Shared Decision-Making and the Patient-Provider Relationship

14

Kathryn J. Rowland and Mary C. Politi

Introduction

Approximately 82 % of Americans over age 40 have made a medical decision within the past 2 years across decisions ranging from initiating medications to type and timing of cancer screening to whether or not to have surgery (Zikmund-Fisher et al. 2010a). More than half (56 %) have made two or more health decisions in the past 2 years (Zikmund-Fisher et al. 2010a). Some health decisions are relatively simple to make based on strong data about a beneficial intervention with minimal associated risks, minimal lifestyle disruptions, and minimal costs. However, most medical decisions are burdened with unclear, conflicting, or unknown data (Esserman et al. 2009). Intervention options often require significant trade-offs between their associated benefits and risks. In these situations, shared decision making can assist clinicians and patients as they together weigh the scientific evidence with patient's preferences and goals to reach an agreement about health decisions with no clear best option from an evidence standpoint. In this chapter, we will introduce the concept of shared decision making between patients and clinicians, and we will discuss current and future applications of shared decision making in clinical practice.

Supporting Good Quality Health Decisions

It is tempting to equate "good" medical outcomes with "good" healthcare decisions. In the era of CT scanners, robotic surgery, and genome mapping, patients often expect the certainty of medical success when treating diseases. However, over half of all medical interventions have unknown or uncertain benefits (Esserman et al. 2009). Even healthcare decisions made based on strong evidence can lead to unanticipated or anticipated negative effects. Invasive interventions may prolong a patient's duration of life but result in a significantly lower quality of life. Therefore, decisions could be perceived both positively and negatively by patients and clinicians depending on the context and aspect of the decision being evaluated (Politi and Street 2011). In this paper, we define quality medical decisions as those that are made based on the best available clinical evidence, incorporate patients values and preferences, involve patients in the decision making process, and are feasible to implement (Elwyn et al. 2000; Sepucha et al. 2007).

K.J. Rowland
Department of Surgery, Washington University
School of Medicine, 660 South Euclid Avenue,
Campus Box 8109, St. Louis, MO 63110, USA
e-mail: rowlandk@wudosis.wustl.edu

M.C. Politi (✉)
Division of Public Health Sciences,
Department of Surgery, Washington University
School of Medicine, 660 South Euclid Avenue,
Campus Box 8100, St. Louis, MO 63112, USA
e-mail: mpoliti@wustl.edu

M.A. Diefenbach et al. (eds.), *Handbook of Health Decision Science*,
DOI 10.1007/978-1-4939-3486-7_14

Unfortunately, good quality decisions in healthcare are not always the norm. Only 36 % of patients feel well informed when facing important medical decisions (Sepucha et al. 2010). Most patients want to be informed to some extent about their diseases, although preferences for the amount of involvement may vary by patient characteristics (Benbassat et al. 1998). Although a balanced discussion of the clinical evidence and incorporation of patient values and preferences are essential to quality medical decisions, clinicians are much more likely to actively discuss the advantages of a treatment rather than its potential harms (Zikmund-Fisher et al. 2010b), and they are more likely to express an opinion about a decision than solicit patients' preferences (Zikmund-Fisher et al. 2010b).

Lack of information and failure to solicit patient preferences can lead to significant discrepancies between a physician's assessments and recommendations and the actual implementation of appropriate care (Benbassat et al. 1998; Rimer et al. 2004). Most medical interventions require patient input and acceptance in order to be effective. For example, while clinicians can prescribe a medication or recommend surgery, the impetus is on the patient to fill and take the prescription or schedule and show up for surgery. These behaviors are unlikely to occur if a patient does not support or agree with his/her physician's recommendation.

Shared decision making can improve patients decision quality by improving their knowledge about the decision, clarifying their values for the possible outcomes of the decision, and improving the match between their values and choice. (Sepucha et al. 2004). Improving decision quality may improve the quality of overall care by better matching the right patients with the right care for them. The 2012 National Quality Strategy announced patient and family engagement (including shared decision making) as a priority in healthcare reform with the potential to eradicate disparities, reduce harm, increase underuse, and decrease overuse of interventions in the American healthcare system (Fenwick et al. 2001).

Shared Decision Making

Shared decision making is a collaborative approach during which clinicians and patients work together to reach an agreement regarding a healthcare decision (Charles et al. 1997; Edwards and Elwyn 2006; O'Connor et al. 2009). The process involves reviewing the best medical evidence, soliciting patient preferences and values, and addressing potential outcomes so that the patient can understand the implications of their choice before a joint decision is reached (Charles et al. 1997).

