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A Demonstration Of Shared Decision Making In Primary Care Highlights Barriers To Adoption And Potential Remedies

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ABSTRACT Recent developments in health reform related to the passage of the Affordable Care Act and ensuing regulations encourage delivery systems to engage in shared decision making, in which patients and providers together make health care decisions that are informed by medical evidence and tailored to the specific characteristics and values of the patient. To better understand how delivery systems can implement shared decision making, we interviewed representatives of eight primary care sites participating in a demonstration funded and coordinated by the Informed Medical Decisions Foundation. Barriers to shared decision making included overworked physicians, insufficient provider training, and clinical information systems incapable of prompting or tracking patients through the decision-making process. Methods to improve shared decision making included using automatic triggers for the distribution of decision aids and engaging team members other than physicians in the process. We conclude that substantial investments in provider training, information systems, and process reengineering may be necessary to implement shared decision making successfully.

Providing patient-centered care is a key goal of health system improvement efforts.[1] Shared decision making, in which patients and providers make health care decisions together, represents one approach to operationalizing patient-centeredness and is featured in new policies intended to improve the quality of care. For example, the final rule for Medicare accountable care organizations requires delivery systems that participate in the Medicare Shared Savings Program to engage in shared decision making.[2]

In shared decision making, providers and patients exchange important information: Providers help patients understand medical evidence about the decisions they are facing, and patients help providers understand their needs, values, and preferences concerning these decisions.[3,4] Then, ideally after allowing time for reflection, patients and providers decide together on a care plan consistent with medical science and personalized to each patient's needs, values, and preferences.

Recent controversial breast and prostate cancer screening recommendations from the US Preventive Services Task Force have highlighted the importance of shared decision making.[5,6] Even when providers disagree about the optimal screening strategy for populations, they agree that for individuals, shared decision making can produce care that is tailored to each patient's preferences, which is better than a "one size fits all" approach such as screening all patients or screening none of them.[7,8]

For example, screening for prostate cancer by checking the blood level of prostate-specific antigen may reduce the risk of dying from prostate cancer. However, screening has its own risks. "False alarm" levels of the antigen can lead to biopsies of the prostate gland, which are painful

and may cause bleeding or infection, even when no cancer is present. This screening can also detect slow-growing cancers that might never harm a patient if left untreated but whose detection typically leads to a cascade of treatments with major and potentially harmful side effects.

With shared decision making, the patient would learn about the pros and cons of being screened for prostate cancer and could decide with his provider whether to have a screening test. Patients differ in how they feel about the trade-offs involved in being screened or not. Therefore, a provider who truly engages in shared decision making would probably have some patients who choose to be screened and others who do not.

Despite its growing importance, shared decision making is still infrequent in American medicine. Providers often make treatment recommendations and deliver care without adequately explaining treatment options or soliciting patients' input.[9–11] Insufficient time and expertise may underlie providers' failure to communicate with patients about their treatment options, values, and preferences.[3]

To address these barriers, organizations such as the Informed Medical Decisions Foundation[12] and Health Dialog[13] have developed decision aids—videos and booklets that give patients unbiased, expert-reviewed information about treatment or testing options. In many cases, patients can use decision aids outside the medical office and without a provider's assistance.

Despite evidence that they can inform patients, decision aids alone are not sufficient to ensure that shared decision making will take place.[14] Even after a patient uses a decision aid, shared decision making still requires that the provider learn the patient's values and preferences, that the patient and provider reach a decision together, and that the patient receive care concordant with this decision.

Little is known about fully implementing shared decision making in clinical practice, and providers may face unanticipated logistical barriers, especially in the busy primary care practices that may be central to new accountable care organizations.[3,15] Lessons from early adopters could inform the strategies that accountable care organizations, medical homes, and other providers use to implement shared decision making.

In this article we describe the experiences of eight primary care sites participating in an ongoing three-year demonstration of shared decision making funded and coordinated by the Informed Medical Decisions Foundation.

Study Data And Methods

OVERVIEW We performed a qualitative description of the initial implementation of shared decision making in all eight primary care sites participating in the demonstration mentioned above.[16,17] We based this description on semistructured interviews with key informants who explained how they implemented shared decision making and what barriers and facilitators they encountered during the first eighteen months of the demonstration.

