Review

Medical Care
Research and Review
Volume 64 Number 6
December 2007 623-649

10.1177/1077558707305941
http://mcr.sagepub.com
hosted at
http://online.sagepub.com

Instruments for Evaluating Shared Medical Decision Making

A Structured Literature Review

Sydney Morss Dy
Johns Hopkins Bloomberg School of Public Health and School of Medicine

The author conducted a structured literature review of instruments for evaluating shared medical decision making. She included relevant instruments that were generalizable beyond specific situations and had been formally evaluated and organized them by domains of values or preferences, information and communication in decision making, and other aspects of decision making. For values or preferences, the author identified 11 instruments, mostly on preferences for roles and information. For information and communication, she found a systematic review of instruments for observational assessment of decision making, 3 additional observational instruments, and 3 questionnaires. For other aspects of decision making, the author identified 3 instruments in domains such as decision self-efficacy and 4 multidimensional instruments. Although instrument development tended to cluster in several areas and there were clear gaps in the literature, the diversity of instruments demonstrates the broad range of constructs involved in assessing shared decision making.

Keywords: *shared decision making; measurement instruments; roles; satisfaction; preferences*

Improving the patient-centeredness of medical care, one of the six primary aims of the Institute of Medicine's (2001) Health Care Quality Initiative, requires improving how patients and physicians make medical decisions together. One approach, the shared-decision-making model, involves the exchange of information, joint consensus building, and agreement on the choice of treatment between patients and providers (Charles, Gafni, and Whelan 1997). This style of care is important for providing care most consistent with patients' preferences, is preferred by patients in many situations, and can help improve outcomes such as adherence to treatment, health status, and satisfaction (Hall, Roter, and Katz 1988; Guadagnoli and Ward 1998). However, in situations in which patient-centered care is important, shared

Author's Note: This article, submitted to *Medical Care Research and Review* on May 22, 2006, was revised and accepted for publication on May 15, 2007.

decision making is frequently absent or limited in scope (Braddock et al. 1999; Stevenson et al. 2000).

Demonstrating that increasing shared decision making is important requires better understanding of how good decision making occurs between health care professionals, patients, and families; what factors promote it; and how it can improve patient outcomes. Evaluating shared decision making and adequately measuring the impact of interventions to improve it require the use of appropriate areas for assessment and useful measurement tools, but the lack of a framework and synthesis of this literature may make this difficult for researchers. Although studies have evaluated shared decision making and attempted to increase its use, reviews have found that many of these were not based on theory and did not include evaluations of decision making. Among those that did, few used psychometrically evaluated instruments, and there was little overlap between studies, complicating attempts to synthesize the literature (Bekker et al. 1999).

New Contribution

Although several recent systematic reviews have addressed shared decision making, they have generally focused on the use of decision aids and relatively uncomplicated decisions rather than actual physician-patient or more complex health care interactions, and they have not focused on the use of instruments (Kennedy 2003; Molenaar et al. 2000; O'Connor et al. 2003). A previous extensive systematic review of informed decision making also did not focus on instruments and included areas, such as adherence and self-care, that range beyond shared decision making between a health care professional and a patient (Bekker et al. 1999). Some articles on instrument development describe other available measures in a specific area but do not evaluate the full range of relevant instruments.

I therefore performed a structured review of measurement instruments relevant to shared medical decision making across different situations. My objectives were to review and categorize relevant instruments with published evaluations, describe how they might be used to quantitatively evaluate or assess interventions to improve shared decision making, and delineate areas in need of further instrument development or evaluation.

Conceptual Model

The conceptual model for organizing the review was adapted from a systematic review of decision aids (O'Connor et al. 2004). This review describes three key elements in the design of decision aids, which are one tool for improving patient decision making. The elements are values clarification, or sorting out the relative desirability of different options; the provision of information about the condition, options, and risks; and guidance or coaching in deliberation or communication,

including the steps in good decision making. I modified this to meet the requirements of this review, which addresses the related issue of how physician-patient decision making can be measured and is specific to instruments relevant to decision making. I redefined the concept of values in this context to preferences about decision making; the provision of information to information about decision making, also including communication about decision making in this category because most tools in this area covered both; and included in the final category instruments addressing other aspects of decision making, or instruments assessing decision making more globally.

Methods

I conducted a structured review of sources of systematic reviews and published evaluations of instruments, including Medline, the Cochrane Library, the U.S. Agency for Healthcare Research and Quality evidence reports, and the U.K. National Institute for Health and Clinical Evidence. I also reviewed relevant instrument databases, books, and annotated bibliographies for other published instruments and reviewed the reference lists of relevant articles and the publication lists of key authors in the field. Search terms, adapted from related systematic reviews (Bekker et al. 1999; O'Connor et al. 2003), included: *quality*, *process*, *outcome*, *instrument*, *tool*, *assessment*, *evaluation*, or *intervention*; and *decision*, *decision-making*, *shared decision-making*, *shared medical decision-making*, *participatory decision-making*, *informed decision-making*, *informed medical decision-making*, *informed patient decision-making*, *partnership*, or *patient-centered communication*. I conducted searches for instruments published beginning in 1980 and updated them through October 2005. I excluded instruments published before 1980 because this literature tends to reflect the more paternalistic physician-patient relationships of the time, and its terminology is different from what would be included in modern questionnaires, such as the concept of "willingness to challenge physician authority" (Haug and Lavin 1979).

I included instruments designed or used for evaluating medical decision making by patients and/or families and physicians or other health care professionals together. I limited my definition to decisions about single events, such as treatments, excluding areas such as behavior modification or chronic care. Instruments could be completed by health care professionals, patients, or observers and could be designed either for the assessment of actual decisions or with vignettes. The tools had to be available in English, accessible to researchers, designed for quantitative analysis, and have published psychometric or other evaluations, including validity and/or reliability. I excluded questions that were small parts of larger instruments and publications that reported unacceptable psychometric properties. I also excluded instruments not relevant to usual clinical practice, such as those designed for utility assessment and those for assessing population patterns or the effects of educational

interventions, as well as those that were limited to particular diseases or situations, unless they appeared to be easily adaptable to other settings. I categorized the systematic reviews and instruments into the domains adapted from the systematic review of decision aids: values and preferences, information and communication in decision making, and other aspects of decision making and multidimensional scales (O'Connor et al. 2004). I described systematic reviews of instruments and their psychometric properties in the text. For instruments not included in these reviews, I abstracted descriptions of each instrument from the publications, as well as information on purpose, development, population tested, reliability, validity, and how it has been used, on the basis of methods used in another review of measurement instruments (Cagney et al. 2000).