The process of shared decision making is especially important for patients facing preference-sensitive conditions where treatment options are accompanied with substantial trade-offs between benefits and risks to the patient. Compared to usual care, patients who participate in shared decision making demonstrate improved understanding of their choices and are more likely to receive treatment that is aligned with their personal preferences and values (Stacey et al. 2011a). Patients who receive more information regarding their treatment options may choose to receive a lower intensity of services than those who are less informed about options and their associated uncertainty (Stacey et al. 2011a). A study of patients with preference-sensitive conditions—including heart conditions, benign uterine conditions, benign prostatic hyperplasia, joint pain, and back pain—found that patients who received enhanced support through contact with health coaches (via telephone, mail, e-mail, or the internet) opted for fewer preference-sensitive surgeries, had fewer hospital admissions, and had lower overall medical costs (Veroff et al. 2013). In medical ethics, shared decision making has been advocated as the balancing force between the principles of patient autonomy and beneficence (Elwyn et al. 1999; Stiggelbout et al. 2012).

Quality shared decision making for complex decisions requires clinician and patient skills and engagement. Clinicians first must have the necessary clinical knowledge, reasoning, and judgment to correctly interpret medical evidence and its associated uncertainty (Dy and Purnell 2012). The content, quantity, and level of detail of information, verbal versus written form, and timing of presentation are all important considerations (Epstein et al. 2004). Framing of this information can also impact patients' understanding and decisions (Moxey et al. 2003). For example, presenting information in a formats using frequencies (e.g., *X* out of 100), pictorial representations of risk, and using both positive and negative frames are associated with improved patient knowledge (Edwards et al. 2001).

In addition, interpersonal skills including respect, empathy, and fidelity towards the patient are essential to establishing a relationship from which to engage in shared decision making (Dy and Purnell 2012). Shared decision making respects patient autonomy and seeks to foster a sense of partnership between clinician and patient. For this partnership to succeed, clinicians must elicit, understand, and validate the patient's perspective, involve the patient in care and decision making to the extent the patient desires to be, provide clear and understandable explanations, and foster trust and commitment (Epstein and Peters 2009). Lack of trust can inhibit shared decision making and patients' willingness to engage in the shared decision making process (Pearson and Raeke 2000; Poses et al. 1995).

Patients also require shared decision making skills, including an ability to understand clinical information, appreciate its significance, and apply the information to make value-consistent decisions (Dunn et al. 2006). In addition, patients need communication skills and self-efficacy to ask questions, state preferences, express concerns, and offer opinions (Street and Millay 2001). As a process, shared decision making requires communicating about the patient's health condition, sharing both a patient's and his/her clinician's perspective on the decision, and reaching an agreement about the best treatment option for the individual patient (Politi and Street 2011). However, during the process, patients can disagree with some of what their clinician suggests about treatment or preferences for possible outcomes of treatment. Patients may fear being labeled as a "difficult patient," or feel as if they will receive inferior care if they express disagreement (Adams et al. 2012). Thus the process can present challenges even for patients with skills understanding clinical information and communicating their preferences.

Although patients typically want some level of involvement in medical decisions, the degree that a patient desires to be in control of the decisions may change across different medical scenarios (Deber et al. 1996). In one study, patients preferred clinicians to be more involved in decisions that ultimately impacted mortality, but preferred to remain in greater control of decisions impacting morbidity or quality of life (Deber et al. 1996). The act of involving the patient in the decision making process may be more important than whether the patient or clinician ultimately makes the final decision (Edwards and Elwyn 2006). For patients with reluctance or hesitance to engage in the process, encouragement and patient-centered communication can increase patient empowerment, self-efficacy, and involvement and improve decision making (Dy and Purnell 2012).

Decision aids may also facilitate the shared decision making process. Decision aids serve as balanced sources of information regarding the treatment options for a particular health condition (Stacey et al. 2011b). They aim to present information in plain language, describe alternatives to treat or manage a condition, and provide information about the risks and benefits to various treatment options. Decision aids can take the form of paper-based brochures or pamphlets, videos, or websites The use of decision aids in making treatment choices has been shown to increase patient knowledge of options, risks, and benefits, create more realistic expectations, lower decisional conflict, reduce uncertainty, enhance active patient participation, decrease the number of undecided patients, and improve agreement between values and choices (Stacey et al. 2011b).

Shared Decision Making in Practice

Future Opportunities for the Application of Shared Decision Making: High-Risk Surgical Procedures, Postoperative Care, and Surgical “Buy-in”

Shared decision making can be used to facilitate the implementation of care that aligns with patient preferences and values (Fenwick et al. 2001; Sepucha et al. 2004). While applicable to many medical care decisions, shared decision making is especially important for preference-sensitive decisions. In the past, shared decision making has been applied to medical decisions regarding screening, medical drug therapy initiation, and elective surgery. Decision aids designed to promote shared decision making have been developed for a variety of clinical decisions, including but not limited to prostate cancer screening and treatment, prenatal screening, obstetrical decisions, male newborn circumcision, vaccination, colon cancer screening, genetic testing, diabetes treatment, hormone replacement therapy, treatment for abnormal uterine bleeding, back surgery, breast cancer treatment, heart disease management, and osteoporosis treatment (Stacey et al. 2011b). However, discussions about high-risk surgical procedures, postoperative care, and surgical “buy-in” is one area in which shared decision making could greatly improve clinical care, but has yet to be applied.

