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Moving from Disease-Centered to Patient Goals-Directed Care for Patients with Multiple Chronic Conditions: Patient Value-Based Care

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Decision-making in cardiology concentrates on disease-specific outcomes following practice guidelines for specific conditions. Quality metrics implemented for value-based purchasing and public reporting also largely focus on individual diseases. Disease-centered approaches are appropriate when individuals have a single predominant disease and everyone with the disease desires the same outcome such as prolonged survival or stroke prevention.[1] This disease-centered framework is ill-suited, however, for persons with multiple chronic conditions which includes the majority of older adults with cardiovascular conditions and of all adult healthcare users.[2] Disease-centered decision-making for this population results in treatment burden when patients must adhere to multiple guidelines and harm when guideline recommendations conflict.[3] Furthermore, disease-centered recommendations may not address what matters most to these patients who vary in their health priorities.[4]

To consider an alternative to disease-centered decision-making that better aligns care with what matters most to patients and reduces treatment burden, it is helpful to think of healthcare decisions as value propositions in which *Value = health outcome/cost.* From the population perspective, healthcare value is defined as survival or disease benefit (output) per dollar spent (input). From patients' perspective, however, the personal health outcomes that they hope to achieve are more appropriate outputs.[4] The appropriate inputs may include financial costs, but often more relevant are costs in terms of the time, discomfort, harms, and workload required to achieve their health outcomes.[3] When defined as what patients are willing and able to do for their health, these broader costs inform care preferences.

An alternative approach to decision-making, therefore, is predicated on achieving patients' specific health outcome goals within the context of their acceptable workload. High value care is defined as achievement of each patient's highest level health outcome goals given the

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workload each is willing and able to perform. This is not as daunting a task as it may seem; patients implicitly consider tradeoffs between outcome and workload even if it is not explicitly discussed.[3] Examples of health outcome goals and patient workload are shown in the Box.

This approach represents a shift from disease-centered, to patient goals-directed, care. The idea that healthcare decisions should include patients' health outcome goals and care preferences is not new. Many disease management guidelines mention patient preferences. The ACCF/AHA heart failure guideline, for example, notes that, *"… issues of patient preference that may influence the choice of tests or therapies are considered*".[5] While done increasingly well with advanced illness and end-of-life, however, patients' goals and preferences are rarely translated into actual care decisions.

In practice, patient goals-directed care begins with a skilled clinician eliciting patients' health outcome goals and care preferences. Clinically feasible methods are available to help patients move from general values or unrealistic goals to specific, measurable, achievable, realistic, and timebound (SMART) goals that integrate understanding of prognosis, clinical course, and realistic outcomes as essential for use in clinical decision-making.[6] While many clinicians can do it, APRNs or nurses may be more likely than physicians to have the requisite time and communication training to elicit goals effectively.[6] Regardless of which health team member does the elicitation, all clinicians should verify these outcome goals and care preferences when discussing care options. While a concern for clinicians, patients are unlikely to identify unrealistic or unachievable goals or change their goals in the absence of change in health status or life circumstances when skilled individuals conduct the goals elicitation.[6] Requests for low value care are also minimized when diagnostic tests and treatments are offered within the context of likelihood of achieving the person's own goals.

Under patient goals-directed care, clinicians present care options within their area of expertise, not only from the perspective of prolonging life or achieving disease-specific outcomes such as lower lipid levels or stroke prevention, but within the context of each patient's desired outcomes and care preferences (Box). Fortunately, most chronic conditions affect a shared set of health domains such as function, symptom burden, or survival, facilitating the mapping of disease-specific outcomes onto patients' health outcomes goals and the alignment of care options with these goals.[4]

Patient goals-directed care addresses important challenges in healthcare. First, because all clinicians focus on the same outcomes, coordination is easier and conflicting recommendations fewer. Adherence improves when recommendations align with patients' goals and preferences.[1] If communicated well, patient goals-directed care addresses concerns about rationing because care is tailored to each patient's own stated goals and preferences.

Many challenges face implementation of patient goals-directed care, not the least of which is that practice guidelines and quality metrics remain disease-centric. Even in integrated health systems, clinicians independently determine desired outcomes within the context of their own specialty. Integrated systems and accountable care organizations do, however, offer the

structure and financial incentives for patient goals-directed care once quality metrics evolve from disease-based to metrics that reflect individual variability in desired outcomes.[7] Interest in development of quality measures that reflect the value of care from the patient's perspective is growing.