Results

I identified six systematic reviews including instruments for shared medical decision making (Bekker et al. 1999; Benbassat, Pilpel, and Tidhar 1998; Consumer Health Education Institute 2005; Gaston and Mitchell 2005; Hall et al. 2002; Lewin et al. 2001) and four systematic reviews on decision aids (Kennedy 2003; Molenaar et al. 2000; O'Connor et al. 2003; Whelan et al. 2002). I also identified a bibliography on shared decision making listing a number of tools (O'Connor et al. n.d.), a bibliography of tools related to decision aids (O'Connor n.d.), two related bibliographies of tools (Health and Psychosocial Instruments [University of California, San Francisco, Library and Center for Knowledge Management 2006] and the Ethics Tool Database [Boston College William F. Connell School of Nursing n.d.]), and two related books on measurement instruments in clinical ethics and patient education (Redman 2002, 2003).

Instruments that met the selection criteria are summarized in tables 1 to 3, and key areas are discussed below. There is considerable overlap between domains, and many of the instruments could be easily adapted or used in other areas. In general, few studies (often the more recent ones) described the theoretical backgrounds for the instruments or development work such as focus groups or semistructured interviews. Almost all instruments included here had some reliability testing; in general, for questionnaires, this was limited to internal consistency, although a few did evaluate test-retest reliability; for observational instruments, this was usually limited to interrater reliability. Studies also did not compare patients' reported preferences or behavior with their actual behavior in clinical encounters, with a few exceptions (Beisecker and Beisecker 1990).

(*text continues on p. 641*)

Table 1
Instruments for Evaluating Shared Medical Decision Making: Values and Preferences

Tool	Description	Development	Population Tested and Reliability	Validity	References
Preferences for decision-making role only					
Control Preferences Scale	Patient self-report 5-point scale ranging from passive to collaborative and active decision-making role; uses card-sort procedure	Based on field study of factors influencing how treatment decisions in life-threatening illness are made; pilot study	Newly diagnosed oncology outpatients; household survey Reliability not reported	Large difference between oncology and household groups; significantly associated with education and cancer type; preferences for each care sort significantly correlated	Degner and Sloan (1992); adapted for other studies (e.g., shared decision making with friends/family; Collins et al. 2004)
Decision Involvement Questionnaire	For each of nine vignettes for outpatient treatment in which patients could be more autonomous, subject rates preferences for participation in decision making	Review of literature and related instruments	Mailed questionnaire to health maintenance organization members (23% response rate) Cronbach's $\alpha = .87$	Younger and more educated patients had significantly higher values; significantly correlated with other scales measuring desire for involvement (Autonomy Preference Index, described below); significantly higher values for decisions not requiring medical knowledge	Thompson, Pitts, and Schwankovsky 1993

(continued)

Table 1 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
Patient Preferences for Control	Patient self-report; scenarios with 7-point scale ranging from passive to collaborative and active decision-making role	Literature review and other instruments	Family practice adult outpatients Cronbach's $\alpha = .81$	Factor analysis by scenarios; significant differences by age group, education, and income; significant differences between all scenarios and a general question and between scenarios	Bradley, Zia, and Hamilton 1996 Deber, Kraetschmer, and Irvine 1996
Problem-Solving Decision-Making Scale	Three vignettes focusing on morbidity, mortality, and quality of life; asks about patient vs. physician roles on problem solving (diagnosis, treatments, risks/benefits, and probabilities) and decision making (utilities, decision)	Review of other instruments and literature on decision making vs. problem solving	Day bed/short stay unit patients undergoing diagnostic coronary artery angiograms Cronbach's $\alpha = 0.67$ to 0.93	Factor analysis confirmed two factors; significant differences between the decision-making and problem-solving elements, confirming two separate concepts; significant differences between vignettes	Ende et al. (1989); variations of scenarios have been used for different situations (e.g., (Catalan et al. 1994)
Role and information preferences	Measures patient's preferences for autonomy (participation in decision making) on two	Modified Delphi study with clinicians, sociologists, and ethicists interested in autonomy	Primary care Test-retest reliability = .83 to .84 Cronbach;s $\alpha = .82$	Factor analysis supported two dimensions; no correlation between information seeking and decision	Beisecker (1988), Beisecker and Beisecker (1990); also adapted for use with health

	dimensions, information to seeking (8 items) and decision making (15 items); includes scenarios on different levels of illness severity			making; significantly associated with age, education, health status; significantly correlated with satisfaction, desire for information, severity of illness in vignette	care professionals in breast cancer (Beisecker et al. 1994)
Beisecker Locus of Authority Scale, Beisecker Desire for Information Scale	Two parallel scales, used together, for importance of information and who should make decisions in a list of 13 clinical areas (e.g., risks and benefits of diagnostic tests/whether to have the tests); each scale asks about information or decisions in the same clinical areas	Literature review and previous research on medical consumerism	Outpatient rehabilitation medicine patients Desire for Information Scale α = .86, Locus of Authority Scale α = .73	Locus of authority significantly associated with age, but questioning behavior in tape-recorded physician-patient interactions was not; not significantly correlated with questioning behavior (r = .11), but the two scales together explained a significant amount of variance in questioning for longer interactions (>18 minutes)	Beisecker (1988), Beisecker and Beisecker (1990); also adapted for use with health care professionals in breast cancer (Beisecker et al. 1994)
Information Styles Questionnaire	Cancer patients' attitudes about information and participation in decision making; most can be used for noncancer diagnoses; addresses	Pilot testing with 50 patients for meaningfulness, comprehensibility, discriminatory ability		Preferences significantly associated with age, ethnicity, education, time with disease; more active involvement and desire for	Cassileth et al. (1980)