Elective high-risk surgical procedures include many vascular procedures, cardiac surgery, thoracic surgery, transplant surgery, extensive abdominal operations, and neurosurgery. Such procedures are considered elective if the patient’s life is not in immediate jeopardy (requiring emergent surgery) and if the operation is planned in advance. These high-risk elective procedures have a high mortality rate (generally considered to be above 3 %) and may result in the need for prolonged postoperative intensive care unit stay and temporary or permanent respiratory failure requiring tracheostomy, renal failure requiring hemodialysis, use of artificial nutrition, and/or non-healing surgical wounds. Given the inherent risks of the surgery and postoperative care, and given the fact that these operations are planned in advance, discussion of the risks, benefits, and postoperative care is necessary for patients to make informed decisions about surgery.

Unfortunately, detailed discussion of risks, benefits, and postoperative care is often either left out of preoperative discussions or is very briefly discussed with patients. A study of surgeon-patient discussions regarding treatment for abdominal aortic aneurysms revealed that only a minority of discussions (29 %) addressed the disorder, the proposed procedure, the consequences and risks of surgery, the option of watchful observation, and individual prognosis (Knops et al. 2010). Moreover, 18 % of patients after aneurysm surgery indicated that they would not have undergone surgery had they understood the recovery process involved (Williamson et al. 2001). Even when patients are provided with adequate information, they may fail to comprehend important details necessary to make an informed decision (Mulsow et al. 2012). For example, among patients consenting to carotid endarterectomy, most had unrealistic expectations as to the risks and benefits of surgery and postoperative care (Lloyd et al. 2001); And a study of postoperative laparoscopic cholecystectomy patients found that while 84 % believed they were well informed and satisfied with the information provided to them, only 51 % demonstrated satisfactory knowledge of the procedure, and only 30 % could list a potential complication of the procedure (Kriwanek et al. 1998). A similar lack of understanding of the basic information required for surgical consent has been shown in patients undergoing coronary artery bypass grafting, carotid surgery, lower-limb bypass, hip arthroplasty, and varicose vein surgery (Dillon et al. 2005; Larobina et al.

2007; Mishra et al. 2006; Stanley et al. 1998; Turner and Williams 2002).

In addition, surgeons often assumed or infer patient preferences without explicitly discussing how patient preferences might affect surgery decisions and subsequent postoperative care. Surgical “buy-in” has been described by surgeons as the informal contract between surgeons and patients that commits a patient to the surgeon’s anticipated postoperative care when the patient consent for an operative procedure (Schwarze et al. 2010). Surgeons often view this commitment to postoperative care as a packaged deal, a roughly 30 day commitment by the patient to receive intensive life-sustaining therapy, including mechanical ventilation, hemodynamic support, hemodialysis, artificial nutrition, and additional invasive procedures after a surgical intervention (Schwarze et al. 2010). While such anticipated postoperative care may involve preference-sensitive life-sustaining therapies, it is unclear if patients are aware of having consented to such care upon arrival in the operating room for a preference-sensitive, elective procedure (Schwarze et al. 2010).

Surgeons invest time, operating facilities, and resources (including scarce resources such as blood products) in their patients, and while poor outcomes are expected to occasionally occur, these outcomes are often viewed as personal failures of the surgeon (Schwarze et al. 2010). These factors all contribute to the sentiment of the surgeon to do everything possible to prolong the patient’s life. However, many patients have strong opinions regarding the use of life-sustaining interventions. Surgeons performing such operations recognize the importance of preoperative discussion with patients prior to proceeding to the operating room (McKneally et al. 2009), but it is not clear that patients fully understand and consent to the plan for postoperative care that is assumed by the surgeon. The lack of patient input preoperatively results in patients proceeding with surgery and subsequently finding themselves in situations postoperatively where life-supporting therapy is implemented, potentially against their wishes.

In one study, none of the surgeons in the study reported formal documentation of this explicit contract (Schwarze et al. 2010). Some view the presence of a signed informed consent document as evidence that such a contract exists (Schwarze et al. 2010). Ideally, surgical consent should include a discussion of whether the patient authorizes the surgeon to treat complications after the procedure, including prolonged mechanical ventilation or intensive care unit stay (Bernat and Peterson 2006). Unfortunately, in many cases, patients remain uninformed and unaware of surgical “buy-in”. Many suggest that informed consent should be a process and not simply a document. However, often, clinicians simply request signatures from patients without any engagement in shared decision making prior to signing informed consent documents (Weinstein et al. 2007).