We also developed a logic model to show how, in theory, decision aids fit into a larger sequence of steps necessary to perform shared decision making successfully. This model allowed us to organize informants' responses and identify steps for which multiple sites reported implementation problems—as well as their solutions.

SHARED DECISION MAKING DEMONSTRATION In July 2009 the Informed Medical Decisions Foundation began a demonstration of shared decision making in the primary care setting. The goal of the demonstration was to show the feasibility of using decision aids to conduct shared decision making in a variety of practice settings, ranging from small, independent primary care practices to large academic institutions.

The foundation selected the following eight sites in different regions of the United States to participate in the demonstration: Dartmouth-Hitchcock Medical Center, in New Hampshire; MaineHealth; Massachusetts General Hospital; Mercy Clinics, in Iowa; the Oregon Rural Practice–Based Research Network; the Palo Alto Medical Foundation, in California; the Stillwater Medical Group, in Minnesota; and the University of North Carolina at Chapel Hill.[18]

The sites were selected based on their records of successful quality improvement initiatives. Some of the sites had prior experience with decision aids, and each site contained one or more primary care clinical practices. A total of thirty-four of these practices participated in the demonstration.

The Informed Medical Decisions Foundation provided the participating sites with support for planning and implementing shared decision making. In the demonstration, shared decision making was facilitated by using decision aids.

This support was structured around the following eight key steps of implementation: engage and train providers and staff, identify types of patients or patient populations to receive decision support, direct support to those specific patients or populations, distribute decision aids, encourage decision aid viewing, provide support to patients and providers, measure the impact at the patient and program levels, and provide feedback using data from those levels. A visual

representation of this process is available in the online Appendix.[19]

In addition, the foundation provided demonstration sites with access to decision aids, funding to support project leadership and staff, project management tools, patient questionnaires, and a registry for collecting patient-reported data. The decision aids, which were produced by Health Dialog and the foundation, covered nearly fifty medical decisions applying to a variety of health conditions. The decisions included choosing among options for low back pain treatment, cancer screening, chronic condition care, and orthopedic procedures.[12]

The demonstration project was structured as a learning collaborative. Demonstration sites participated in monthly meetings and communicated with each other by blog to share implementation lessons and early results.

SEMISTRUCTURED INTERVIEWS Based on a review of the literature and initial interviews with Informed Medical Decisions Foundation leadership, we developed protocols for forty-five-minute semistructured interviews with demonstration site leaders and practitioners, including physicians, nurses, and other health educators. These protocols used open-ended questions to ask about each site's experiences with implementing shared decision making, including barriers and facilitators of implementation.

All interviews were conducted by one or two RAND investigators and digitally recorded with the interviewee's consent. Multiple members of the research team took notes during each interview. To mitigate note-taker influence on findings, a research assistant created a unified set of notes for each interview, supplemented with verbatim quotations.

We selected and interviewed twenty-three key informants from the demonstration sites, using purposeful sampling to obtain at least one demonstration leader and at least one clinician or health educator at each site.[16] These informants included administrative leaders, primary care physicians, nurses, and specially trained decision coaches. To gain insight into patients' perspectives on implementing shared decision making, we also interviewed ten patients from one demonstration site. We conducted the interviews between December 2010 and March 2011.

ANALYSIS We coded interview notes and recordings to identify recurrent responses, expressed in language similar to that used by informants. Building from a small group of themes described by informants in two or more sites, we developed a set of generalizations that held true for the data collected from all of the sites.

By applying these generalizations to existing knowledge about shared decision making, we identified key steps of using decision aids to conduct shared decision making. We then identified themes that represented barriers and facilitators. The RAND Human Subjects Protection Committee approved this study.

LIMITATIONS Our study had limitations. The primary care sites that we studied were led by early adopters who had volunteered to participate in a demonstration of shared decision making. Because of their enthusiasm and prior experiences with quality improvement, this small group of self-selected sites may have experienced fewer implementation problems, compared to later adopters.

