Goal-Oriented Patient Care — An Alternative Health Outcomes Paradigm

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The largest U.S. health insurer, the Centers for Medicare and Medicaid Services (CMS), has set a triple aim: better care for individuals, better health for populations, and lower costs. Simultaneously, major efforts have been launched to make care more patient-centered, defined as “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Attention to patient-centered measures and outcomes will be particularly important as CMS moves increasingly to link health care providers’ reimbursement to their performance on selected measures.

So far, assessments of quality of care and health outcomes have not incorporated patient-centeredness. Rather, measurement of quality has addressed preventive and disease-specific care processes (e.g., smoking-cessation counseling and initiation of appropriate medications after myocardial infarction). Similarly, outcomes measurement has focused on condition-specific indicators, both short-term (e.g., glycated hemoglobin levels and hypertension control) and longer-term (e.g., disease-free survival), as well as overall mortality.

Though these process and outcome measures work well for relatively healthy patients with single diseases, they may be inappropriate for patients with multiple conditions, severe disability, or short life expectancy. For such patients, the overall quality of care depends on more than just disease-specific care processes. Furthermore, disease-specific outcomes may not adequately reflect treatment effects in patients with multiple coexisting diseases. Adoption of more universal outcomes, such as functional status, would not ensure patient-centeredness unless they were considered within the context of individual patients’ goals and preferences in the face of trade-offs.

An alternative approach to providing better care would be to focus on a patient’s individual health goals within or across a variety of dimensions (e.g., symptoms; physical functional status, including mobility; and social and role functions) and determine how well these goals are being met (see table). For example, a person with Parkinson’s disease may es-
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<table>
<thead>
<tr>
<th>Measurement Domain</th>
<th>Examples of Diseases</th>
<th>Traditional Outcomes</th>
<th>Goal-Oriented Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survival</td>
<td>Cancer, heart failure</td>
<td>Overall, disease-specific, and disease-free survival</td>
<td>None if survival not a high-priority goal; survival until personal milestones are met</td>
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<td></td>
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<td></td>
<td>(e.g., grandchild’s wedding)</td>
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<tr>
<td>Biomarkers</td>
<td>Diabetes, COPD</td>
<td>Change in indicators of disease activity (e.g., glycated hemoglobin level, CRP level, and pulmonary-function tests)</td>
<td>None (not a meaningful outcome observed or felt by patient)</td>
</tr>
<tr>
<td>Signs and symptoms</td>
<td>Heart failure, COPD, arthritis</td>
<td>Inventory of disease-specific signs and symptoms (e.g., dyspnea, edema, and back pain)</td>
<td>Symptoms that have been identified as important by the patient (e.g., control of dyspnea or pain sufficient to perform an activity such as bowling or walking grandchild to school)</td>
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<tr>
<td>Functional status, including mobility</td>
<td>Cancer, heart failure, COPD</td>
<td>Usually none or disease-specific (e.g., Karnofsky score, NYHA functional classification, and 6-minute walk test)</td>
<td>Ability to complete or compensate for inability to complete specific tasks identified as important by the patient (e.g., ability to get dressed without help)</td>
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* COPD denotes chronic obstructive pulmonary disease, CRP C-reactive protein, and NYHA New York Heart Association.

Establish goals for symptoms, such as decreased rigidity and no falls; goals for functional status, such as the ability to get to the bathroom without assistance although requiring a walker; and goals for social function, such as the ability to use the Internet to communicate with a grandson at college and the ability to go to church. However, the patient may not be aiming to reduce tremor, walk without a walker, or continue to work for pay. Alternatively, he or she may prioritize being as mobile as possible even at the expense of medication-induced dyskinesia and mild confusion.

This goal-oriented approach to making health care decisions, assessing outcomes, and measuring success has several advantages. First, it frames the discussion in terms of individually desired rather than universally applied health states. For example, a new therapy may extend life for patients with metastatic prostate cancer for several months, on average. Yet a particular patient may not perceive this small gain as worthwhile. Similarly, extended physical therapy may enable a patient with a fractured hip to transition from needing an assistive device to walking independently. But the patient may perceive the work required to make this transition as too hard and the amount of gain as not worth the effort.