(continued)

Table 1 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
	amount and types of information (e.g., good vs. bad news, side effects, treatment effectiveness)			information significantly correlated with more hopefulness	
Health Opinion Survey	Preferences for approach to treatment; two subscales, preferences for information and for behavioral involvement	Item pool based on previous questionnaire to measure physician attitudes toward self-care and literature review administered to healthy population in two stages, with questions eliminated that did not show variation in response or correlate with scales	University students, including groups enrolled in medical self-help course and using the college medical office	Significantly discriminated between students in a medical self-help group and a general student group and significantly correlated with self-diagnosis and with use of a medical clinic; independent of a health locus of control scale; significantly related to number of questions that patients asked during clinical encounters, as rated by a clinic nurse	Krantz, Baum, and Wideman (1980)

Role and risk disclosure preferences					
Patient Preference Tool	Assesses patients' desired level of involvement in decision making, preference for risk disclosure, and preferred type of risk disclosure (verbal vs. numeric)	Not described	Continuity primary care visit decision making about invasive medical procedures No reliability testing	Differences with age, disease status, and decision made; correlation between decision making and risk communication preferences (those preferring less involvement in decision making also tended to prefer qualitative over quantitative risk disclosure)	Mazur and Hickam (1997) Arora, Ayanian, and Guadagnoli (2005)
Readiness for decision making Patient Attitudes and Beliefs Scale	Twelve statements on perceptions about participating in decision making, based on the transtheoretical model of health behavior change; subscales for pros, cons, and decisional balance	Literature review; adaptation of items from existing scales; seven focus groups with patients with different diseases and different specialists	Primary care Internal consistency: Cronbach's α = .71 and .72	Factor analysis; scores significantly different among four stages of readiness for decision making	Hollen (1994); study also describes a related scenario-based scale for decision-making style, the Decision-Making Quality Inventory, but tested only in healthy populations

(continued)

Table 1 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
Decision-making style Decision-Making Quality Scale	Self-rating tool; assesses degree to which person adheres to seven decision-making quality criteria (searching for three or more choices, accounting for values and goals, weighing pros and cons, finding more information when needed, considering new information and advice, reviewing carefully before making final choice, and planning)	Based on Janis and Mann conflict model of rational (or quality) decision making, which proposes six stages and seven criteria	Adolescent and young adult survivors of childhood cancer Cronbach's α = .71 to .86 Test-retest reliability: Kendall's τ = .57 and .92 Interrater reliability: κ = .28	Content validity reviewed by experts; significantly negatively correlated with risk-taking behavior	Hollen (1994); study also describes a related scenario-based scale for decision-making style, the Decision-Making Quality Inventory, but tested only in healthy populations

Table 2
Instruments for Evaluating Shared Medical Decision-Making: Information and Communication in Decision Making

Tool	Description	Development	Population Tested and Reliability	Validity	References
Observational tools					
Decision Support Analysis Tool	Assesses clinicians' ability to facilitate decision making; six categories of decision support skills and four of communication skills; raters code transcripts of patient-physician decision making	Based on Ottawa Decision Support Framework and Ivey's problem-solving model and developed from verbal response analysis processes	Family physicians and menopausal patients Interrater reliability on codes: $\kappa = .59$ to .68	Significantly correlated with three of six outcome measures (patient satisfaction with decision and resolution of patient decisional conflict and physician satisfaction with decision-making process)	Guimond et al. (2003)
Elements of Informed Decision Making	Measures presence of seven elements, including role, nature of decision, alternatives, pros and cons, uncertainties, assessment of patient understanding, and preferences; raters code audiotapes	Synthesis of literature and professional consensus	Primary care and surgery patient visits Interrater reliability on codes: $\kappa = .53$ to .66	Significantly correlated with type and complexity of decision and with physician type	Braddock et al. (1999); adapted for decision making including family members/companions (Clayman et al. 2005)

(continued)

Table 2 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
Observing Patient Involvement in Decision Making	Measures extent to which clinicians involve patients in decision making. Twelve items, including whether problems are well defined, whether options are formulated, information provided, patient understanding and role preference evaluated, and decisions from both professional and patient perspectives	Based on systematic review and theoretical framework, qualitative studies with key informants, evaluation of consultations, testing and revisions	Primary care Interrater reliability: κ = .45 to .98; interrater reliability: interclass correlation coefficient = .77; Cronbach's α = .68; test-retest reliability: .65 to .82; interclass correlation between clinicians = .22	Factor analysis; construct validity: significantly correlated with patient age and clinical topic; responsive to training of clinicians in shared decision making	Elwyn et al. (2003); revised in Elwyn et al. (2005): reliability data listed are updated with this revised version where available
Rochester Participatory Decision-Making Scale	Measure of physician behaviors that encourage participatory decision making; raters code audiotapes	Adapted from the Elements of Informed Decision Making described above; pilot testing	Primary care Interclass correlation = .72; reliability with physician style = .53 (Spearman Brown prophecy formula using to standardized patient encounters)	Significantly correlated with measure of patient-centered communication and with patient and standardized patients' perceptions of physician-patient relationship	Shields et al. (2005)

Questionnaires					
Decision-Making Process Questionnaire (also called Satisfaction With Decision Making Process Questionnaire)	Twelve items, developed to test a shared decision-making program; addresses information, role, other process issues	Not described	Urology visits for benign prostatic hypertrophy Cronbach's α = .95	Correlated with satisfaction with health care (r = .65)	Barry et al. (1997)
Participatory Decision-Making Styles	Patients' ratings, using three questions, of whether and how often their physician generally involves them in decisions		Primary care and specialist outpatient visits Intraclass correlation among scores for each physician = .62	Significantly correlated with patient satisfaction and with physicians' self-report of participatory decision-making style; higher scores were significantly associated with less changing of physicians; significantly correlated with audiotape-rated measure of physicians' involvement of patients in decision making	Kaplan et al. (1996)

(continued)

