.org/

Cene CW et al. *Patient Educ Couns*. 2017;100(2):250-258.

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

Compare - Contrast

Kennedy BM, et al. *Ochsner J.* 2017;17(1):93-102.

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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*

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Shared Decision Making

Self Care Management Strategies

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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?