To better communicate about surgical “buy-in” and engage in shared decision making about these high-risk elective procedures, clinicians could design improved informed consent documents for surgery that include postoperative care as a distinct entity on the forms. However, in current practice, patients feel misinformed about the surgeries themselves, much less the unaddressed issue of “buy-in” and postoperative care. In addition, focusing only on improving consent documents to include stipulations on postoperative care is likely to have little effect on current practice. One study demonstrated that 70 % of surgical patients do not read the informed consent form (Lavelle-Jones et al. 1993). Most adults admit that the forms are too long, intimidating, with small, crowded text and unexplained medical and legal terms (Han et al., in press), and the readability of these documents exceeds the average reading level in the United States (Einhorn and Hogarth 1986). Developing consent documents that pay attention to principles of health literacy (Lorenzen et al. 2008) and including personalized risk assessments (Krumholz 2010) can improve patient-centered decision making. Yet research suggests that going beyond improving informed consent documents and focusing on the informed consent process and discussion is needed to improve understanding and decision making (Flory and Emanuel 2004).

Patients express a strong desire to be informed about the risks of surgical procedures (Larobina et al. 2007). Surgeons greatly underestimate patients need for information relating to surgery and the perioperative period (Keulers et al. 2008). Some believe that providing patients with detailed information regarding the risks of procedures may increase anxiety, however this is not supported by the research (Garrud et al. 2001). Shared decision making can help improve the surgical “buy-in” and informed consent discussion by involving patients in conversations about surgery and all postoperative care, incorporating patients’ values into the discussion, and agreeing on a plan based on possible outcomes of surgery and postoperative complications. Consenting to surgery with agreed upon limitations to postoperative care, or not consenting to the high-risk elective procedures are both reasonable options depending on patients’ goals and values. Surgeons should include their patients in shared decision making to ensure that proceeding with surgery and postoperative care aligns with the patient’s preferences. The major limitation of preoperative discussion of the patient’s preferences about postoperative care is the lack of familiarity and experience that patients have with life-sustaining interventions. Patients sometimes report higher quality of life postoperatively than they would have predicted preoperatively when forced to deal with previously unimaginable situations (such as a colostomy or paraplegia) (Ubel et al. 2005). It is possible that patients opposed to life sustaining interventions preoperatively may support such measures postoperatively.

The role of decision aids and patient narratives during surgical “buy-in” might assist in this process, although the role of decision aids for informed consent remains unclear. In studies on surgical consent, paper based tools have been shown to have little effect on patient’s understanding of surgical consent and are often too difficult to read (Mulsow et al. 2012). Multimedia interventions as an adjunct to informed consent have been shown to increase recall and knowledge (Danino et al. 2005; Evrard et al. 2005; Mulsow et al. 2012). However, these interventions have failed to have an effect on patient understanding of potential complications (Danino et al. 2005), with surgical patients who had adverse outcomes showing poor recollection of key messages in respect to complications (Evrard et al. 2005).

Challenges in Shared Decision Making

The above section described one potential application of shared decision making to an important clinical context. However, across many areas, shared decision making in clinical practice remains a challenge.

Work Flow and Time Limitations

Time constraints are the most frequently cited barrier to implementation of shared decision making in clinical practice (Legare et al. 2008). Despite the perceived time constraints, no robust evidence exists that more time is required to engage in shared decision making than to offer usual care (Legare et al. 2010, 2012; Stacey et al. 2011a). As Legare and Witteman argue, time constraints are the most frequently cited barrier to *any* change in clinical practice and implementation of shared decision making is no different in this sense than implementation of any other practice improvement (Legare and Witteman 2013).

Health Literacy Skills

Health literacy represents “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Einhorn and Hogarth 1986). In the shared decision making process, limited health literacy skills may affect a patient’s ability to understand and process the medical information required to make an informed decision. Patients with limited health literacy skills have more difficulty understanding physician instructions (Schillinger et al. 2004; Williams et al. 2002), and ask fewer questions (Katz et al. 2007). Clinicians commonly overestimate patients' literacy levels (Bass et al. 2002; Powell and Kripalani 2005), and patients may hide their limited understanding out of embarrassment (Parikh et al. 1996). Patients with limited health literacy skills are overrepresented among those with chronic diseases (Dewalt et al. 2004; Howard et al. 2005). Health literacy skills are not related to the amount of information that patients desire, however, patients with lower literacy skills may have lower knowledge recall and might be less likely to want an active role in medical decision making (Lillie et al. 2007). Clarifying decision role preference, using everyday language/avoiding of medical jargon, limiting the amount of information discussed at each visit, and using teach-back techniques to confirm patient understanding can help this population (Kripalani and Weiss 2006).

Numeracy Skills

Shared decision making involves an understanding of treatment options and the associated benefits and harms, and the process often requires clinicians to communicate statistical information to patients. Low numeracy skills are pervasive across the US population (Nelson et al. 2008) and can present challenges when communicating and interpreting risk/benefit information. One study demonstrated that only 20 % of participants were able to convert the frequency 1 in 1000 to a percentage (Lipkus et al. 2001). Low numeracy skills cannot be predicted based on education or other sociodemographic characteristics (Nelson et al. 2008). When numeric data is available, risks and benefits of treatment options should be presented as frequencies (e.g., *X* out of 100 or *X* out of 1000) with a consistent denominator (Fagerlin et al. 2011). In some cases, qualitative "gist" understanding may result in superior quantitative processing (Nelson et al. 2008; Reyna 2005). One drawback to the gist approach is that individuals may interpret qualitative values such as "not likely", "somewhat likely", and "very likely" or "high risk" or "low risk" differently from that of the clinician. As patients weigh the risks and benefits, it is important to reinforce the time interval over which risk occurs (Fagerlin et al. 2011). Risks may or may not be assumed immediately and may or may not dissipate over time, while the expected benefits of treatment may or may not be realized immediately or over the course of years, if at all. Research has demonstrated that patients with limited numeracy skills are less likely to prefer active roles in shared decision making, although education efforts to improve numeric understanding and using non-quantitative communication may foster the involvement of patients with limited numeracy skills during shared decision making (Galesic and Garcia-Retamero 2011).