Table 2 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
Patients' Perceived Involvement in Care Scale	Patient self-report on three facets of encounters: doctor facilitation of patient involvement, level of information exchange, and patient participation in decision making	Based on theory, literature review, observation of physician-patient interactions, physician survey	Primary care patients presenting with new symptoms or exacerbation of previous symptoms	Factor analysis; significantly different by gender; significantly associated with satisfaction, changes in illness attitudes	Lerman et al. (1990)

Table 3
Instruments for Evaluating Shared Medical Decision Making: Other Aspects of Decision Making and Multidimensional Scales

Tool	Description	Development	Population Tested and Reliability	Validity	References
Patients					
Instruments addressing one aspect of decision making					
Decision Emotional Control Scale	Measures the affective dimension of decision making; six items addressing different emotions, such as fear and frustration	Based on decisional conflict conceptual framework and research on decision aids	Patients with schizophrenia (version modified for this purpose through consultation with psychiatrists, pilot) Cronbach's $\alpha = .79$	Face validity with expert panel; significantly discriminated between psychiatric patients who wanted to continue treatment and those who were unsure or wanted to delay the decision	Bunn and O'Connor (1996); simplified version available
Decision regret scale	Measures remorse or distress about a decision; five items	Developed by experts and practitioners; pilot testing	Four studies of decision making about hormone replacement therapy and breast and prostate cancer initial treatment choices	Correlated with decision satisfaction, decisional conflict, and quality of life; significantly higher among those who changed decisions than those who did not; significantly associated with differences in feelings about decisions	Brehaut et al. (2003)

(continued)

Table 3 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
Decision Self-Efficacy Scale	Measures social aspects of working with team on decision making; based on definition of self-efficacy as "sense of adequacy and efficiency in dealing with life situations" and self-perceived ability to participate in treatment; 11 items, including ability to obtain information, ask questions, make a choice	Based on decisional conflict conceptual framework, concept of self-efficacy, and research on decision aids	Patients with schizophrenia (version modified for this purpose through consultation with psychiatrists, pilot) Cronbach's $\alpha = .84$	Face validity with expert panel; significantly discriminated between psychiatric patients who wanted to continue treatment and those who were unsure or wanted to delay the decision	Bunn and O'Connor (1996); also evaluated in women considering hormone replacement therapy; simplified version available
Multidimensional instruments					
Decisional conflict scale	Designed to measure the effectiveness of decision aids; three subscales addressing cognitive aspects of decision making, based on the dimensions of uncertainty, factors contributing to the uncertainty (such as lack of	Based on conceptual model of decision conflict and research on decision aids	Immunization and breast cancer screening Cronbach's $\alpha = .79$ to .92 Test-retest reliability = .81	Face validity: expert review; discriminates significantly between those with strong vs. uncertain intentions to accept health interventions; patients who were unsure or delayed their decision have significantly higher	O'Connor (1995); simplified version available; has been used in many different clinical settings

	information), and perceptions of effective decision making (after the decision is made)			conflict scores; inversely related to feeling informed and feeling that they had made an informed decision	
Decision attitude scale	For evaluating a decision right after it has been made; subscales include satisfaction with choice, usability of information, and adequacy of information	Review of scales for related constructs	Consumers' choice of health plan Cronbach's $\alpha = .86$	Factor analysis; different subscales significantly correlated with ability to choose, change in choice, and attitudes about information; satisfaction with choices and rating of adequacy of information were significantly improved after more information was provided; those who had good attitudes felt that they had been given enough information	Sainfort and Booske (2000)
Satisfaction With Decision Scale	Questions address satisfaction with the information available; that the decision was consistent with the decision maker's values; that the decision was his or hers to make;	Based on conceptual models of an effective decision and patient-provider interaction; for evaluating decision making; pilot tested	Hormone replacement therapy decision-support intervention, and influenza immunization Cronbach's $\alpha = .86$	Moderately correlated with decision confidence and with decision certainty 12 months later; appeared to measure a different construct than the decision conflict scale	Holmes-Rovner et al. (1996)

(continued)

Table 3 (continued)

Tool	Description	Development	Population Tested and Reliability	Validity	References
	with the decision itself; and if he or she intended to carry out the decision				
Health care professionals					
Provider decision process assessment instrument	Physician version of decisional conflict scale (above): addresses uncertainty, difficulty making decision, understanding of patient's preferences, patient understanding, likely adherence to treatment, and satisfaction with decision and process	Items adapted from patient scale	Internal medicine house staff and faculty members in outpatient settings Cronbach's $\alpha = .88$	Face validity with internists; strongly negatively correlated with general questions about satisfaction with the decision (although some related satisfaction questions are also part of the instrument)	Dolan (1999)

Values and Preferences in Decision Making

Most included instruments focused on patient preferences for roles and for information (Table 1). I identified four instruments designed specifically for assessing how much patients want to participate in decision making. An adaptation of one of these (the Control Preferences Scale; Degner and Sloan 1992) has also been used for preferences for having friends and family members participate in decision making (Collins et al. 2004). I identified four additional instruments for assessing both role preferences and preferences for information, and one that included preferences for both decision-making role and risk communication (the Patient Preference Tool; Mazur and Hickam 1997). These instruments usually divide the separate constructs into subscales. They generally are based on assessments with scenarios, although some (the Health Opinion Survey [HOS]; Krantz, Baum, and Wideman 1980) ask questions about different aspects as part of a scale. Only one (the Information Styles Questionnaire; Cassileth et al. 1980) addresses preferences for different types of information. Two instruments (the HOS and the Information Styles Questionnaire) were published in 1980 and have not been revised to reflect shifts in partnership in physician-patient relationships, and some of the language used appears outdated. The instruments addressing information preferences, developed prior to the Internet, may also be out of date given that patients now may depend less on health care professionals for medical information.

