Peering Inside the Black Box of Patient-Centered Care

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Patient centeredness is a distinct dimension of healthcare quality. Patient-centered care is respectful of and responsive to individual patient preferences, needs, and values in ways that guide treatment decisions. Translating patient centeredness into routine care is challenging. Citing evidence that patients often do not want a role in treatment decision making, many initially questioned the utility of engaging patients or eliciting their preferences. It is not surprising that many subjects enrolled in older studies of medical decision making would endorse passive decision making styles, given the paucity of tools to facilitate meaningful patient or caregiver engagement. When such tools were available, they were often overly complex and technical with little appreciation for health literacy, numeracy, or cognitive biases. The purpose of these tools was to facilitate decision making for clinicians rather than explore or uncover patient preferences, values, and goals. In essence, these earlier studies attempted to measure patient participation, experiences, and preferences within the context of clinician-centric medical encounters.

The results described by Dunlay et al in this issue of Circulation Cardiovascular Quality and Outcomes are illustrative of these early attempts in understanding patient centeredness within the context of a clinician-centered healthcare environment. Their study sought to better understand the end-of-life preferences of patients with heart failure and how those preferences changed during the disease course and, in particular, during hospitalizations for acute exacerbation. The focus on do-not-resuscitate (DNR) orders as a surrogate is indicative of our limited capacity to clearly understand, elicit, and document end-of-life preferences. DNR orders are rudimentary measures of patient values and preferences for end-of-life care; orders are often placed with little or no previous discussions and are largely for the purpose of clinician decision making. Dunlay et al found that changes in DNR status in patients with heart failure are associated with acute heart failure exacerbations and with predictors of mortality (eg, age, functional impairment, malignancy, and comorbid chronic obstructive pulmonary disease). The disconnect between DNR orders and advance care planning is evident by the finding that patients with class 3 or 4 heart failure symptoms were less likely to have DNR orders in place on study enrollment. The results of this study highlight the lack of standardized, patient-centered measures of advanced care planning. In contrast, the presence of DNR orders has surprisingly powerful effects on clinicians’ decision making that go far beyond the simple intent of documenting the patient’s preferences for resuscitation. In a previous study, Beach and Morrison found that the presence of a DNR order was associated with significantly lower willingness to draw blood cultures, place central lines, or provide blood transfusions among physicians. The findings of Dunlay et al add to the body of research suggesting that the timing of DNR order changes is often indicative of clinician-centered care.

A significant challenge to assessing patient centeredness is overcoming long-held conclusions, supported by previous studies, that patients with certain demographic and clinical traits are less likely to benefit from patient-centered care. These studies suggest that patients who are older, less educated, and of minority race are less likely to engage in shared medical decision making. However, the contrasting results of Coylewright et al, also in this issue of Circulation Cardiovascular Quality and Outcomes, suggest that differences in age, sex, education, income, and type of health insurance are not predictive of preferences for or outcomes of shared decision making. The authors conducted a rigorous systematic review and meta-analysis of decision support tools related to myocardial infarction, angina, diabetes mellitus medications, cardiovascular primary prevention, and osteoporosis care. Each of the tools reviewed in this study was designed to facilitate patient-centered communication during clinical encounters. In diabetes mellitus care, patient-centered communication is associated with improved medication adherence, blood pressure, and hemoglobin A1c. One important caveat must be raised. Each of the decision support tools reviewed in this study was developed and initially implemented within the Mayo Clinic health system. This limitation may affect the external validity of the study by Coylewright et al, given the selection bias of this population. However, this limitation may also suggest that when decision support tools are placed within a setting known to encourage patient-centered care, sociodemographic traits previously associated with low patient engagement become less salient. As decision support tools gain acceptance in other clinical settings, it will be interesting to observe whether the findings by Coylewright et al remain as valid and refreshing.

Another challenge to assessing patient centeredness is that most useful measures rely on subjective ratings of care by patients. Subjective assessments of quality by nonexperts have constraints. For example, there is little validity to asking...
patients whether their physician is providing guidelines-concordant care for heart failure. In contrast, using standardized measures to gather subjective ratings of specific communication with healthcare providers during clinical encounters will often predict health outcomes related to those encounters. For example, patient perceptions that their doctors gave them choices related to their diabetes mellitus care are likely to predict improved self-care behaviors and blood pressure control.

Subjective measures of patient centeredness also include those designed to capture patients’ experiences of care. Patient experiences include emotions, bodily feelings, social interactions, and judgments associated with specific encounters, interactions, and procedures comprising health care. Accounts of patient experiences suffer from availability bias, an empirical finding that cognitions that come readily to mind have a disproportionate influence on our normative judgments and decision making. Given this bias, subjective reports of patient experiences may not be completely consistent with objective facts or they may overemphasize a particular aspect of the healthcare experience. For example, a recent qualitative study of patients’ experiences with upper endoscopy found that satisfaction with the procedure centered on a few salient memories of the periprocedure experience (eg, time in waiting room, discomfort associated with the procedure, feeling respected by procedure staff, and trust in physician postprocedure). These are the memories that come to define a healthcare experience and shape a patient’s judgment of the care received; therefore, they influence subsequent health behaviors and are worth measuring despite their flaws.

The novel study by Ottenberg et al, also in this issue of Circulation Cardiovascular Quality and Outcomes, provides further evidence of the need to systematically measure patient experiences. Their qualitative study describes patient experiences from pre- to postimplantation of left ventricular assist devices (LVAD) as destination therapy in patients with advanced heart failure. The authors found that preparing patients and their caregivers for LVAD as destination therapy before implantation is important for addressing emotional and interpersonal concerns. Receiving information and education was less important. In fact, patients reported feeling overwhelmed by the high volume of information received. Patient experiences can extend to nearly all facets of life for interventions such as LVAD. Patients and caregivers faced numerous mundane and daily challenges such as how to take a shower with an LVAD. As a result, the team has developed a preparedness planning consultation for LVAD as destination therapy to improve outcomes for both patients and caregivers after implantation. Furthermore, the raw emotions, dread, and uncertainty associated with some healthcare encounters can narrow the range of perceptions and options that patients consider (ie, availability bias). For example, patients considering LVAD for destination therapy frequently cited that immediate implantation was their only choice despite the presence of other treatment options or timing choices for implantation. Given the emotions surrounding advanced heart failure, patients struggle to consider (bring to mind) these other options and preferences. Preparedness planning presents the full range of options with their attendant experiences in a standardized manner to better facilitate patient awareness and consideration.

By systematically measuring patient experiences and incorporating preparedness planning that includes these mundane challenges, the overall effectiveness of interventions such as LVAD for destination therapy may be improved.

The articles in this issue of Circulation: Cardiovascular Quality and Outcomes make significant strides in our understanding of patient centeredness. Far more than a marketing slogan, patient centeredness is an important dimension of high-quality health care. The limitations of human decision making and interpersonal communication pertinent to health care may be predicted and ameliorated through the use of validated measures of patient centeredness. Better measurement of patient centeredness can lead to more effective methods of shared decision making, such as values clarification methods, decision support tools, and advanced care planning. In addition to providing evidence during shared decision making, these methods can improve understanding of emotions, values, and goals of patients and their family when choosing wisely for interventions as diverse as LVAD for destination therapy, end-of-life resuscitation, and medication therapy for coronary artery disease. Additional studies, like the ones in this issue, are needed to better understand and measure patient centeredness.

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References


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