Surrogate Decision Making

Surrogate decision making introduces additional challenges into the shared decision making process. Surrogates may not know patient preferences for a particular situation or may encounter difficulty in applying the patient's preferences rather than their own (Shah et al. 2009). Conflicts of interest, family conflict, emotions, and role expectations may affect decision making (Schenker et al. 2012). Research has shown that treatment options that seem reasonable for oneself may seem less appropriate when giving advice or acting on behalf of another (Zikmund-Fisher et al. 2006). Surrogate decisions can suffer from omission bias, where an error of omission is seen as preferable to an error of commission (Asch et al. 1994). For example, a parent may choose not to vaccinate a child (an omission) due to unsubstantiated or exaggerated fears that vaccination (a commission) will result in serious side effects. Research on surrogate decision making is recent and growing, and will help clinicians better learn how to incorporate surrogates into shared decision making with patients.

Teaching Shared Decision Making

Shared decision making has the potential to improve patient health while helping control healthcare costs (Frosch et al. 2011). Despite its promise, shared decision making has not been universally integrated into clinical practice (Pellerin et al. 2011). The Accreditation Council for Graduate Medical Education has recognized the need to train physicians in communication and interpersonal skills, and endorses such skills as a general competency requirement for medical education during residency. Despite this requirement, studies have demonstrated that physician residents overestimated the clarity to which they were able to communicate with patients and, on average, used two medical jargon terms per minute in interactions with standardized patients (Howard et al. 2013). While it is clear that clinicians need more training in clear communication and the shared decision making approach, the best interventions to teach such skills or to measure professional competency of such skills remains unclear (Epstein and Hundert 2002; Legare et al. 2010; Legare and Witteman 2013). Use of educational meetings, giving healthcare professionals feedback, giving healthcare professionals learning materials, and using patient decision aids have been tried to increase the adaptation of shared decision making by established healthcare professionals (Legare et al. 2010); standardized patients, workshops, and role modeling have been suggested for training resident physicians and medical students in the use of shared decision making (Kripalani and Weiss 2006; Lagan et al. 2013).

Conclusions

Shared decision making involves providing information to patients as to the benefits and risks associated with different treatment options and incorporating patient values into the treatment decision (Charles et al. 1997). Shared decision making respects patient autonomy and seeks to foster a sense of partnership between clinician and patient. For this partnership to succeed, clinicians must elicit, understand, and validate the patient's perspective, involve the patient in care and decision making to the extent the patient desires to be, provide clear and understandable explanations, and foster a relationship of trust and commitment (Epstein and Peters 2009). The clinician-patient relationship can have a significant impact on medical decision making. In some settings, when discussions occur in clinical practice without a shared decision making approach, physician recommendations have been shown to lead patients to make decisions against what they would otherwise prefer (Gurmankin et al. 2002). In addition, there is a delicate balance between involving patients in medical decision making without leaving them feeling unsupported through the complex process of making sense of uncertain clinical evidence. Patients should feel empowered, and not abandoned, during the shared decision making process. Overall, the goal of shared decision making is to encourage a patient-clinician discussion that goes beyond factual information giving, resulting in the physician and patient understanding the patient's health condition, discussing each other's perspective about the decision and its associated uncertainty, incorporating patients' values into the decision, and agreeing on a decision and follow-up plan. In this chapter, we present current and future applications of shared decision making, and discuss some challenges incorporating shared decision making in clinical practice. Additional research, shared decision making training opportunities, and institutional policy approaches can illuminate possible solutions to these challenges.

Key Points

Shared decision making is a collaborative approach where physicians and patients work together to reach an agreement regarding a preference-sensitive healthcare decision where valid treatment options are accompanied by both risks and benefits.

The shared decision making process involves presenting the medical evidence clearly, soliciting patient preferences and values, and addressing potential outcomes so that the patient can appreciate the implications of their decision before an agreement is reached.

Shared decision making facilitates the implementation of care that aligns with patient preferences and values, and may increase patient compliance and adherence with medical treatment. Several innovative applications of shared decision making are discussed in this chapter.

One innovative application in the field of surgery is to practice shared decision making regarding high-risk surgical procedures and postoperative care. This chapter discusses how shared decision making could enhance informed consent and patient-centered care for high-risk surgical procedures that carry significant risk of need for intensive, life-sustaining, postoperative care.