Although there are a number of instruments addressing patient preferences, they may measure somewhat different constructs. In a comparison of the Autonomy Preference Index (Ende et al. 1989) and the HOS, information scores were significantly higher on the Autonomy Preference Index, probably because it focuses more on desire for information than actual behavior in requesting information (Nease and Brooks 1995). In general, studies found that patients usually prefer to have information, but preferences for participation in or control of decision making vary substantially. A comparison of two of the role instruments with qualitative assessments of preferences found that these constructs are more complex than the instruments reflect and that further development is needed (Entwistle 2002). I identified one recently developed instrument (the Patient Attitudes and Beliefs Scale; Arora, Ayanian, and Guadagnoli 2005) that builds on these issues and approaches involvement in decision making as a behavior to be modified rather than as a preference to be respected. One of the patient scales has also been adapted to assess health care professionals' preferences for patients' decision-making control (the Beisecker Locus of Authority Scale; Beisecker 1998; Beisecker and Beisecker 1990; Beisecker et al. 1994). Finally, I identified a scale that assesses patients' adherence to criteria of quality decision making (the Decision-Making Quality Scale; Hollen 1994); a related scale on decision-making style was not evaluated in the setting of medical care.

I also identified a number of other concepts related to shared decision making, although they either did not have instruments that had been evaluated or had

not been studied in this context. Decisional competence or ability is an important construct and was addressed in a recent systematic review focusing on the cognitively impaired elderly (Kim, Karlawish, and Caine 2002) and in a few additional instruments evaluating competency (Bean et al. 1994), health literacy, and numeracy, or quantitative literacy (Consumer Health Education Institute 2005). Another related concept is locus of control in health care, which addresses the broader concept of self-care or control of health or health care (Consumer Health Education Institute 2005). A number of instruments also address aspects of health care professionals' decision making, such as cognitive biases (Hershberger et al. 1994) or ethical reasoning or values (McAlpine, Kristjanson, and Poroch 1997) but have not been evaluated in the context of shared decisions with patients.

Information and Communication in Decision Making

In a clinical encounter, the shared decision making that occurs can be measured either by direct observation or by questionnaires measuring the perceptions of the participants. Elwyn et al. (2001) systematically reviewed the literature for observational instruments to measure patient involvement in decision making. They identified eight instruments with some relevant items but concluded that none were either specifically designed for this purpose or had undergone careful development for items important from the patient's perspective (Edwards, Elwyn, Smith et al. 2001). In particular, the authors concluded that these instruments were not thorough and did not address the issue of actively involving patients in decision making. I identified a study with a modified version of one of the instruments included in this review, the Elements of Informed Decision-Making (Braddock et al. 1999), as well as an adaptation of this instrument (Clayman et al. 2005) for the presence of companions or family members in consultations (Table 2). I also found three subsequently published observational instruments, including another related to the Elements of Informed Decision-Making and an instrument developed by Elwyn et al. on the basis of their review, which was associated with training in shared decision making.

I also found three questionnaires for asking patients about the process of decision making; one addresses how often their physicians generally involve them in decisions, and two evaluate different aspects of the decision-making process, such as roles and information, in a specific encounter. All three were associated with outcomes, primarily patient satisfaction. A number of related concepts may also be important in evaluating decision-making processes. Two areas of particular relevance that have been well summarized in systematic reviews are instruments to address physician-patient communication, such as the provision of information, interpersonal processes, and relationship building (Hall, Roter, and Katz 1988) and risk communication and framing (Edwards, Elwyn, Covey et al. 2001).

Other Aspects of Decision Making and Multidimensional Scales

Table 3 includes both instruments with a focus on other aspects of decision making and those that are more multidimensional. The three unidimensional scales address decision self-efficacy (described as the social aspects of decision making), emotional control, and decisional regret, but none has been used for evaluating interventions. Among the four multidimensional instruments, a decisional conflict scale (O'Connor 1995), which has also been adapted for use by health care professionals, addresses the cognitive aspects of decision making, and the other instruments address multiple different constructs. Many of these instruments were developed to evaluate decision aids or tools to help patients with the decision process. Although relevant to shared decision making, decision aids do not address joint physician-patient decision making directly, because they are not administered as part of physician-patient interactions. Some of these concepts have also been addressed as structural variables in related areas; for example, self-efficacy has also been evaluated as a patient characteristic in self-care (Woodward and Wallston 1987).

Several reviews have summarized the use of these tools for evaluating decision aids. Of the measures discussed here, Kennedy (2003) found that the most commonly used were satisfaction with decision making and the nature of the interaction with the physician. Although decision aids effectively lowered decisional conflict, they did not affect satisfaction with decision making, the decision-making process, or decisional regret (O'Connor et al. 2003). Effects on increasing patients' willingness to participate in decision making have been evaluated in only a few studies, and the results were mixed (Kennedy 2003; Molenaar et al. 2000). Evaluations of decision aids and other informed decision-making interventions have also included a variety of measures in areas other than decision making, including acceptability, knowledge, preferences, expectations of risks and benefits, and decision adherence. For decision aids, the most commonly used measures in these areas were knowledge and the decision made (Kennedy 2003). Although decision aids effectively increased knowledge, agreement between value and choice, realistic expectations, and the proportion making a decision, they have not been found to affect persistence with the chosen option or health outcomes (O'Connor et al. 2003).

Discussion

I identified a large number of published and evaluated instruments to measure values and preferences, information and communication in decision making, and other aspects of decision making. The 11 instruments for values focused mainly on preferences for decision-making roles, both generally and in specific situations, and on preferences for information. Several observational instruments have been developed to assess information and communication in decision making, and three

questionnaires focus on this domain as well. For other aspects of decision making, instruments have been developed for the emotional, social, and cognitive aspects, as well as more global constructs such as satisfaction, but these instruments account for only a small proportion of outcomes measured in decision-making evaluations.

Although this synthesis of the literature's descriptions of instruments provides a framework for structuring future evaluations of shared decision making, it may be challenging to choose from the variety of domains here and the many others that are related to decision making. An appropriate theoretical model and the use of other systematic reviews and studies described here may help determine which areas fit best with particular research questions. In addition, the factors measured should depend on the nature of the decision: complex decisions may require instruments addressing cognitive issues; for a difficult decision, such as at the end of life, emotional issues may be more important. In intervention studies, researchers should choose domains by the goals of the intervention and what is remediable. Given the limitations in the literature and the variable impacts of interventions (Molenaar et al. 2000), evaluating more than one domain is advisable. Pilot studies qualitatively evaluating the situation and allowing subjects to prioritize domains may also be helpful.

