Preferences, Disparities, and the Authenticity of Patient Choices

Economic evaluation includes consideration of costs, consequences, and ultimately choices. A key component of patient choice is the patient's preferences for each of the options he or she confronts. This article discusses preferences, with attention to the relationship between patient preferences and disparities in the utilization of health services.

DEFINITIONS

Preferences are used in 2 different ways in the decision-making and economic evaluation fields. In the decision-making literature, preferences refer to the patient's valuations of specific outcomes. Patients are presented with risks, benefits, and alternatives, and they weave these considerations into choices. The choices are driven by the extent that patients value each particular outcome. These valuations are termed preferences. Should a patient choose surgery or watchful waiting? Should a patient choose a risky treatment that is more potent or a less risky, less potent treatment? These choices typically hinge upon the value patients attach to improving their health status and avoiding adverse consequences.

In a more formal econometric sense, preferences also refer to patient valuations of one option as opposed to another. However, in the more formal analytic setting, these preferences are derived formally and represented quantitatively. The time tradeoff and standard gamble are 2 of several techniques used to elicit quantitative patient preferences.

Preference-based care refers to a paradigm of treatment that hinges upon patient preferences. In this paradigm, providers inform patients of the probability and consequences of all potential outcomes, including short and longterm risks and benefits. Providers then elicit the extent to which patients value each of these distinct outcomes. Patients place a value on each outcome and then they weigh the different valuations of benefits and adverse consequences. This weighting of preferences ultimately drives decisions^{1,2}.

Several examples of preference-based care make the paradigm more transparent. Sexually active men may decline prostate surgery because of their concern about impotence, a potential consequence of surgery. Less sexually active men may not be concerned about this side effect and elect surgery. Patients with rheumatoid arthritis who drink alcohol may decline methotrexate because in order to take the drug they would need to abstain. Non-drinkers may find methotrexate an ideal medication. Other examples abound. The point is that for each patient the careful weighing of the benefits and adverse consequences of treatment choices help them arrive at a decision that reflects their preferences.

DISPARITIES IN HEALTH CARE UTILIZATION

Disparities in utilization of health services have been documented across vulnerable populations including women and racial and ethnic minorities, and across cardiac, oncologic, musculoskeletal, renal and other procedures, and medical care for HIV, cardiac disease, and other conditions^{3,4}. There are many proposed explanations for disparities. Most of the explanations can be considered "calls to action" that warrant remedy. These include financial barriers such as inadequate access to insurance or the inability to afford out-of-pocket costs and logistical barriers such as lack of geographic proximity to care or to transportation to receive care. More difficult barriers include cultural explanations such as differences in literacy, cultural tradition, and distrust of physicians as well as underlying racism. Each of these barriers is unacceptable and should prompt corrective action.

Contrasting with these "calls to action," patient preferences comprise a seemingly benign explanation for health care disparities. After all, if patients are receiving the treatments they prefer, is there any reason for concern or for intervention? Substantial evidence documents that preferences underlie aspects of gender, racial, and ethnic disparities. For example, men often choose total joint replacement when they can no longer do demanding activities such as work and sports, whereas women often choose total joint replacement when they are having difficulty with more fundamental activities of daily living⁵. Similarly, whites with chronic renal failure are somewhat more likely than African Americans to prefer transplantation as opposed to dialysis⁶.

What are the origins of patient preferences? Certainly there are important historical roots. Lingering effects of discrimination against African Americans, for example, have created cultural expectations of avoiding medical interventions in favor of home remedies. Long denied care, African Americans have learned to self-manage, and have a higher utilization of lay advice and prayer^{7,8}.

Additionally, the quality and timeliness of care that African Americans, Latinos, and other minorities experience also gives rise to preferences to avoid intervention. On average, minorities receive care at lower quality hospitals and present at later stages of disease. Because there is a higher prevalence of adverse events in patients treated at more advanced stages, and in lower quality hospitals, many minority patients logically perceive interventions as risky and avoid them.

These considerations give rise to a fundamental question: Do preferences represent fixed traits of individuals or a variable set of attitudes with environmental, situational, and cultural determinants? The approach to this question depends upon whether one takes a strictly economic versus a broader sociocultural view of decision-making. In the traditional economic model, an informed decision maker dispassionately weighs risks and benefits and applies his or her valuations of these outcomes to arrive at a decision. In this scenario, preferences are viewed as fixed and inherent to the individual. In a sociocultural model, on the other hand, a person's valuation of benefits and consequences directly reflects their horizons of opportunity, which have cultural and economic determinants. Some patients view surgery as frightening because others in the community describe it that way. Some do not view the benefits of surgery as being within reach because none in their community have undergone the procedure or recommend it. It is logical that these patients prefer not to have the intervention. The question is whether this preference reflects their own deeply held beliefs or, alternatively, community attitudes reflecting generations of substandard care and discrimination. We shall return to this point after introducing total hip replacement as a lens for viewing some of these concepts.