In addition, our findings were based on interviews with site leaders and clinicians who were local "champions" of shared decision making. Other clinicians and staff might have reported different facilitators and barriers to implementation.

Study Results

KEY STEPS OF SHARED DECISION MAKING Our logic model for shared decision making based on decision aids included four main steps.[19]

▶**RECOGNIZE OPPORTUNITY:** First, patients and providers recognize the occurrence of a decision opportunity and select a decision aid corresponding to this opportunity. For example, a primary care physician might recognize that a patient's knee arthritis has worsened and select a decision aid that discusses treatment options for this condition. Alternatively, administrative data might trigger the recognition of a decision opportunity. In this case, a practice might send decision aids about colorectal cancer screening options to patients who turned fifty in the prior year and who were scheduled to have visits.

▶**USE DECISION AIDS:** Second, patients receive and use decision aids, possibly with the endorsement of and instruction from a provider or staff member. For example, the patient might view a video or read a booklet about colorectal cancer screening options. Some decision aids also contain worksheets that help patients weigh their values and preferences concerning the decision.

▶**HAVE A CONVERSATION:** Third, patients and providers, or specialized staff such as decision coaches, have a "post–decision aid" conversation during which they reach a shared decision. In this conversation, the provider may check the patient's understanding of medical facts concerning the decision and continue to help clarify the patient's values and preferences.

For example, the provider might check whether the patient understands that the major colorectal cancer screening options have roughly equal effectiveness, but some are more invasive,

and others require more frequent repetition. The patient might also verify that the provider truly understands the patient's preference for more frequent over more invasive testing.

This post–decision aid conversation can take many forms; involve multiple providers and other parties, including patients' family members; and either occur over a period of time, to allow provisional decisions to be made and reconsidered, or take place more quickly if a rapid decision is needed for clinical reasons. The result of the conversation should be a final shared decision. When providers perform this conversation poorly—for example, by dismissing a patient's preference for screening with stool cards instead of a colonoscopy—shared decision making has not occurred.[20]

▶RECEIVE CARE: Fourth, the patient receives care consistent with the final shared decision. If the patient instead receives health care inconsistent with that decision, perhaps because the decision was not communicated to other providers, the entire process will have failed to produce patient-centered care.

BARRIERS TO IMPLEMENTING SHARED DECISION MAKING Sites reported the following three main barriers to implementing shared decision making based on decision aids: overworked physicians, insufficient provider training, and inadequate clinical information systems.

▶OVERWORKED PHYSICIANS: Because primary care physicians frequently address multiple health issues during each visit, shared decision making that started with physician-driven distribution of decision aids was unreliable. One interviewee observed, "As long as you have the physicians in the middle of [distributing decision aids], they have too many other things on their plate to reliably ensure this would happen every time...in a ten-to-fifteen-minute appointment."

Site leaders who relied on physicians to trigger the distribution of decision aids estimated that only 10–30 percent of patients facing decision opportunities received the aids. One interviewee reported trying to remind physicians about applicable decision aids on a patient-by-patient basis, but this process was unsustainable: "I started viewing the schedule ahead of time and flagging [eligible patients] by putting a little blue dot by their name, but that resulted in a lot of chart review.... I only did the chart reviews for a month to a month and a half because it was so [time-]consuming."

▶INSUFFICIENT PROVIDER TRAINING: Providers' lack of prior training in shared decision making was another barrier to participation. Some site leaders reported having to convince physicians that they were not already performing shared decision making. One of these leaders told us: "We did a physician survey to get physician feedback about shared decision making, and we found that physicians felt that they were already doing shared decision making before we introduced the decision aids. To me, it's not really shared decision making when there is only a fifteen-minute appointment, and patients can't really engage in a conversation when they don't know much about the topic."

Another site leader expressed a need to achieve a balanced emphasis on both patient and provider education: "You really have to pay attention to the clinicians in this equation. You can't just ask them to do something and assume that they'll know what you mean. We paid a lot of attention to getting the decision aids to patients, but we underattended [to] the training of our clinicians."

▶INADEQUATE CLINICAL INFORMATION SYSTEMS: Clinical information systems, either paper or electronic, posed major barriers to implementing the multiple steps of shared decision making. For example, nearly all sites' records lacked capabilities to flag patients as candidates for decision aids or indicate which patients had received them; mechanisms for communicating patient-reported values and preferences to providers; and longitudinal functions to track patients through the shared decision-making process, including determining whether patients had timely post–decision aid conversations with providers.

Sites' clinical information systems also were unable to integrate with the decision aids. Some decision aids included questionnaires that elicited patients' decision-relevant values and preferences. However, no site reported having a medical record that incorporated patients' responses to these questionnaires. This lack of integration meant that in general, the responses were unavailable to clinicians who might perform post–decision aid conversations. One site leader explained: "All of the information from the [decision aid questionnaires] is off the chart. There is documentation that the decision aid was given...but anything from the surveys is kept completely separate."

No participating site reported having an information system that included tools for tracking whether patients actually received care concordant with their decisions.

FACILITATORS OF IMPLEMENTING SHARED DECISION MAKING Leaders and front-line clinicians in the demonstration sites consistently identified the following two key facilitators of implementation: using automatic triggers for decision aid distribution and engaging team members other than physicians.

▶AUTOMATIC TRIGGERS: Site leaders reported that recognizing decision opportunities and using decision aids occurred more reliably when these steps were "automated" than when providers had to remember to take them. One commented: "The more automatic you can make it, the more successful decision aids can be in primary care, whether that's having the health tech [nician] prescribe it or having it be an automatic mailing based on visit type. Anything you can do to streamline process and not rely on clinicians' memory to include [the decision aid] as part of visit routine will be a successful strategy."

There were two general models for automating the distribution of decision aids. First, some sites distributed the aids to all patients who, based on age and sex, might be eligible for a type of cancer screening for which a decision aid existed. Under this model, decision aid distribution was timed to precede a patient's next scheduled primary care appointment, with the assumption that the post–decision aid conversation would occur at this appointment.

Second, some sites reported linking the automatic distribution of decision aids to specialist referrals. These sites created protocols that prompted staff members to prescribe the aid corresponding to the reason for referral. For example, a patient referred to an orthopedic surgeon for consideration of knee replacement would receive a decision aid about treatment options for knee arthritis. The post–decision aid conversation then took place at the specialist clinic. Alternatively, a primary care provider could follow up with a patient before the specialist appointment, provide decision support, and reach a shared decision about whether to proceed with a referral.

The limited range of issues addressed in specialty clinics improved the chances of performing the post–decision aid conversation there. One site leader commented: "In the specialty clinic, the [decision aids] are much more frequently discussed. It is a bigger challenge for the primary care practice because there may be several things a patient wants to discuss, but when you see a specialist, you see the doctor for a particular purpose."

▶ENGAGING NONPHYSICIANS: Some site leaders reported better frequency and quality of decision aid distribution when it was performed by personnel other than physicians. For example, one leader reported: "We have had a less exciting response about the [decision aids] from physicians. Some physicians are incredibly resistant. On the positive side...there has been a remarkable and helpful response [from other clinic staff who] want to be sure we are delivering patient education and decision support."

Some patients also suggested that practice staff had more time than physicians to introduce patients to decision aids and explain how to use them. One patient told us: "When you're with the doctor, you don't get a chance to ask a lot of questions. ...A nurse I had never met [before] came in and introduced me to [the decision aid]. She had a CD and a book about the surgery. ...Of course I was interested in that."

Discussion

Shared decision making has the potential to increase patient engagement, leading to treatment choices that are more concordant with patients' wishes. Implementing shared decision making in primary care, where there is currently little financial incentive to guide patients toward particular treatment choices, may be an especially promising way to improve quality while avoiding unwanted and costly medical interventions.[21,22]

However, widespread implementation will not be easy. Our interviews revealed that even primary care sites receiving additional resources and guidance from a demonstration project encountered major educational, operational, and informatics challenges to implementation.

