The Patient Provider Shared Decision Making Project: A Pilot to Evaluate the Use of Healthcare Decision Aids Among Patients Living in Poverty

Michael Clark and Nancy Rothman 24 September 2011

Summary

Shared decision making is a process that promotes patient involvement in decisions affecting their health care. The Patient Provider Shared Decision Making Project is a collaborative pilot project that used standardized decision aids with a poor underserved population in the Greater Philadelphia area. A high percentage of patients in the pilot perceived themselves to be legitimate participants in the decision-making process, and exposure to the decision-making aids (DVDs, which they preferred, and written booklets) enhanced this perception.

Shared Decision Making and the Chronic Care Model

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Shared decision making is a process that supports patients in the self-management of disease. It attempts to translate the latest evidence into forms that are accessible and useful for supporting informed decisions consistent with the patient's values and preferences. Current trends indicate that shared decision making and a patient's self-management of disease will evolve as important quality measures that will be tied to reimbursement in the future.

Conceptually, shared decision making is one of the dimensions of the Wagner Chronic Care Model (Wagner, Austin, and Michael 1996). The Chronic Care Model outlines important systems components necessary to improve the health of populations. Included in this model is an emphasis on patient involvement in their own care. This includes making informed choices about the care and the management of their chronic disease. However, utilization research on the Chronic Care Model indicates that shared decision making implementation is lagging behind other aspects of the model such as the adoption of the electronic health record, the construction of patient registries and clinical decision-making support (Coleman et al. 2009). This pattern may be due, in part, to a logical response on the part of healthcare service organizations to pressures to adopt "meaningful use" of electronic data systems. However, once these systems are in place, more attention will likely shift to developing collaborative care

processes that serve to improve outcomes related to patients' self-management of their disease.

Despite its logical appeal, there is scant research supporting best practice recommendations for shared decision making, particularly among poor and underserved populations (Galesic and García-Retamero 2011a, 2011b; Liebman, Heffernan, and Sarvela 2007; Peek et al. 2011). Evidence to support this development will likely emerge in a decentralized manner as healthcare delivery models such as the Patient Centered Medical Home and Accountable Care Organizations are charged with developing programs tailored to optimize outcomes for the specific populations that they serve. This project evaluated efforts to implement a shared decision making program to meet the needs of the urban poor and other underserved populations.

The Patient Provider Decision Sharing Project

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One of the main barriers to engaging in effective shared decision making practices has been the amount of time that such efforts can take. Using decision aids in the form of printed material and DVDs is one method to improve efficiency. The Patient Provider Decision Sharing Project was designed as a pilot to evaluate whether the use of a

particular set of materials developed by the Foundation for Informed Medical Decision Making and produced by Health Dialog Services Corporation could be effective in promoting shared decision making in a population of poor patients who receive care at nurse-managed primary care clinics. The goal of the project was to empower patients to take a more active role in the healthcare decision-making process, thus enabling them to access treatment that appropriately reflects their values. It also sought to support patients in the self-management of chronic conditions.

This pilot project was a collaborative effort that involved the National Nursing Centers Consortium, the Pennsylvania Governor's Office of Healthcare Reform, the Foundation for Informed Medical Decision Making, Public Health Management Corporation and Temple University. The planning and design of the project began at the end of 2009 when Ann Torregrossa, the Director of Pennsylvania's Governor's Office of Health Care Reform, and Nancy Rothman, Independence Foundation Professor of Urban Community Nursing, Department of Nursing, College of Health Professions and Social Work, Temple University, visited the Dartmouth Hitchcock Center for Shared Decision Making. The impetus and funding for the program evolved from initiatives associated with the Chronic Care Initiative in Pennsylvania designed to increase quality and decrease costs associated with the management of chronic diseases (Siminerio et al. 2009).

The Foundation for Informed Medical Decision Making (n.d.) agreed to provide, free of charge, a set of decision aids to be used in the project. The Director of Patient Support Strategies for the Foundation, Richard Wexler, MD, and Kate Clay, MSN, RN, from the Dartmouth Center for Shared Decision Making (n.d.), provided ongoing consultative support throughout the year- long project. This included participation in monthly project calls that also involved Nancy Rothman, the clinical directors of five nurse-managed centers, and support staff for the project. The five centers involved in the project provided care for underserved populations in the Greater Philadelphia area. These centers included one serving primarily a homeless population, two serving public housing residents and one serving immigrant farm workers in Chester County. Decision aids were provided for these sites along with pre- and post-viewing surveys and forms for tracking the distribution of the decision aids. Permission was sought from patients for contacting them to offer coaching support from nurse practitioners working on the project. These nurse practitioner counselors offered coaching support either on-site or via telephone follow-up encounters.