Choosing individual instruments within domains is also challenging, because few of the measures described here have undergone extensive development or validity testing or been evaluated across settings, and some older tools may be outdated. The selection of instruments can be guided by whether they are comprehensive or focused, whether the items appear to fit well with the study situation, how extensively they have been tested and used, and, for intervention studies, whether they have been evaluated for associations with outcomes or responsiveness to change. Pilot studies can also evaluate the appropriateness of instruments or adapted instruments for particular situations. The choice of an instrument for values depends on whether the goal is to assess general decision making or a specific treatment decision, with the caveat that decision-making preferences often vary by scenario. If one domain is of particular interest, given the limitations of these instruments, choosing two tools that address the issue differently, have undergone different types of evaluation, or using one that is general and one that is disease-specific is also advisable. Broad concepts may include different domains or vary among settings; for example, although decision-making preferences vary widely in many situations, almost all patients want risk disclosure in the setting of relatively straightforward but invasive medical procedures (Mazur and Hickam 1997).

Measures developed for particular situations should often be used in addition to the more general instruments summarized here, because the characteristics of decision making vary widely by setting (Bekker et al. 1999). For example, Guyatt et al. (1995) developed a set of tools for use in life-threatening situations that address both involvement in decision making and satisfaction with the level of aggressiveness of care. Although there may not be a psychometrically evaluated instrument for a specific area, often other studies have developed observational tools or questionnaire

items for specific clinical situations. Medical decision making involves many factors in addition to the instruments described here, such as the clinical situation, previous care, and personality traits. Many disease-specific or other instruments exist to measure these, and researchers may want to include them in evaluations. Factors such as patients' other preferences, values, goals, and expectations are all also important structural constructs in decision making, but almost all the instruments I identified in these areas are applicable only to specific clinical situations or are descriptive or otherwise not amenable to psychometric testing.

This review is also limited by the focus on shared decision making and the medical arena. The measures that I identified were relatively focused in certain areas; a brief review of the nonmedical literature, in areas such as psychology, revealed a number of related concepts and scales that have not been evaluated in medical settings, such as postdecisional confidence or decision comfort. Much of decision making between health care professionals and patients is not really shared but made by individuals and therefore subject to cognitive biases and other individual factors researchers might want to evaluate. Although I focused on single-event decision making, most medical care involves multiple interactions over time and changing behavior, which I did not address (and is rarely studied in the literature). In fact, some studies suggest that decision-making issues may not be of primary importance in clinical encounters. In one study, cancer patients rated the provision of information as far less important than the perception of caring by the physician (Roberts et al. 1994). A study using scenarios with breast cancer patients found that they rated control over treatment decisions much lower in overall importance than continuity of care or empathetic treatment, although 10% did rate control as the most important issue (Sutherland et al. 1989). Shared decision making therefore needs to be evaluated in the broader context of what matters to patients.

The framework and instruments described here provide a foundation for researchers evaluating or improving decision making. These domains are critical to many other fields, such as quality improvement, and the quality and breadth of instruments in this review should encourage researchers in related areas to consider evaluating decision making in their studies. The process of making medical decisions varies widely and can be extremely complicated, and quantitative assessment tools can address only a small proportion of the factors involved and the variation between different participants and situations (Schneider 1998). Few of the instruments I identified have been tested beyond specific settings, or have been evaluated for associations with longer term outcomes, so researchers should consider further evaluation, using more than one instrument, and including situation-specific instruments or those addressing concepts other than decision making.

Further instrument development and evaluation should address filling in the gaps identified in this review, including evaluating other decision-making instruments in the medical context and improving understanding outside the context of decision aids and of variation across settings. More research is needed in how patients' values and

preferences relate to the actual decision making that occurs, or whether these tools can be used to improve physician recognition of patient preferences and patients' participation in their care. Assessing patients' preferences for decision-making roles, information, and risk communication could be valuable in evaluating decision making or interventions, or even in tailoring them to patient characteristics; more research is needed on how and whether these tools could be part of clinical practice.

References

Arora, N. K., J. Z. Ayanian, and E. Guadagnoli. 2005. Examining the relationship of patients' attitudes and beliefs with their self-reported level of participation in medical decision-making. *Medical Care* 43 (9): 865–72.

Barry, M. J., D. C. Cherkin, Y. Chang, F. J. Fowler, and S. Skates. 1997. A randomized trial of a multimedia shared decision-making program for men facing a treatment decision for benign prostatic hyperplasia. *Disease Management and Clinical Outcomes* 1:5–14.

Bean, G., S. Nishisato, N. A. Rector, and G. Glancy. 1994. The psychometric properties of the Competency Interview Schedule. *Canadian Journal of Psychiatry* 39 (8): 368–76.

Beisecker, A. E. 1998. Aging and the desire for information and input in medical decisions: Patient consumerism in medical encounters. *The Gerontologist* 28 (3): 330–35.

Beisecker, A. E., and T. D. Beisecker. 1990. Patient information-seeking behaviors when communicating with doctors. *Medical Care* 28 (1): 19–28.

Beisecker, A. E., L. Helmig, D. Graham, and W. P. Moore. 1994. Attitudes of oncologists, oncology nurses, and patients from a women's clinic regarding medical decision making for older and younger breast cancer patients. *The Gerontologist* 34 (4): 505–12.

Bekker, H., J. G. Thornton, C. M. Airey, J. B. Connelly, J. Hewison, M. B. Robinson, J. Lilleyman, M. MacIntosh, A. J. Maule, S. Michie, and A. D. Pearman. 1999. Informed decision making: An annotated bibliography and systematic review. *Health Technology Assessment* 3 (1): 1–156.

Benbassat, J., D. Pilpel, and M. Tidhar. 1998. Patients' preferences for participation in clinical decision making: A review of published surveys. *Behavioral Medicine* 24 (2): 81–88.

Boston College, William F. Connell School of Nursing. n.d. Ethics tool database. http://www.bc.edu/bc_org/avp/son/ethics/pdf/tools.pdf.

