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Consumer and Provider Perspectives on Shared Decision Making: A Systematic Review of the Peer-Reviewed Literature

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Comparative effectiveness research (CER) is intended to give consumers and providers the information they need to make evidence-based, patient-centered clinical decisions at the point of care.¹ Without consumer engagement in these decisions, however, the information itself cannot help patients make an informed decision that would, from their perspective, improve their health.² Only if consumers join providers in the decision-making process can CER lead to better health care quality and efficiency. Although this may be a big “if,” consumers and providers are more likely to make decisions together when they see some value in doing so. This brief reports on findings from a systematic review of the peer-reviewed literature on consumer and provider perspectives on shared decision making, or “SDM.”

It Takes Two

SDM is effective only if patients and providers are invested in the process. Patients are more likely to engage if they know that their feelings and opinions will be considered by their provider—especially with regard to more serious clinical decisions.³ Patients are also more likely to participate in SDM if they feel they have the information and support they need to make an informed decision.⁴ For instance, patient “decision aids” are often used to help patients understand the evidence regarding clinical options and clarify their own preferences and values.

Providers are more likely to facilitate SDM when they feel that a patient takes an interest in his or her care, when they are comfortable discussing emotionally charged issues with a patient, and when they are comfortable acknowledging their own uncertainty.³

But even if these conditions are in place, other factors can impede SDM and undermine the decision itself. For instance, provider values regarding clinical options may differ from those of the patient, patients may not feel qualified to assign personal value to various treatment outcomes or side effects, and patient-provider communication may be poor.³

To explore the dynamics of SDM, we conducted a systematic review of the peer-reviewed literature to describe current consumer and provider perspectives on the process. We examined attitudes toward and engagement in SDM as well as changes in attitudes or engagement as a result of an intervention with a patient decision aid intended to promote SDM.

Methods

We searched specifically for articles that report on findings from surveys, interviews, and focus groups that examined

consumer and provider views of SDM. Although countries other than the U.S. have conducted considerable research on SDM (the U.K. and Australia in particular), it is likely that perspectives on SDM vary widely—both across countries and by their different policy histories regarding the use of CER. We therefore limited ourselves to research conducted in the U.S. and to articles written in English and published within the past five years (June 22, 2006, through June 21, 2011).

The search returned 467 articles, 96 of which were screened in for coding and analysis. (For a more detailed description of the search and coding methodology as well as the full reference list, go to www.mathematica-mpr.com/chce/sdm_appendix_9_11.asp.)

Study Characteristics

Table 1 shows the study characteristics as well as the findings on patient

Table 1.**SUMMARY OF STUDIES AND FINDINGS**

	Studies Focusing on Patients/Consumers	Studies Focusing on Providers	Studies Focusing Jointly on Patients/Consumers and Providers
Total Number of Articles	61	13	22
Data Collection Activities			
Surveys	34	12	12
Focus groups	12	0	4
Interviews	22	1	6
Literature reviews	0	0	3
Clinical Focus			
Screening	24	4	6
Treatment	38	5	12
Other	3	4	4
Demographic Focus (of Patients/Consumers)			
No specific focus	33	n.a.	18
Racial, ethnic, or SES focus	15	n.a.	0
Gender focus	18	n.a.	3
Involved Patient Decision Aid Intervention	14	0	4
Clinical practice intervention	7	n.a.	2
Outcome Variable Measured			
Attitudes toward SDM	39	8	18
Engagement in SDM behavior	47	5	16
Findings			
Positive attitudes	21	8	13
Negative or passive attitudes	17	5	5
Improved attitudes	7	n.a.	1
No change in attitudes	3	n.a.	2
Higher engagement	22	3	9
Lower engagement	31	5	11
Increase in engagement	9	n.a.	0
No change in engagement	5	n.a.	2

Notes: Coding categories are not mutually exclusive. SES = socioeconomic status. n.a. = not applicable.

and provider views of SDM. The most common data collection method was a survey (60 percent of the studies), followed by interviews (30 percent) and focus groups (17 percent). The most common clinical focus was a treatment or intervention (57 percent), such as cardiac catheterization, lung transplant, drug treatment, or total knee replacement. Most of the remaining studies focused on screening (35 percent) and on colon, prostate, or breast cancer screening in particular.

Most of the studies involving consumers (61 percent) did not target a particular demographic group or make

comparisons between such groups. However, a few focused on race, ethnicity, or socioeconomic status (18 percent) or on gender (25 percent).

Eighteen of the studies that included consumers (either exclusively or jointly with providers) used a patient decision aid as an intervention (21 percent). Nine of these studies were conducted in a clinical practice setting in which the aid was typically used at the point of care. In some cases, patients were counseled at home by phone, or patient decision aid materials were mailed to them. The other nine studies were conducted in a research setting.

Consumer and Provider Perspectives on SDM

Attitudes toward SDM for both consumers and providers are somewhat more likely to be positive than negative, whereas engagement is somewhat more likely to be lower than higher. We defined attitudes toward SDM as patient or provider preferences regarding the clinical SDM process, including the perceived quality of patient-provider communication, patient and provider desire for the patient to engage in SDM versus delegation to the provider, satisfaction with the decision-making process, perceived self-efficacy

TERMINOLOGY

Consumer engagement—Patient or family caregiver engagement in making evidence-based clinical decisions that also reflect personal preferences or values.

Informed decision making—Patients' or family caregivers' clinical decision making informed by evidence and personal preferences or values.

Shared decision making—Communication between patients or family caregivers and providers to support informed clinical decision making.

Patient decision aids—Tools that support SDM by providing patients or family caregivers with evidence regarding clinical options and by clarifying the values-sensitive nature of the decision.

regarding SDM, and attitude toward information seeking or preference for information. We defined engagement in SDM behavior as the patient's or provider's reported use of SDM processes, including discussing treatment options, patient preferences, and goals, and assessing the patient's understanding of both conditions and the pros and cons of treatment options. Based on these coding definitions, the same proportion of studies examined attitudes toward SDM (68 percent) and engagement in SDM behavior (71 percent).

For all studies, we examined attitudes toward SDM (coded as positive, versus negative or passive) and engagement in SDM behavior (coded as higher or lower). For studies that reported findings on the use of a patient decision aid to promote SDM, we also examined changes in attitudes (coded as improved or no change) and changes in engagement (coded as increase or no change). The studies that focused on both consumers and providers generally reported synthesized outcomes, such as patient-provider communication or patient-provider agreement in their attitudes toward SDM, opinions of the quality

of the decision, or satisfaction with the decision-making process.

Most of the studies (64 percent) focused on consumers, and more of them found positive (34 percent) rather than negative or passive (28 percent) attitudes toward SDM. However, more of them also found lower engagement (51 percent) rather than higher engagement (36 percent) in SDM behavior.

Relatively few studies (14 percent) focused on providers. Like the consumer studies, more of them appeared to show a positive (67 percent) rather than a negative or passive (38 percent) attitude toward SDM. More of these studies also appeared to show lower (38 percent) as opposed to higher (23 percent) engagement in SDM behavior. However, these findings should be interpreted with caution because there were so few provider-focused studies.

Many of the studies (23 percent) focused on both consumers and providers. Again, more of them found positive (59 percent) rather than negative (23 percent) attitudes toward SDM, and more found lower engagement (50 percent) rather than higher engagement (41 percent) in SDM behavior.

Among the few studies in which a patient decision aid was used as an intervention, more appeared to show improved attitudes (44 percent) rather than no change in attitudes (28 percent). More also appeared to show an increase in engagement (50 percent) as opposed to no change in engagement (39 percent). These findings should also be interpreted with caution, not only because of the small number of studies that involved patient decision aids but also because it was beyond the scope of this review to evaluate the quality of the interventions.

Many studies examined whether consumers and providers felt that patient preferences were addressed or whether certain information was provided during patient-provider encounters. A consumer's attitude toward SDM was often influenced by

whether his or her preferences were adequately addressed or considered by the provider. Negative attitudes or lower engagement were often tied to the patient's perception that providers did not consider or discuss either the patient's desired role in the decision-making process or the patient's understanding of his or her treatment or screening options. Several studies showed that providers often failed to discuss the uncertainties or harm associated with various treatments or screening options. Similarly, several studies revealed that providers often failed to discuss alternatives to various treatment and screening options.

A few studies suggest that engagement might be influenced by the extent to which a condition is serious. For example, a few studies of patients with cancer showed that more patients preferred to take a more passive role in the decision-making process. The same is true in a few studies that focused on providers. For example, in one study of terminally ill patients, physicians were often not supportive of resuscitation decisions patients or family caregivers made.

Next Steps

The findings from this literature review are promising. They suggest that consumers and providers are already positively inclined toward SDM. However, the findings also suggest that actual engagement in SDM behavior is still lagging behind attitudes toward the process. If CER is to ensure that clinical decisions at the point of care are evidence based and patient centered, thus promoting health care quality and efficiency, the positive attitudes of consumers and providers must be translated into behavior. This could be achieved through policies that support key SDM processes of sharing evidence, considering patient preferences, and discussing the relative advantages of different clinical options.

Endnotes

¹ Institute of Medicine. “Initial National Priorities for Comparative Effectiveness Research.” Washington, DC: National Academies Press, 2009; Federal Coordinating Council for Comparative Effectiveness Research. “Report to the President and the Congress.” Washington, DC: U.S. Department of Health and Human Services, June 2009.

² Esposito, Dominick, Arnold Chen, Margaret Gerteis, and Timothy Lake. “Using Comparative Effectiveness Research: Information Alone Won’t

Lead to Successful Health Care Reform.” Mathematica Policy Research Center on Health Care Effectiveness Issue Brief, 2010, no. 2.

³ Gerteis, Margaret, and Rosemary Borck. “Shared Decision Making in Practice: Lessons from Implementation Efforts.” Report submitted to the Medicare Payment Advisory Commission. Cambridge, MA: Mathematica Policy Research, July 2009.

⁴ The Foundation for Informed Medical Decision Making. Available at [<http://www.informedmedicaldecisions.org/>]. Accessed September 14, 2011.

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For a more detailed description of the search and coding methodology and the full reference list, go to www.mathematica-mpr.com/chce/sdm_appendix_9_11.asp.

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