References

Adams, J. R., Elwyn, G., Legare, F., & Frosch, D. L. (2012). Communicating with physicians about medical decisions: A reluctance to disagree. *Archives of Internal Medicine, 172*, 1184–1186.

Asch, D. A., Baron, J., Hershey, J. C., Kunreuther, H., Meszaros, J., et al. (1994). Omission bias and pertussis vaccination. *Medical Decision Making, 14*, 118–123.

Bass, P. F, 3rd, Wilson, J. F., Griffith, C. H., & Barnett, D. R. (2002). Residents' ability to identify patients with poor literacy skills. *Academic Medicine: Journal of the Association of American Medical Colleges, 77*, 1039–1041.

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

Bernat, J. L., & Peterson, L. M. (2006). Patient-centered informed consent in surgical practice. *Archives of Surgery, 141*, 86–92.

Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes at least two to tango). *Social Science and Medicine, 44*, 681–692.

Danino, A. M., Chahraoui, K., Frachebois, L., Jebrane, A., Moutel, G., et al. (2005). Effects of an informational CD-ROM on anxiety and knowledge before aesthetic surgery: A randomised trial. *British Journal of Plastic Surgery, 58*, 379–383.

Deber, R. B., Kraetschmer, N., & Irvine, J. (1996). What role do patients wish to play in treatment decision making? *Archives of Internal Medicine, 156*, 1414–1420.

Dewalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes: A systematic review of the literature. *Journal of General Internal Medicine, 19*, 1228–1239.

Dillon, M. F., Carr, C. J., Feeley, T. M., & Tierney, S. (2005). Impact of the informed consent process on patients' understanding of varicose veins and their treatment. *Irish Journal of Medical Science, 174*, 23–27.

Dunn, L. B., Nowrangi, M. A., Palmer, B. W., Jeste, D. V., & Saks, E. R. (2006). Assessing decisional capacity for clinical research or treatment: A review of instruments. *The American Journal of Psychiatry, 163*, 1323–1334.

Dy, S. M., & Purnell, T. S. (2012). Key concepts relevant to quality of complex and shared decision-making in health care: A literature review. *Social Science and Medicine, 74*, 582–587.

Edwards, A., & Elwyn, G. (2006). Inside the black box of shared decision making: Distinguishing between the process of involvement and who makes the decision. *Health Expectations, 9*, 307–320.

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

Einhorn, H. J., & Hogarth, R. M. (1986). Decision making under uncertainty. *Journal of Business, 59*, S225–S250.

Elwyn, G., Edwards, A., & Kinnersley, P. (1999). Shared decision-making in primary care: The neglected second half of the consultation. *British Journal of General Practice, 49*, 477–482.

Elwyn, G., Edwards, A., Kinnersley, P., & Grol, R. (2000). Shared decision making and the concept of equipoise: The competences of involving patients in healthcare choices. *British Journal of General Practice, 50*, 892–899.

Epstein, R. M., Alper, B. S., & Quill, T. E. (2004). Communicating evidence for participatory decision making. *JAMA: The Journal of the American Medical Association, 291*, 2359–2366.

Epstein, R. M., & Hundert, E. M. (2002). Defining and assessing professional competence. *JAMA: The Journal of the American Medical Association, 287*, 226–235.

Epstein, R. M., & Peters, E. (2009). Beyond information: Exploring patients' preferences. *JAMA: The Journal of the American Medical Association, 302*, 195–197.

Esserman, L., Shieh, Y., & Thompson, I. (2009). Rethinking screening for breast cancer and prostate cancer. *JAMA, 302*, 1685–1692.

Evrard, S., Mathoulin-Pelissier, S., Larrue, C., Lapouge, P., Bussieres, E., & Tunon De Lara, C. (2005). Evaluation of a preoperative multimedia information program in surgical oncology. *European Journal of Surgical Oncology: The journal of the European Society of Surgical Oncology and the British Association of Surgical Oncology, 31*, 106–110.

Fagerlin, A., Zikmund-Fisher, B. J., & Ubel, P. A. (2011). Helping patients decide: Ten steps to better risk communication. *Journal of the National Cancer Institute, 103*, 1436–1443.

Fenwick, E., Claxton, K., & Sculpher, M. (2001). Representing uncertainty: The role of cost-effectiveness acceptability curves. *Health Economics, 10*, 779–787.

Flory, J., & Emanuel, E. (2004). Interventions to improve research participants' understanding in informed consent for research: A systematic review. *JAMA: The Journal of the American Medical Association, 292*, 1593–1601.

Frosch, D. L., Moulton, B. W., Wexler, R. M., Holmes-Rovner, M., Volk, R. J., & Levin, C. A. (2011). Shared decision making in the United States: Policy and implementation activity on multiple fronts. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen, 105*, 305–312.

Galesic, M., & Garcia-Retamero, R. (2011). Do low-numeracy people avoid shared decision making? *Health psychology: Official Journal of the Division of Health Psychology, American Psychological Association, 30*, 336–341.