Braddock, C. H., III, K. A. Edwards, N. M. Hasenberg, T. L. Laidley, and W. Levinson. 1999. Informed decision making in outpatient practice: Time to get back to basics. *JAMA* 282 (24): 2313–20.

Bradley, J. G., M. J. Zia, and N. Hamilton. 1996. Patient preferences for control in medical decision making: A scenario-based approach. *Family Medicine* 28 (7): 496–501.

Brehaut, J. C., A. M. O'Connor, T. J. Wood, T. F. Hack, L. Siminoff, E. Gordon, and D. Feldman-Stewart. 2003. Validation of a decision regret scale. *Medical Decision Making* 23 (4): 281–92.

Bunn, H., and A. O'Connor. 1996. Validation of client decision-making instruments in the context of psychiatry. *Canadian Journal of Nursing Research* 28 (3): 13–27.

Cagney, K. A., A. W. Wu, N. E. Fink, M. W. Jenckes, K. B. Meyer, E. B. Bass, and N. R. Powe. 2000. Formal literature review of quality-of-life instruments used in end-stage renal disease. *American Journal of Kidney Disease* 36 (2): 327–36.

Cassileth, B. R., R. V. Zupkis, K. Sutton-Smith, and V. March. 1980. Information and participation preferences among cancer patients. *Annals of Internal Medicine* 92 (6): 832–36.

Catalan, J., N. Brener, H. Andrews, A. Day, S. Cullum, M. Hooker, and B. Gazzard. 1994. Whose health is it? Views about decision-making and information-seeking from people with HIV infection and their professional careers. *AIDS Care* 6 (3): 349–56.

Charles, C., A. Gafni, and T. Whelan. 1997. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine* 44 (5): 681–92.

Clayman, M. L., D. Roter, L. S. Wissow, and K. Bandeen-Roche. 2005. Autonomy-related behaviors of patient companions and their effect on decision-making activity in geriatric primary care visits. *Social Science & Medicine* 60 (7): 1583–91.

Collins, M., R. Crowley, J. H. Karlawish, and D. J. Casarett. 2004. Are depressed patients more likely to share health care decisions with others? *Journal of Palliative Medicine* 7 (4): 527–32.

Consumer Health Education Institute. 2005. Tailored Educational Approaches for Consumer Health (TEACH): Literature review and analysis. http://www.healthsystem.virginia.edu/ internet/hes/chedi/ Literature-Review-and-Analysis.pdf.

Deber, R. B., N. Kraetschmer, and J. Irvine. 1996. What role do patients wish to play in treatment decision making? *Archives of Internal Medicine* 156 (13): 1414–20.

Degner, L. F., and J.A. Sloan. 1992. Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Epidemiology* 45 (9): 941–50.

Dolan, J. G. 1999. A method for evaluating health care providers' decision making: The provider decision process assessment instrument. *Medical Decision Making* 19 (1): 38–41.

Edwards, A., G. Elwyn, J. Covey, E. Matthews, and R. Pill. 2001. Presenting risk information—A review of the effects of framing and other manipulations on patient outcomes. *Journal of Health Communication* 6 (1): 61-82.

Edwards, A., G. Elwyn, C. Smith, S. Williams, and H. Thornton. 2001. Consumers' views of quality in the consultation and their relevance to "shared decision-making" approaches. *Health Expectations* 4 (3): 151–61.

Elwyn, G., A. Edwards, S. Mowle, M. Wensing, C. Wilkinson, P. Kinnersley, and R. Grol. 2001. Measuring the involvement of patients in shared decision-making: A systematic review of instruments. *Patient Education and Counseling* 43 (1): 5–22.

Elwyn, G., A. Edwards, M. Wensing, K. Hood, C. Atwell, and R. Grol. 2003. Shared decision making: Developing the OPTION Scale for measuring patient involvement. *Quality and Safety in Health Care* 12 (2): 93–99.

Elwyn, G., H. Hutchings, A. Edwards, F. Rapport, M. Wensing, W. Y. Cheung, and R. Grol. 2005. The OPTION Scale: Measuring the extent that clinicians involve patients in decision-making tasks. *Health Expectations* 8 (1): 34–42.

Ende, J., L. Kazis, A. Ash, and M. A. Moskowitz. 1989. Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine* 4 (1): 23–30.

Entwistle, V. 2002. *Exploring patient participation in decision-making: A report from the PAPAYA Project Team to the Department of Health*. York, UK: University of York.

Gaston, C. M., and G. Mitchell. 2005. Information giving and decision-making in patients with advanced cancer: A systematic review. *Social Science & Medicine* 61 (10): 2252–64.

Guadagnoli, E., and P. Ward. 1998. Patient participation in decision-making. *Social Science & Medicine* 47 (3): 329–39.

Guimond, P., H. Bunn, A. M. O'Connor, M. J. Jacobsen, V. K. Tait, E. R. Drake, I. D. Graham, D. Stacey, and T. Elmslie. 2003. Validation of a tool to assess health practitioners' decision support and communication skills. *Patient Education and Counseling* 50 (3): 235–45.

Guyatt, G. H., A. Mitchell, D. W. Molloy, R. Capretta, J. Horsman, and L. Griffith. 1995. Measuring patient and relative satisfaction with level of aggressiveness of care and involvement in care decisions in the context of life threatening illness. *Journal of Clinical Epidemiology* 48 (10): 1215–24.

Hall, J. A., D. L. Roter, and N. R. Katz. 1988. Meta-analysis of correlates of provider behavior in medical encounters. *Medical Care* 26 (7): 657–75.

Hall, M. A., B. Zheng, E. Dugan, F. Camacho, K. E. Kidd, A. Mishra, and R. Balkrishnan. 2002. Measuring patients' trust in their primary care providers. *Medical Care Research and Review* 59 (3): 293–318.

Haug, M. R., and B. Lavin. 1979. Public challenge of physician authority. *Medical Care* 17 (8): 844–58.

Hershberger, P. J., H. M. Part, R. J. Markert, S. M. Cohen, and W. W. Finger. 1994. Development of a test of cognitive bias in medical decision making. *Academic Medicine* 69 (10): 839–42.

Hollen, P. J. 1994. Psychometric properties of two instruments to measure quality decision making. *Research in Nursing & Health* 17 (2): 137–48.

