If You Build It, Will They Come?
A Qualitative Evaluation of the Use of Video-based Decision Aids in Primary Care
Alita Newsome, MA; William Sieber, PhD; Michele Smith, PhD; Dustin Lillie, MD

BACKGROUND AND OBJECTIVES: Given the growing presence of Patient-centered Medical Home practices and the need for patient participation, it is concerning that tools to improve patient participation are not widely used in primary care. Despite demonstrated effect on decision quality and patient satisfaction, decision aids (DAs) are not broadly utilized. We conducted focus groups to examine the use of DAs and uncovered barriers to greater DA utilization in primary care.

METHODS: The University of California, San Diego family medicine clinics use an integrated process to prescribe DA videos. We conducted provider and patient focus groups to explore use of DAs in three clinics. Using a qualitative phenomenological design, we analyzed thematic content using immersion techniques.

RESULTS: Focus group discussions identified six categories: patient benefits, physician benefits, process improvements needed, reasons DAs are prescribed, barriers to watching DAs, and the role of the DA. These categories encompassed 21 themes. Four themes were salient for improving DA utilization: follow-up process needs improvement, prescribing process needs improvement, patients were unclear regarding each DA’s purpose, and patient benefits.

CONCLUSIONS: While previous studies have described expected barriers to hypothetical DA distribution, our analysis reveals barriers reported by physicians, staff, and patients based on actual experience in practice. Decision aids can improve patient participation in health decisions. However, physicians and patients have to recognize a need for these tools before they will be adopted in practice.

(Fam Med 2012;44(1):26-31.)

Medical care delivery has evolved from a paternalistic model to one of shared decisions and shared responsibility. This concept of partnership is fundamental to the model of the Patient-centered Medical Home (PCMH). In practice, implementing this shift is often problematic given constraints of both time and attitude. Tools available to foster the practice of shared decision making include decision aids (DAs). The PCMH model is central to current efforts to shape primary care, and it is the environment most evident to incorporate shared decision making. DAs are not widely used in primary care despite evidence of their effectiveness.

Background and Objectives
Current legislative health reform, The Patient Protection and Affordable Care Act, aims to improve the quality of care and renews focus on patient-centered care. Implicit in this change to patient-centered care, patients will take a more participatory role in their health care than in the past. The legislation includes provisions to facilitate and require a shared decision-making process. Shared decision making (SDM) is the process by which engaged and informed patients participate with their provider in making their health care decisions. Charles and colleagues outlined this concept as “involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment, and reaching an agreement about which treatment to implement.” Crawford

From the Department of Family and Preventive Medicine, University of California, San Diego.
and colleagues’ systematic review found that higher levels of patient involvement resulted in increased satisfaction for patients as well as better quality of care.  

DAs are one type of tool used to facilitate SDM in the medical encounter. DAs come in various formats, including brochures, videos, and worksheets. These tools provide patients with evidence-based information that is designed to engage informed patients to make a health decision shaped by their own feelings and preferences. Regardless of format, DAs have three elements: clinical information, values clarification, and preparation for communicating with the physician. A Cochrane review demonstrated that DAs improve patient knowledge, create realistic patient expectations, and enhance active patient participation in decision making. Identifying barriers to the real-world use of DAs in primary care will help to better utilize these tools.

DAs are tools designed to communicate the best available evidence to patients in ways that encourage them to engage with their providers regarding intervention choices and are not the same as conventional educational materials that simply present health information to a patient. DAs present “balanced personalized information about ‘options’ in sufficient detail for patients to arrive at informed judgments about the personal value of those options.” Patient DAs promote patient action by preparing people to make an informed, considered decision. As the evidence supporting the use of DAs and SDM increases, researchers have begun examining the difficulties with implementation of these tools.

Informed and shared decision making processes produce better clinical outcomes. However, the brief encounter model often used in primary care leaves little room for shared decision making. Hill and colleagues reported recently that even when DAs were freely available, they were not used in primary care offices. This pattern of use may be due in part to the perceived additional time it would take to present a DA to a patient.

Issues identified as probable barriers to SDM include time constraints, financial disincentives, and lack of supportive infrastructure. Graham and colleagues interviewed physicians not currently using DAs and had them evaluate a DA and propose anticipated barriers. These providers were concerned about time, absence of reimbursement for decision counseling, and the need for support infrastructure. Recently, researchers reported that physicians and staff perceived that DAs “were not designed with ‘real life’ consultation pressures in mind.” They had particular concern about the time it would take to incorporate them into practice. These authors suggested that for a DA to be used in conjunction with a physician/office visit it would be best if the patient could take the DA home first.