Cardiology uses trial-derived evidence to inform its decisional guidelines. Multi-morbid older adults have largely been excluded from these evidence-generating trials, leading to therapeutic uncertainty for this large segment of the clinical population. Interest in the movement from disease-based to patient goals-directed care will hopefully fuel generation of evidence linking cardiovascular and other treatments to patient outcome goals. These data should be a welcome corrective to the current uncertainty shrouding decision-making for persons with multiple conditions.

Patient goals-directed care may initially seem overwhelming and time-consuming. Experience with this approach, however, will stimulate efforts to simplify the process within the context of busy clinical workflows. Focusing all care on a unified set of individualized patient outcome goals, rather than on disparate disease-specific outcomes, should reduce fragmentation among, and demands on, overwhelmed clinicians while raising patient trust in, and satisfaction with, their healthcare. Patient goals-directed care may be particularly useful for persons with multiple chronic conditions for whom a plethora of often contradictory and burdensome care options are available. But this approach works across the age and health span, making it a compelling path toward value-based care from the patient's perspective.

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References

1. Naik AD, Dyer CB, Kunik ME, McCullough LB. Patient autonomy for the management of chronic conditions: a two-component re-conceptualization. Am J Bioethics 2009; 9(2): 23–30.
2. Alecxih L, Shen S, Chan I, Taylor D, Drabek J. Individuals living in the community with chronic conditions and functional limitations: A closer look. http://aspe.hhs.gov/daltcp/reports/2010/closerlook.pdf. Accessed October 14, 2015.
3. May CR, Eton DT, Boehmer K, Gallacher K, Hunt K, MacDonald S, et al. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. BMC Health Serv Res 2014;14:281. [PubMed: 24969758]
4. Fried TR, Tinetti ME, Iannone L, O'Leary JR, Towle V, Van Ness PH. Health Outcome Prioritization as a Tool for Decision Making among Older Persons with Multiple Chronic Conditions. Arch Intern Med 2011; 171: 1854–1856. [PubMed: 21949032]
5. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE Jr, Drazner MH, et al.; American College of Cardiology Foundation; American Heart Association Task Force on Practice Guidelines. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. J Am Coll Cardiol 2013; 62(16):e147–239. [PubMed: 23747642]

6. Naik AD, Palmer N, Petersen NJ, Street RL Jr, Rao R, Suarez-Almazor M, Haidet P. Comparative effectiveness of goal setting in diabetes mellitus group clinics: randomized clinical trial. Arch Intern Med 2011; 171(5): 453–459. [PubMed: 21403042]

7. Burwell SM. Setting Value-Based Payment Goals — HHS Efforts to Improve U.S. Health Care. N Engl J Med 2015; 372:897–899. [PubMed: 25622024]

8. Lynn J, McKethan A, Jha AK. Value-Based Payments Require Valuing What Matters to Patients. JAMA 2015;314(14):1445–1446. [PubMed: 26378889]

Box.

Patient Health Outcome Goals and Workload (Care Preferences)*

Domains and examples of health outcome goals	Domains and examples of patient workload†
• Function (e.g., Walk two blocks without shortness of breath; live in my own home until I need help from someone at night). • Symptoms (e.g., Reduce back pain enough to perform morning activities without medications that cause drowsiness; get my appetite back and be able to eat the foods I like) • Life prolongation (e.g., See my grandson graduate from high school in 5 years) • Well-being (e.g. Be as free from anxiety or uncertainty about cancer recurrence as possible) • Occupational/social roles (e.g., Work three more years; pick up my granddaughter from school).	• Interactions with clinicians (e.g., number of clinicians, recommendations; conflicting recommendations) • Healthcare utilization (e.g., hospitalizations; intensive care unit stays; clinician and emergency department visits) • Medication management (e.g., complexity; associated tasks such as laboratory testing, physiological monitoring; adverse medication effects) • Self-management tasks (e.g., diet; exercise; monitor weights, blood pressure, glucose) • Diagnostic and laboratory testing • Procedures (e.g., preparation, discomfort, complications, anxiety, time to recovery) • Financial costs (e.g., out-of-pocket expenses, uncompensated time off work)

*Health outcome goals are the individual health outcomes that persons hope to achieve through their health care. To inform care, these health outcome goals must be specific, measurable, actionable, reliable, and time bound. Health outcome goals are distinct from behavioral goals such as stopping smoking or disease goals such as improved blood pressure.

†When these activities and consequences are understood as what patients are willing and able to do, this workload activities define care preferences. They are also referred to as treatment burden.