Garrud, P., Wood, M., & Stainsby, L. (2001). Impact of risk information in a patient education leaflet. *Patient Education and Counseling, 43*, 301–304.

Gurmankin, A. D., Baron, J., Hershey, J. C., & Ubel, P. A. (2002). The role of physicians' recommendations in medical treatment decisions. *Medical Decision Making, 22*, 262–271.

Han PK, Korbrin SC, Klein WMP, Davis WW, Stefanak M, Taplin SH. Perceived ambiguity about screening mammography recommendations: Association with future mammography uptake and perceptions. *Cancer Epidemiology Biomarkers and Prevention* (in press).

Howard, D. H., Gazmararian, J., & Parker, R. M. (2005). The impact of low health literacy on the medical costs of medicare managed care enrollees. *The American journal of medicine, 118*, 371–377.

Howard T, Jacobson KL, Kripalani S. (2013). Doctor talk: Physicians' use of clear verbal communication. *Journal of health communication*

Katz, M. G., Jacobson, T. A., Veledar, E., & Kripalani, S. (2007). Patient literacy and question-asking behavior during the medical encounter: A mixed-methods analysis. *Journal of General Internal Medicine, 22*, 782–786.

Keulers, B. J., Scheltinga, M. R., Houterman, S., Van Der Wilt, G. J., & Spauwen, P. H. (2008). Surgeons underestimate their patients' desire for preoperative information. *World Journal of Surgery, 32*, 964–970.

Knops, A. M., Ubbink, D. T., Legemate, D. A., de Haes, J. C., & Goossens, A. (2010). Information communicated with patients in decision making about their abdominal aortic aneurysm. *European Journal of Vascular and Endovascular Surgery: The Official Journal of the European Society for Vascular Surgery, 39*, 708–713.

Kripalani, S., & Weiss, B. D. (2006). Teaching about health literacy and clear communication. *Journal of General Internal Medicine, 21*, 888–890.

Kriwanek, S., Armbruster, C., Beckerhinn, P., Blauensteier, W., & Gschwantler, M. (1998). Patients' assessment and recall of surgical information after laparoscopic cholecystectomy. *Digestive surgery, 15*, 669–673.

Krumholz, H. M. (2010). Informed consent to promote patient-centered care. *JAMA: The Journal of the American Medical Association, 303*, 1190–1191.

Lagan, C., Wehbe-Janek, H., Waldo, K., Fox, A., Jo, C., & Rahm, M. (2013). Evaluation of an interprofessional clinician-patient communication workshop utilizing standardized patient methodology. *Journal of Surgical Education, 70*, 95–103.

Larobina, M. E., Merry, C. J., Negri, J. C., & Pick, A. W. (2007). Is informed consent in cardiac surgery and percutaneous coronary intervention achievable? *ANZ Journal of Surgery, 77*, 530–534.

Lavelle-Jones, C., Byrne, D. J., Rice, P., & Cuschieri, A. (1993). Factors affecting quality of informed consent. *BMJ, 306*, 885–890.

Legare, F., Ratte, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions. *Patient Education and Counseling, 73*, 526–535.

Legare F, Ratte S, Stacey D, Kryworuchko J, Gravel K, et al. (2010). Interventions for improving the adoption of shared decision making by healthcare professionals. *Cochrane Database Syst Rev*, CD006732

Legare, F., Turcotte, S., Stacey, D., Ratte, S., Kryworuchko, J., & Graham, I. D. (2012). Patients' perceptions of sharing in decisions: A systematic review of interventions to enhance shared decision making in routine clinical practice. *Patient, 5*, 1–19.

Legare, F., & Witteman, H. O. (2013). Shared decision making: Examining key elements and barriers to adoption into routine clinical practice. *Health Affairs (Millwood), 32*, 276–284.

Lillie, S. E., Brewer, N. T., O'Neill, S. C., Morrill, E. F., Dees, E. C., et al. (2007). Retention and use of breast cancer recurrence risk information from genomic tests: The role of health literacy. *Cancer Epidemiology, Biomarkers and Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology, 16*, 249–255.

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making, 21*, 37–44.

Lloyd, A., Hayes, P., Bell, P. R., & Naylor, A. R. (2001). The role of risk and benefit perception in informed consent for surgery. *Medical Decision Making, 21*, 141–149.

Lorenzen, B., Melby, C. E., & Earles, B. (2008). Using principles of health literacy to enhance the informed consent process. *AORN Journal, 88*, 23–29.

McKneally, M. F., Martin, D. K., Ignagni, E., & D'Cruz, J. (2009). Responding to trust: Surgeons' perspective on informed consent. *World Journal of Surgery, 33*, 1341–1347.

Mishra, P. K., Ozalp, F., Gardner, R. S., Arangannal, A., & Murday, A. (2006). Informed consent in cardiac surgery: Is it truly informed? *Journal of Cardiovascular Medicine (Hagerstown), 7*, 675–681.

Moxey, A., O'Connell, D., McGettigan, P., & Henry, D. (2003). Describing treatment effects to patients. *Journal of General Internal Medicine, 18*, 948–959.

Mulsow, J. J., Feeley, T. M., & Tierney, S. (2012). Beyond consent—Improving understanding in surgical patients. *American Journal of Surgery, 203*, 112–120.

Nelson, W., Reyna, V. F., Fagerlin, A., Lipkus, I., & Peters, E. (2008). Clinical implications of numeracy: Theory and practice. *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine, 35*, 261–274.

O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, et al. (2009). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*, CD001431

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling, 27*, 33–39.

Pearson, S. D., & Raeke, L. H. (2000). Patients' trust in physicians: Many theories, few measures, and little data. *Journal of General Internal Medicine, 15*, 509–513.

Pellerin, M. A., Elwyn, G., Rousseau, M., Stacey, D., Robitaille, H., & Legare, F. (2011). Toward shared decision making: Using the OPTION scale to analyze resident-patient consultations in family medicine. *Academic Medicine: Journal of the Association of American Medical Colleges, 86*, 1010–1018.

Politi, M. C., & Street, R. L, Jr. (2011). The importance of communication in collaborative decision making: Facilitating shared mind and the management of uncertainty. *Journal of Evaluation in Clinical Practice, 17*, 579–584.

Poses, R. M., Cebul, R. D., & Wigton, R. S. (1995). You can lead a horse to water-improving physicians' knowledge of probabilities may not affect their decisions. *Medical Decision Making, 15*, 65–75.

Powell, C. K., & Kripalani, S. (2005). Brief report: Resident recognition of low literacy as a risk factor in hospital readmission. *Journal of General Internal Medicine, 20*, 1042–1044.

Reyna, V. F. (2005). Fuzzy-trace theory, judgment, and decision-making: A dual-processes approach. In C. Izawa & N. Ohta (Eds.), *Human learning and memory: Advances in theory and applications* (pp. 239–256). Mahwah, NJ: Erlbaum.

Rimer, B. K., Briss, P. A., Zeller, P. K., Chan, E. C., & Woolf, S. H. (2004). Informed decision making: What is its role in cancer screening? *Cancer, 101*, 1214–1228.

Schenker, Y., Crowley-Matoka, M., Dohan, D., Tiver, G. A., Arnold, R. M., & White, D. B. (2012). I don't want to be the one saying 'we should just let him die': Intrapersonal tensions experienced by surrogate decision makers in the ICU. *Journal of General Internal Medicine, 27*, 1657–1665.

Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling, 52*, 315–323.

Schwarze, M. L., Bradley, C. T., & Brasel, K. J. (2010). Surgical "buy-in": The contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy. *Critical Care Medicine, 38*, 843–848.

Sepucha, K., Ozanne, E., Silvia, K., Partridge, A., & Mulley, A. G, Jr. (2007). An approach to measuring the quality of breast cancer decisions. *Patient Education and Counseling, 65*, 261–269.

Sepucha, K. R., Fagerlin, A., Couper, M. P., Levin, C. A., Singer, E., & Zikmund-Fisher, B. J. (2010). How does feeling informed relate to being informed? The DECISIONS survey. *Medical Decision Making, 30*, 77S–84S.

Sepucha KR, Fowler FJ, Jr., Mulley AG, Jr. (2004). Policy support for patient-centered care: The need for measurable improvements in decision quality. *Health Affair (Millwood)*, Suppl Variation, VAR54-62

Shah, S. G., Farrow, A., & Robinson, I. (2009). The representation of healthcare end users' perspectives by surrogates in healthcare decisions: A literature review. *Scandinavian Journal of Caring Sciences, 23*, 809–819.

Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, et al. (2011a). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*, CD001431

Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, et al. (2011b). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, *10*, Article No.: CD001431

Stanley, B. M., Walters, D. J., & Maddern, G. J. (1998). Informed consent: How much information is enough? *The Australian and New Zealand Journal of Surgery, 68*, 788–791.

Stiggelbout, A. M., Van der Weijden, T., De Wit, M. P., Frosch, D., Legare, F., et al. (2012). Shared decision making: Really putting patients at the centre of healthcare. *BMJ, 344*, e256.

Street, R. L, Jr., & Millay, B. (2001). Analyzing patient participation in medical encounters. *Health Commun, 13*, 61–73.

Turner, P., & Williams, C. (2002). Informed consent: Patients listen and read, but what information do they retain? *The New Zealand medical journal, 115*, U218.

Ubel, P. A., Loewenstein, G., Schwarz, N., & Smith, D. (2005). Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association, 24*, S57–S62.

Veroff, D., Marr, A., & Wennberg, D. E. (2013). Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions. *Health Affair (Millwood), 32*, 285–293.

Weinstein, J. N., Clay, K., & Morgan, T. S. (2007). Informed patient choice: Patient-centered valuing of surgical risks and benefits. *Health Affair (Millwood), 26*, 726–730.

Williams, M. V., Davis, T., Parker, R. M., & