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The Potential of Shared Decision Making to Reduce Health Disparities

Jaime S. King, Mark H. Eckman, and Benjamin W. Moulton

Current methods of obtaining an informed consent leave much to be desired. Patients rarely read consent forms or understand all of the risks, benefits, or alternatives associated with their treatment.¹ Evaluating the advantages and disadvantages of treatment options often presents a more significant challenge for patients with lower levels of health literacy. This article reviews the evidence of shortcomings in our informed consent system and then explores the potential for a new approach to engage patients at all levels of health literacy in their treatment decisions. Specifically, the article will examine the potential of shared decision-making (SDM) to bridge gaps in knowledge, increase patient adherence to treatment, and improve health outcomes in low health literacy patient populations. Leveling barriers to treatment information for disadvantaged populations should be a public health imperative, especially if it can be shown to improve health outcomes and reduce health disparities.

In general, physicians have legal and ethical obligations to obtain an informed consent from patients to engage in treatment. With notable exceptions for patients incapable of providing consent, informed consent typically occurs in three steps: (1) a brief conversation with the physician regarding the preferred treatment; (2) the provision of a form that lists the risks of treatment; and (3) execution of the consent

form by the patient. Under this system, patients rarely make a truly informed decision. A review of over 540 informed consent forms at 157 randomly selected hospitals found that informed consent documents had limited informational value for the general patient population.² More concerning, a study of surgical patients found that over 70% failed to read the consent form and did not comprehend the risks of surgery.³ This system also poorly elicits patient preferences regarding the relative risks and benefits of alternative treatment options.

A more recent study at the University of Michigan, known as the DECISIONS study, provides significant clues about the epidemiology of decision-making in the United States.⁴ Through a nationwide random digit dial survey, DECISIONS researchers conducted telephone interviews with 2,575 participants, age 40 and older, to examine whether patients received basic information about their options prior to making health-related decisions.

The DECISIONS study revealed a pattern of inadequate medical decision-making that spanned the country and nine common medical conditions. In the last two years, 56% of survey participants discussed medication changes, 72% discussed cancer screening, and 16% discussed surgery with their providers. A panel of experts articulated five essential facts deemed critical to decision making for each of the conditions surveyed. Researchers found that many patients were “lacking knowledge of key facts needed to make informed choices.”⁵ For eight of the nine decisions, less than 50% of patients could answer more than one basic question about their treatment. Furthermore, patients reported that physicians asked them for their preferences less than one-third of the time. These

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findings were more robust for those with lower education levels.⁶

Interestingly, the DECISIONS survey also found that many patients understand much less than they think they do.⁷ Despite lower knowledge scores, patients with less education and income felt extremely well informed with respect to medication and screening decisions. The researchers suggested that this could be because some patients do not understand the information related to the treatment or the limits of their knowledge. The results imply that the failings of our current informed consent model weigh most heavily on patients who need the information the most.

Alternative models of providing information to patients should be explored to improve patient comprehension of medical decisions and their ability to actively participate in treatment. SDM has received a great deal of attention. It is “a process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment or side effect more or less tolerable than others.”⁸ Both parties use this information to come to a decision. Often as part of SDM, providers offer patients the opportunity to review a decision aid. Decision aids commonly come in pamphlet or video form and provide the patient with detailed information on the risks and benefits of the treatment alternatives for the condition in question (e.g., benign prostatic hypertrophy, obesity, or breast cancer). Decision aids offer patients the opportunity to (1) learn about their disease or condition and their treatment options at home; (2) review information multiple times on their own or with family and friends; and (3) be more prepared to discuss their options with their physician. In addition, many decision aids prompt patients to think about their personal preferences and values for different risks, benefits, and health conditions that should play a part in their decision.