Some of the barriers and facilitators that we identified were consistent with the results of earlier studies. For example, we found that overworked primary care physicians constituted a barrier to distributing decision aids and undertaking shared decision making with patients. Engaging staff other than physicians facilitated the distribution of decision aids, which could lead to better outcomes in shared decision making between patients and providers. These findings echo an earlier study of Los Angeles primary care practices in which the distribution of decision aids was limited by competing demands and time pressures and increased by teamwork between physicians and highly engaged clinical staff.[23,24] In a recent systematic review, time pressure was the most commonly reported barrier to shared decision making.[25]

We also found that insufficient provider training was a barrier to implementation. Similarly, two reviews found that provider knowledge of and attitudes toward shared decision making were barriers to implementation and that provider training can improve the quality of decision-making conversations between providers and patients—for example, by increasing providers' solicitation of patients' input.[25,26]

Our study adds to these prior reviews in two important ways. First, we developed a logic model that presents shared decision making as a sequence of steps, beginning with the recognition of a decision opportunity and ending with

a patient receiving care that is concordant with his or her values and beliefs. This model implies that poor performance of any step, including those that follow use of a decision aid, can undermine the benefits of shared decision making.

Second, we identified a previously underappreciated barrier to shared decision making: the lack of certain capabilities in clinical information systems. These systems were not equipped to facilitate shared decision making, by storing patient-reported values and preferences concerning a care decision, for example. Nor were they equipped to track patients through the key steps of the process, being unable to determine whether post–decision aid conversations occurred or whether patients ultimately received care consistent with their shared decisions. Even sites using electronic health records that included electronic ordering of decision aids lacked these capabilities.

Our findings have implications for primary care practices and larger delivery systems seeking to implement shared decision making. Physicians usually work at or beyond their capacity to provide new services, such as shared decision making, reliably. As a result, implementation models are unlikely to succeed if they rely on physicians to distribute decision aids. Strategies that leverage other staff and automated processes such as referrals to trigger distribution are promising alternatives.

Successful implementation may also depend on developing clinical information systems that can track each patient's progress through the entire process of shared decision making and identify the most difficult steps in this process.

Our findings also have implications for determining whether accountable care organizations have engaged meaningfully in shared decision making. Although distributing decision aids is a crucial first step, measuring only distribution would fail to detect problems with subsequent, equally important steps. An ideal measure would assess all of these steps.

For example, an "all-or-none measure," in which an accountable care organization would get credit for shared decision making only when a patient completed all key decision-making steps and received care concordant with his or her decision, is a conceptually attractive option.[27] In addition, measures of decision quality, which reward the end result of successful shared decision making, could assess meaningful engagement.[28]

Finally, the barriers that we report are similar to those impeding other changes in primary care practices, such as the transformation to patient-centered medical homes and the adoption of electronic health record systems.[29,30] These barriers probably stem from a common source: a payment system that prioritizes the volume of visit-based care delivered by physicians over the reliability of longitudinal care delivered by teams.[31] Payment reforms such as those in the Medicare Shared Savings Program, which tilt the balance of incentives away from visit volume and toward greater care coordination, may be necessary for shared decision making to take hold.

Conclusion

Given the difficulty of implementing shared decision making in primary care, accountable care organizations recognized by Medicare may fail to meaningfully engage patients and change patterns of care in their initial attempts to satisfy Medicare's final rule requirements.[2] To meet this challenge, we recommend that such organizations carefully plan their implementation of shared decision making and make substantial long-term investments in information systems, provider training, and process reengineering.

To foster greater accountability, we also recommend developing measures that capture all the steps of the shared decision-making process. By holding providers to a rising standard for shared decision making, the Centers for Medicaid and Medicare Services can encourage health system transformation that is truly patient-centered. ∎

NOTES

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In this month's *Health Affairs*, Mark Friedberg and coauthors describe the results of interviews conducted with representatives from eight primary care sites participating in demonstration of shared decision making that was funded and coordinated by the Informed Medical Decisions Foundation. The interviews identified key barriers to adopting shared decision making, including overworked physicians, insufficient provider training, and clinical information systems incapable of prompting or tracking patients through the decision-making process. Interviewees also proposed measures that would facilitate adoption. The authors conclude

that substantial investments should be made in these facilitators, so that shared decision making can be implemented successfully.

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