Second, this approach simplifies decision making for patients with multiple conditions by focusing on outcomes that span conditions and aligning treatments toward common goals. Choices to deescalate treatment for one condition in order to optimize treatment for another can be made in the context of whatever therapy is most likely to achieve the patient’s goals. For example, a patient with hypertension and postural hypotension may opt to forgo blood-pressure–lowering treatment in favor of being able to walk with less fear of falling, with a resultant gain in short-term function. Since success or failure in attaining these individualized outcomes is easily determined, it’s feasible to use goal attainment to assess treatment effectiveness and quality of care for people with multiple chronic conditions. Multiple, potentially competing disease-specific outcomes and irrelevant, if not harmful, disease-specific process measures can be replaced by ascertainment of whether individual health goals were elicited and attained.

Third, goal-oriented care prompts patients to articulate which health states are important to them and their relative priority. Thus, patients can be in control when treatment options require trade-offs (e.g., better symptom control at the expense of potentially shorter life span). Such trade-offs are currently made, for example, when patients choose to receive hospice care and decline aggressive treatment of their medical conditions.

Finally, if they know what health states are most desired, patients and clinicians can agree on steps that can be taken to achieve these goals and monitor progress in reaching them. This
approach allows for effective shared decision making, with the patient selecting the health outcome of highest priority and the clinician determining what treatment strategies are most likely to achieve that outcome. In effect, this is the patient-centered care equivalent of strategic planning.

Of course, not all patient goals may be realistic or attainable. For example, a patient with a dense hemiplegia due to a stroke may not be able to live alone even if doing so is a major personal goal. The clinician needs to explain what is possible and negotiate potentially achievable goals with the patient. Then the clinician should provide a treatment plan, encouragement, and advocacy to help the patient meet agreed-on goals and readdress them if the situation changes. By doing so, clinicians embrace the ethical principles of autonomy and beneficence.

Focusing on desired outcomes may also help to achieve the third part of the triple aim, if achieving those outcomes requires fewer resources than traditional disease-specific care. For example, if pain can be adequately controlled, the use of a walker for osteoarthritis in someone who wants only to be able to walk around the house would meet the patient’s goal much less expensively than hip-replacement surgery.

Some may argue that goal attainment is a “soft” outcome and too person-specific to be valuable. However, researchers have been using goal-attainment scaling for decades to measure the effect of treatment for conditions such as dementia and for comprehensive geriatric assessments. It’s also been used in clinical rehabilitation programs — though with skepticism about whether goal attainment is truly an outcome or “stand-alone” measure. Nevertheless, goal-attainment scaling has good psychometric properties and should be robust enough for clinical use.

We must recognize that some decisions to strive for personal goals may worsen clinicians’ performance on aggregated health measures. For example, a patient who chooses to remain wheelchair-dependent after a stroke because it would take too much work to walk would contribute adversely to an overall poststroke outcome of mobility. A family of a patient with dementia who has behavioral problems may elect to continue the use of antipsychotic medications in spite of the increased risk of death from cardiovascular causes because the medication controls behavior well enough to allow the patient to remain at home. In such cases, a positive outcome from an individual-patient perspective would either not be captured or would contribute negatively to measures of the quality of a clinician’s care and population health. Quality metrics that capture individual goal elicitation and attainment must be developed as we move toward goal-directed, patient-centered decision making.

Perhaps the most important barrier to goal-oriented care is that medicine is deeply rooted in a disease-outcome–based paradigm. Rather than asking what patients want, the culture has valued managing each disease as well as possible according to guidelines and population goals.

Ultimately, good medicine is about doing right for the patient. For patients with multiple chronic diseases, severe disability, or limited life expectancy, any accounting of how well we’re succeeding in providing care must above all consider patients’ preferred outcomes.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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