The University of California, San Diego (UCSD) Division of Family Medicine uses video DAs developed by the Foundation for Informed Decision Making (FIMDM) in their primary care practices. Since 2007, the UCSD Division of Family Medicine has been one of 11 demonstration sites working in a shared decision-making research collaborative with FIMDM. Eight DA topics have been available via an electronic prescription in the electronic health record.

Methods

The authors were part of a multidisciplinary team of primary care providers and researchers, each with different theoretical and methodological perspectives: a clinical health psychologist (WS), a family physician (DL), a marriage and family therapist (MS), and an anthropologist (AN). The team was comprised of both quantitative (WS, DL) and qualitative (MS, AN) researchers with varying amounts of experience in SDM. We were aware of, and discussed, these differences in bias throughout the planning, implementation, and analysis portions of this study.

Study Design

This study utilized a phenomenological qualitative research design. We gathered data between January and May 2008 from 10 focus groups. We included multiple participant types from the three UCSD family medicine clinics: physicians (n=11), clinic staff (n=33), and patients (n=37). All focus groups were both audiotaped and video recorded. This project was approved by the UCSD Institutional Review Board (#071838).

Participants

Physician participants were recruited through electronic messages and through faculty meetings. All physicians approached for the focus groups had experience using the DAs in clinical practice. We included physicians who prescribed a high volume of DAs as well as those who prescribed very few DAs, based on prescribing data from our electronic medical record. The physician focus group was held outside the clinic.

Medical assistant staff members were recruited through discussions with clinic managers at the family medicine clinic sites. All staff participants had been exposed to the DAs and were involved in their distribution through the electronic medical record order at the clinics. Staff focus groups were held at clinics during lunch hour.

Patients were recruited through a letter mailed to all patients at any of the three UCSD Family Medicine Clinics who had been prescribed a DA between 2007 and early 2008. Follow-up telephone calls from research staff were used to enroll patients in focus groups. Patient focus groups were held at two of the three family medicine clinic sites to promote geographic variation. Patient focus groups were subdivided to provide a focused scope to the discussion. Focus groups were held separately for patients who had watched a DA and patients who had not watched a DA. Watching a DA
was defined as any patient who had logged onto the video server to watch the video online or who had requested a DVD to be sent to them in the mail. In addition, we divided patients depending on the type of DA they had been prescribed into two groups: cancer screening DAs and chronic illness care DAs.

Compensation was provided to all focus group participants. Physicians were provided with dinner as well as $100 in gift cards for their participation. Clinic staff members were provided lunch and $25 in gift cards for their participation. Patient participants were provided with $50 in gift cards for their participation.

Data Collection
The groups were moderated by a qualitative researcher (MS) with experience in qualitative and focus group methodology using a guide of open-ended questions. A different question guide was used for each participant type. There was a predetermined set of questions; however, additional questions were asked based on the participants’ responses. This flexibility in questioning reflects the exploratory and emergent design of the study. Two members of the research team attended each focus group to observe and answer questions. The moderator and a member of the research team took notes. Transcripts were made of the recordings from each focus group. Both the transcripts and the session notes were utilized in our analysis.

Data Analysis
We conducted thematic content analyses using immersion techniques for each participant type. All focus group participant responses (narratives) were treated as data, as were the researchers’ notes and observations. The narratives were treated as episodic narratives and systemically analyzed for patterns using a combination of constant comparative analysis and immersion. Initial analysis consisted of creating initial categories within the data. The categories were then organized into themes and sub-themes based on the patterns that emerged. Each theme was defined with supporting narratives. The resulting categories, themes, and sub-themes served as the foundation from which all conclusions were drawn. To increase the validity of the findings, the data were triangulated by providing a summary of the findings to each of the focus group participants for clarification and correction.

Results
Thematic analysis of all groups produced six categories: patient benefit, physician benefit, need process improvement, prescription rationale, patient non-use reasons, and DA role. We identified themes within each of these categories resulting in a total of 21 themes (see Table 1). Themes were further subdivided into sub-themes when the responses within the theme diverged. For example, under the category “patient benefit” is the theme “DA supplements information” and under that there are two sub themes “extended exposure to information” and “review information in relaxed environment.”

Thematic analysis revealed that although there was some congruence between participant groups and categories, there was also incongruence, particularly between providers and patients. This disconnect is revealed in the respondents’ statements.

Four of the 21 themes provided particular insight for future clinical action and consideration. These themes include prescribing process, follow-up process, DA role unclear, DA supplements information. Each of these themes is elaborated below.

Prescribing Process
The physicians and the clinic staff reported that infrastructural and technological changes were needed to improve the process of DA prescription and distribution. The DA process needs to be streamlined.