PREFERENCES IN TOTAL HIP REPLACEMENT

Recent studies have shown that Hispanics and African Americans undergo total hip replacements at only 25-40% of the rate of whites⁹. Further, impoverished whites undergo total hip replacement only half as often as non-poor whites⁹. These disparities in utilization at the population level do not appear to be explained by differences in the prevalence of hip osteoarthritis among African Americans, Hispanics, and whites or between poor and non-poor whites. Further, the patients cited in these studies are all Medicare recipients and thus have access to appropriate insurance for joint replacement. The disparities may, however, relate to differences in rates of referral to specialists, rates of presentation to primary care doctors with these complaints, knowledge of risks and benefits, advice provided by family and friends, attitudes towards risk, and ultimately patient preferences for benefits and consequences of hip replacement^{3,4,10,11}.

African Americans' preferences for total hip replacement are influenced by a variety of factors including lower expectation of benefit, higher perceptions of risk, knowing fewer people who have had hip replacement in the past, and preference for use of home remedy and prayer as opposed to more invasive treatments^{10,11}. Thus, it appears that patient preferences play a role in driving utilization and that utilization is substantially lower among these vulnerable groups than among non-poor whites.

An additional consideration in hip replacement is the hospital where patients have their procedures. Hospitals that perform a lower volume of total hip replacement have higher rates of mortality and other complications. In fact, hospitals that perform just 1 to 10 total hip replacements annually in the Medicare population have 2-fold higher rates

of mortality than hospitals that perform greater than 100 cases per year in the Medicare population¹². Our (unpublished) data also show that non-whites and poor people as well as women and the elderly are more likely to use low volume hospitals than high volume hospitals. Thus these populations are selecting hospitals that put them at higher risk for mortality and other complications. Do these choices reflect patient preferences? We do not know and that question deserves urgent study. Some evidence suggests that patient preferences drive choices of low versus high volume hospitals. One study presented a hypothetical example to patients awaiting elective abdominal surgery¹³. Patients were asked whether they would prefer to tolerate higher rates of operative mortality by staying at a local hospital for a Whipple procedure for cancer, or to travel to a distant hospital where mortality rates were lower. Some patients were willing to tolerate 6-fold higher rates of mortality in this hypothetical example before traveling to a more distant hospital because they preferred the convenience, comfort, and social support of receiving care nearby.

In summary, African Americans, Hispanics, and poor whites have just one-third the rate of total hip replacement as non-poor whites. Patients who present to low volume hospitals have worse perioperative outcomes. The poor, non-whites, and the elderly are more likely to present to low volume centers. We are left with the question of whether the choices reflect patient preferences. As noted, evidence suggests that they do, at least in part. If this is what patients want, is any intervention called for?

SHOULD PREFERENCES BE RESPECTED OR RESHAPED?

These arguments return us to the question of whether preferences are inherent characteristics that should be respected, or modifiable characteristics that could potentially be reshaped. The traditional economic model of decision-making portrays a rational decision maker with inherent preferences that should, no doubt, be respected. However, the sociocultural model of decision-making suggests that preferences reflect underlying social and cultural factors that may give rise to inaccurate perceptions of risk, benefit, and opportunity. In this scenario, interventions to reshape preferences could and should be considered if stated preferences reflect a lack of knowledge or opportunity.

The sociocultural model suggests that while we should respect patient preferences, we should also ensure that they are based on accurate perceptions of risk and benefit. Patients should ultimately make choices that are authentic. Specifically, in the total hip replacement area, several intervention strategies come to mind. The perception of the risk and benefit of total hip replacement in the community could certainly be addressed using community based educational interventions. Further, in the clinical setting, patients and providers could be better educated to understand the risks

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and benefits of hip replacement. Finally, referring physicians and surgeons should probe patients regarding the basis of their preferences regarding surgery. Do the preferences reflect an inaccurate understanding of risks and benefits? Do patients feel that they simply do not deserve the health benefits associated with surgery? If so, where do these perceptions come from? Clinicians can gently probe into these areas and in so doing open up an entirely new dialogue that helps both patients and physicians to understand the perceived and real benefits and consequences of the marvelous medical interventions at our disposal.

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