Empirical research demonstrates that SDM with decision aids can significantly improve a patient’s decision-making. The Cochrane Review conducted 55 trials of decision aids addressing 23 different screening or treatment decisions. The research concluded that SDM with decision aids improves patient knowledge of the risks and benefits of treatment, the accuracy of risk perceptions, patient comfort with decisions, and participation in decision-making, as well as lessens the number of patients who remain undecided concerning their treatment.⁹ These beneficial effects are also seen in studies examining segments of the population with the lowest health literacy.¹⁰

Moreover recent pilot studies also suggest that improving informed consent practices for patients with low health literacy may have the collateral benefit of improving health outcomes and, correspondingly, the public’s health.¹¹ The possible link between SDM and improved health outcomes is derived from greater patient activation in their care. In general, results from studies investigating whether SDM improves overall health outcomes have been mixed. A 2006 Cochrane Review of decision aids found that while using decision aids increased patient activation, there was no correlation between use of the aids and health outcomes.¹² However, a number of other studies found linkages between increased patient activation in decision-making and health outcomes.¹³ For example, a recent pilot study found that patients at a senior center who watched three or more decision aid videos on chronic care had significantly higher patient activation scores at both 12 weeks and at 6 months than those who went to fewer screenings.¹⁴ Their walking scores also increased at both the 12-week and 6-month follow up points. In addition, patients who watched three or more videos also demonstrated better health-related quality of life at six months.

Theoretically, improvements in health outcomes occur when patients are better informed and more engaged in treatment decisions because they select treatments that fit better with their values and lifestyle, which improves their ability to adhere to treatment requirements. While more research is needed to verify these early correlations, these findings could be especially important for patients with lower health literacy, commonly elderly patients and those with lower education levels.

Historically, research on medical decision-making preferences has found that older patients and those with less formal education are less active and more likely to say they would defer to physicians for treatment choices than the average patient.¹⁵ Patients with these characteristics are also commonly associated with higher rates of hospitalization,¹⁶ poorer health outcomes,¹⁷ and increased mortality.¹⁸ Studies also demonstrate that they have a poorer understanding of their health conditions and are less engaged in treatment decisions. Not fully understanding one’s treatment options can isolate patients and disengage them from participation in their care.

However, recent evidence from studies on SDM with decision aids suggests that with appropriately designed interventions, health literacy is not a barrier to improving patient activation and health outcomes.¹⁹ In a study of 187 patients with coronary artery disease in a safety-net practice at an urban medical center, patients with lower health literacy benefited as much

as higher health literacy patients from an educational intervention using a SDM tool that focused on life style changes.²⁰ Disease-specific knowledge improved in both groups, as did health behaviors and outcomes measured at six months, including improvement in diet and smoking habits. Other studies have explored the use of low literacy pamphlets, educational materials written at a fifth grade level, consent forms written at a seventh grade reading level, and different versions of a cervical cancer screening brochure (using either illustrated or bulleted text formats).²¹ Generally, materials developed for a lower literacy level demonstrated better results in lower literacy patients. The few studies that have examined the impact of low literacy interventions on health behaviors or outcomes produced mixed results.²² For instance, while one study of a dietary educational intervention demonstrated improved compliance with reduced caloric intake and saturated fat,²³ other studies showed little effect on total caloric intake or cholesterol levels. The potential for SDM and decision aids to engage low health literacy patients in their treatment and improve their overall health outcomes necessitates additional study.

Conclusion

The National Quality Forum recently listed patient and family engagement (including SDM) as one of six health care reforms “with the greatest potential to eradicate disparities, reduce harm, and remove waste from the American healthcare system.”²⁴ Traditional informed consent methods have proven inadequate to engage and inform patients about treatment choices. The burdens of our current informed consent system weigh disproportionately on patients with low health literacy levels, who are often the oldest, sickest, and least educated. Ethically, we have an obligation to improve informed consent for all patients. This obligation further increases if we can demonstrate that the use of SDM could improve health outcomes for some of the most disadvantaged. While prior studies offer conflicting results on the impact of SDM on health outcomes, more recent research targeting disadvantaged patients suggests that SDM may positively affect the patient’s decision-making process and health outcomes. While more research is needed to demonstrate these effects across a range of patient populations and conditions, SDM shows promise to engage patients at all levels of health literacy and improve overall health outcomes.

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