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
</tr>
</thead>
</table>
| Benefits to patients | • Decision aid (DA) supplements information from office visit  
• Patient provided with information to make choices  
• Patient more involved in care  
• Can involve family |
| Benefits to physician | • Doctors feel good knowing they are providing good information  
• DA saves time |
| Process improvement needed | • Prescribing process needs improvement  
• Patient should have information prior to appointment  
• System improvement needed  
• Follow-up process needs improvement  
• Doctor must address feedback questions  
• Patient participation in process  
• Patient access to DA can be improved |
| Why prescribed | • Provide additional information  
• Patient age and family history  
• Include patient in shared decision making |
| Why did not view DA | • Embarrassment related to topic  
• Patient unclear regarding the purpose of the video |
| Role of DA | • Helped patient make decision  
• Confirmed decision patient had already made  
• Patient had not made a decision |

Table 1: Focus Group Categories and Corresponding Themes
seamlessly into clinic workflow for improved adoption in primary care.

Physician: “Let’s say you want to order more than one, you actually have to go back in and order it a second time. It is a big pain.”

Physician: “I mean they have other ones that load, like it is obvious if you are doing colon screening, it should load automatically the colon diagnosis so that when you sign it [it is complete]. Like a Smart Set (a built-in template in the EMR).”

Staff: “The Dr tells you they ordered a DA, then you have to go in to the chart and figure out which one by reading the note. There are too many steps to the process.”

Staff: “You have to take an extra step, where if they were referred to a specialty clinic like ortho its right on the AVS [after visit summary] where if it’s a decision aid, the doctor tells you or you have to look for it.”

Follow-up Process
Every participant group indicated that improvement was needed in the follow-up process after providing the DA. Each group had its own perspective on what part of the process should be changed.

Patients indicated that providers needed to be willing to meet or speak with the patient following DA prescription, and be prepared to answer questions when they did so.

Patient: “I think you have to tell the doctor that if they are using [the videos] then you have to be ready to answer questions”

Physicians, on the other hand, did not indicate a desire to follow up with the patient following DA prescription (likely assuming they were traditional informational aids). Once they provided the DA, they seemed to think they were done with the process. In addition, the providers did not perceive a means or need to have a follow-up conversation; if they wanted to talk about it with the patient, the physician did not remember to do so at a subsequent patient visit.

Physician: “It doesn’t show up in the problem list (a section in the front page of the EMR) for us. So we don’t think about it.”

Physician: “…the people I have given the video to—most of them, or all of them—I have forgotten to ask them. Because they don’t have a mechanism for triggering my memory to ask them.”

The staff expressed a desire to assess patient satisfaction after the DA was ordered. They were interested to know whether the patients received the tools and whether they were helpful for them.

Staff: “Did it meet their [the patient] need? Was it relevant to their [the patient] condition?”

Staff: “I know people thought it was cool when they were going to receive them but nothing [did not know what patient experienced] after they received them.”

Staff: “Was it helpful, was it educational, or was it just boring?”

DA Role Unclear
Patients reported that when prescribed the DA by the physician, they were unclear as to its purpose; this lack of direction affects a patient’s decision to watch the DA. Patients also stated that they were not sure whether or not the DA would benefit them, and this contributed to their ambivalence about watching the DA. Patients said that they did not feel that the physician had motivated them to watch the DA.

Patient: “I wish my doctor had told me more about what I would be watching. He didn’t really explain a whole lot.”

Physician: “Before you watch a video its usually helpful to say… here’s what it is, here’s what it will cover, here’s what the procedure is about … because then you are kind of motivated.”

Patient: “Looking back I would have liked a little more information …about why I should watch it.”

DA Supplements Information
One reason patients may be unclear about the purpose of the DA is that physicians often do not conceive of the DA as its creators intended. Physicians and staff both reported that DAs were beneficial for patients. However, they tended to view the DA purely as patient information and not as a means of eliciting patient values and personal decisions.

Physician: “I think they get more information than they would just talking to us in an office visit.”

Physician: “It supports what we tell them, what we educate them, another media with learning about it.”

Staff: “Patients are more aware of the screenings that are available to them. These DAs help them learn what the screenings are and why.”

Staff: “Before we didn’t have much good info to give to them and now you can give them the decision aids to explain what the colonoscopy is.”

Conclusions
Despite efforts to facilitate the distribution of DAs in clinic by integrating the process into existing systems, several barriers emerged from focus group discussions with patients, physicians, and staff. Patients are often unclear why they have received a DA and what the physician expects them to do after watching a DA. These communication issues are an integral piece of the SDM process and highlight significant barriers to the widespread adoption of DAs in clinical practice. The authors propose improved physician education on the
use of video DAs as well as improved intra-office educational materials for patients to better understand their role in the use of the decision aid.

Physicians and staff statements indicate that DAs are beneficial to patients because they provide useful information to the patient. However, therein lies a disconnect between how DAs are viewed by physicians and the intended use for which they were designed. Physicians most often use the decision aids as patient education materials rather than to help patients become more engaged in care decisions, as they were intended by the shared decision making research and development community. Physicians often fail to see how their current practice falls short in supporting shared decision making and thus how to incorporate tools such as video DAs into the process. We conclude that physician recognition of the value of DAs will be tantamount to the widespread implementation of decision aids within primary care practices.

Moreover, if shared decision making in the primary care PCMH is to be realized, several factors need to be addressed. First, physicians must see DAs as a valuable tool. Second, physicians must better communicate to patients the reason for prescribing the DA. Third, it is essential to specify follow-up action after DA distribution while maintaining a simple prescribing process.

Physician education cannot be overemphasized as a means to improve acceptance of DAs. This needs to begin with the incorporation of SDM into medical student curriculum and residency training programs and extend to continuing education for existing physicians. Elwyn’s work demonstrates the utility of physician education in both SDM and patient-centered care.24,25 Physician acceptance of DAs could be improved by informing physicians of patient satisfaction, adherence, or other outcomes that are both important to physicians and personalized to their specific patient cohort. Physicians may also view increased value of DAs and SDM if documentation of such lowers liability for outcomes a patient might otherwise litigate on grounds of not being fully informed.

Improved physician education will also lead to better provider communication with patients regarding DAs and the shared decision making process. While personal communication between physicians and patient is essential, improved communication need not depend on the physician. Printed materials that are clear and motivational can be distributed at the time the DA is given to the patient. Another way to communicate such information to the patient is enlisting office staff as physician extenders can help to both distribute DAs as well as educate patients on their role in the decision process, to identify patients who would benefit from a DA and provide it to them prior to their clinic visit.

The easier the process of prescribing DAs, the more patients will benefit. Based on the results of this study and other experiences of our team, a pre-visit model of distribution appears beneficial. Patients that received materials days prior to a clinic visit are more likely to engage their physicians regarding materials presented in a DA. Pre-visit distribution also involves a natural process of follow-up given the office visit can be seen as a first follow-up. SDM and the impact this has on patient satisfaction can be more easily assessed. Another option available to a growing number of clinics is the use of a patient portal within an electronic medical record. Patient portals allow secure access between the physician and the patient, offering patient access to a DA via a message from the physician; such a process promotes patients securely and confidentially posing questions or comments to the physician outside of the clinic visit. These methods reduce the burden of follow-up on the physician, relying more on technology and systems to facilitate personal discussion between physician and patient.

This study has both strengths and limitations. The strengths include the physician and staff focus group participants all had over 1-year experience actually implementing various processes of DA distribution and attempted follow-ups with patients. Another strength of the study is that the participants’ experience with DAs involved a variety of medical topics and conditions (ie, colorectal cancer screening, PSA, depression, CAD). Two important limitations should be noted. First, this study was conducted within a large academic health care system with significant technology capabilities (eg, EMR), which may preclude generalizability. While UCSD’s patient population is an ethnically and economically diverse group, this population and the organizational and electronic infrastructure may not translate to other sites. Replicating this study in a community-based practice or smaller group practices might address this shortcoming. A second limitation is that all of the focus groups (patient, staff, and physician) were made up of volunteers and thus may show volunteer bias. For the physician group in particular, this led to receiving input from few physicians who rarely used DAs. Further exploring the topic of DAs with physicians who choose to rarely prescribe would be important in future research.

We conclude that physicians must perceive value of DAs in their practice prior to addressing technological and infrastructural issues that make prescribing DAs easier. Patients must also perceive the value of DAs, which can be addressed by providing a clear personalized rationale for the DA and clear communication of expectations of how to utilize the tool. Only after value is perceived by both physicians and patients can technological advances improve shared decision making.
ACKNOWLEDGMENTS: This project was supported in part by a grant from the Foundation for Informed Medical Decision Making, Boston, MA. Material included in this manuscript was presented as a poster at the 2009 International Shared Decision Making Conference in Boston, MA. We thank Catherine Cheung, MA, for her work with the Shared Decision Making project and these focus groups.

CONFIDENTIALITY: The authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

CORRESPONDING AUTHOR: Address correspondence to Ms Newsome, University of California, San Diego, Division of Family Medicine, 9500 Gilman Drive, #0807, La Jolla, CA 92039. 619-315-4775. amnewsome@ucsd.edu.

References
24. Elwyn G. Developing professional ability to involve patients in their care: pull or push? Qual Health Care 2001;10:129-34.