Holmes-Rovner, M., J. Kroll, N. Schmitt, D. R. Rovner, M. L. Breer, M. L. Rothert, G. Padonu, and G. Talarczyk. 1996. Patient satisfaction with health care decisions: The satisfaction with decision scale. *Medical Decision Making* 16 (1): 58–64.

Institute of Medicine. 2001. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press.

Kaplan, S. H., S. Greenfield, B. Gandek, W. H. Rogers, and J. E. Ware, Jr. 1996. Characteristics of physicians with participatory decision-making styles. *Annals of Internal Medicine* 124 (5): 497–504.

Kennedy, A. D. 2003. On what basis should the effectiveness of decision aids be judged? *Health Expectations* 6 (3): 255–68.

Kim, S. Y., J. H. Karlawish, and E. D. Caine. 2002. Current state of research on decision-making competence of cognitively impaired elderly persons. *American Journal of Geriatric Psychiatry* 10 (2): 151–65.

Krantz, D. S., A. Baum, and M. Wideman. 1980. Assessment of preferences for self-treatment and information in health care. *Journal of Personality and Social Psychology* 39 (5): 977–90.

Lerman, C. E., D. S. Brody, G. C. Caputo, D. G. Smith, C. G. Lazaro, and H. G. Wolfson. 1990. Patients' Perceived Involvement in Care Scale: Relationship to attitudes about illness and medical care. *Journal of General Internal Medicine* 5 (1): 29–33.

Lewin, S. A., Z. C. Skea, V. Entwistle, M. Zwarenstein, and J. Dick. 2001. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* 4 (4): CD003267.

Mazur, D. J., and D. H. Hickam. 1997. Patients' preferences for risk disclosure and role in decision making for invasive medical procedures. *Journal of General Internal Medicine* 12 (2): 114–17.

McAlpine, H., L. Kristjanson, and D. Poroch. 1997. Development and testing of the Ethical Reasoning Tool (ERT): An instrument to measure the ethical reasoning of nurses. *Journal of Advanced Nursing* 25 (6): 1151–61.

Molenaar, S., M. A. Sprangers, F. C. Postma-Schuit, E. J. Rutgers, J. Noorlander, J. Hendriks, and H. C. de Haes. 2000. Feasibility and effects of decision aids. *Medical Decision Making* 20 (1): 112–27.

Nease, R. F., Jr., and W. B. Brooks. 1995. Patient desire for information and decision making in health care decisions: The Autonomy Preference Index and the Health Opinion Survey. *Journal of General Internal Medicine* 10 (11): 593–600.

O'Connor, A. n.d. Recent advances in developing patient decision aids to promote shared decision making: Annotated bibliography. http://decisionaid.ohri.ca/docs/Resources/Annotated_Bib.pdf.

O'Connor, A., V. Entwistle, M. Holmes Rovner, and H. Llewellyn-Thomas. n.d. The principles of shared decision-making: An annotated bibliography. http://www.dbmi.columbia.edu/~cmr7001/sdm/pdf/BiblShared%20Decision%20Making.pdf.

O'Connor, A. M. 1995. Validation of a decisional conflict scale. *Medical Decision Making* 15 (1): 25–30.

O'Connor, A. M., H. A. Llewellyn-Thomas, and A. B. Flood. 2004. Modifying unwarranted variations in health care: Shared decision making using patient decision aids. *Health Affairs*. http://content.healthaffairs.org/cgi/content/abstract/hlthaff.var.63v1.

O'Connor, A. M., D. Stacey, V. Entwistle, H. Llewellyn-Thomas, D. Rovner, M. Holmes-Rovner, V. Tait, J. Tetroe, V. Fiset, M. Barry, and J. Jones. 2003. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2 (2): CD001431.

Redman, B. K. 2002. *Measurement instruments in clinical ethics*. Thousand Oaks, CA: Sage.

———. 2003. *Measurement tools in patient education*. New York: Springer.

Roberts, C. S., C. E. Cox, D. S. Reintgen, W. F. Baile, and M. Gibertini. 1994. Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer* 74 (1 Suppl.): 336–41.

Sainfort, F. and B. C. Booske. 2000. Measuring post-decision satisfaction. *Medical Decision Making* 20 (1): 51–61.

Schneider, C. 1998. *The practice of autonomy: Patients, doctors, and medical decisions*. New York: Oxford University Press.

Shields, C. G., P. Franks, K. Fiscella, S. Meldrum, and R. M. Epstein. 2005. Rochester Participatory Decision-Making Scale (RPAD): Reliability and validity. *Annals of Family Medicine* 3 (5): 436–42.

Stevenson, F. A., C. A. Barry, N. Britten, N. Barber, and C. P. Bradley. 2000. Doctor-patient communication about drugs: The evidence for shared decision making. *Social Science & Medicine 50* (6): 829–40.

Sutherland, H. J., G. A. Lockwood, S. Minkin, D. L. Tritchler, J. E. Till, and H. A. Llewellyn-Thomas. 1989. Measuring satisfaction with health care: A comparison of single with paired rating strategies. *Social Science & Medicine* 28 (1): 53–58.

Thompson, S. C., J. S. Pitts, and L. Schwankovsky. 1993. Preferences for involvement in medical decision-making: Situational and demographic influences. *Patient Education and Counseling* 22 (3): 133–40.

University of California, San Francisco, Library and Center for Knowledge Management. 2006. HaPI. http://www.library.ucsf.edu/db/record.html?idrecord=52.

Whelan, T. M., M. A. O'Brien, M. Villasis-Keever, P. Robinson, A. Skye, A. Gafni, M. Brouwers, C. Charles, F. Baldassarre, M. Gauld. 2002. Impact of cancer-related decision aids. Evidence Report/Technology Assessment Number 46. (Prepared by McMaster University Under Contract No. 290-97-0017.) AHRQ Publication No. 02-E004. Rockville, MD: Agency for Healthcare Research and Quality.

Woodward, N., and B. Wallston. 1987. Age and health care beliefs: Self-efficacy as a mediator of low desire for control. *Psychology and Aging* 22:3–8.