The topical areas for the decision aids were abnormal uterine bleeding, chronic pain, chronic low back pain, colorectal screening, coronary artery disease, depression, diabetes, osteoarthritis and decisions about management including hip replacement surgery, knee replacement

surgery, menopause, prostate cancer, prostate enlargement, PSA testing and weight reduction surgery. Decision aid material consisted of a DVD that takes approximately 30 minutes to view and a companion booklet. The decision aid DVD employs a series of interviews with patients and providers that are based on case studies involving particular healthcare decisions or patterns of behavioral strategies for the self-management of disease. The interviews integrate the use of evidence with an exploration of the values and perspectives of patients and providers.

Outcomes from the Pilot Project

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Two issues were addressed in evaluating outcomes for the pilot project: efforts to promote the distribution and use of the decision aids, and the impact of the decision aids on the process of informed choice.

A total of 80 decision aids were distributed to patients during the year-long pilot project. This outcome fell short of the targeted goal to distribute 100 decision aids. All of the patients watched the DVD, but they indicated that they did not read the accompanying booklet. Feedback from both patients and clinicians indicated that the booklet material was too dense and not at an appropriate reading level for this population.

An analysis of the distribution processes has indicated the

need to promote increased awareness by both clinicians and patients of the availability and utility of the decision aids. During the project, posters and flyers were provided for the centers. Further efforts will now include having a decision aid request form distributed to all patients on their arrival in the waiting room. In addition, the RN care managers at the centers are being asked to take responsibility for the distribution, tracking and post-viewing counseling of patients. It is believed that these providers are best suited for this task. Descriptive statistics associated with outcomes are described in Table 1.

Table 1. Descriptive statistics for the Patient Provider Decision Sharing Project

Gender	Race	Educational Level	Decision Aids Viewed
Male: 64% Female: 46%	African American: 48% Hispanic: 32% White: 16%	8th grade or below: 37% Some high school: 26% High school graduate: 16% Some college: 21%	Diabetes: 49% Chronic pain: 8% Depression: 8% Weight reduction surgery: 8% Abnormal uterine bleeding: 8% Osteoarthritis of the knee: 6% PSA testing: 6% Menopause: 5% Chronic low back pain: 2%

Feedback indicated that the viewers thought that the

information provided was both needed and useful to them. The results indicated that viewing the DVDs enhanced an underlying positive disposition toward patients' active involvement in the decision-making process. Prior to viewing, 87 percent of patients thought that decision making should be done in collaboration with their provider, while 11 percent believed that they should make choices alone and 2 percent felt that the provider should make the decisions. After viewing, 92 percent preferred collaborative decision making with their provider, and 8 percent indicated that they alone should make decisions about their care.

Conclusions and Future Directions

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The most surprising outcome is that so many patients perceived themselves to be legitimate participants in the decision-making process prior to exposure to the decision-making aids, and that exposure to the decision-making aids enhanced this perception. This indicates that interested members of this population would likely benefit from the use of decision aids. It is clear that this population prefers the DVD to the written booklet. Although DVDs are more expensive to produce, the cost may be necessary in providing decision support for this population. Further work is needed to get more decision aids to patients. The centers will need to continue to

evaluate this outcome as well as work on processes for ensuring adequate follow-up counseling and coaching of patients who have been exposed to the information in the decision aids.

Funding for the year-long pilot was provided by funds from the Pennsylvania Governor's Office of Health Care Reform as part of the Chronic Care Initiative. Future finding sources are being sought. Currently, the Foundation for Informed Medical Decision Making has promised to continue to supply the decision aids to the centers. The center serving immigrant farm workers was unable to continue with the project, and one new center serving the urban poor has been added.

Work continues on the development of an integrated referral management system for enrollments, tracking both the distribution and return of decision aids as well as the patients' progress in the decision-making process, pre- and post-viewing surveys and surveys 30 days after viewing. De-identified patient data will be entered within the Foundation for Informed Medical Decision Making's web-based system.

The project will continue to engage in monthly phone conversations among key participants such as care managers at the centers, Nancy Rothman, Richard Wexler and other representatives from the Institute for Informed Medical Decision Making in order to refine the program and evaluate outcomes. The program will also seek to strengthen its alliance with the Public Health Management

Corporation and the National Nursing Centers Consortium in developing this project. The project team is optimistic that this program can have a very beneficial impact in promoting active participation in decision making among patients in the identified safety-net populations.

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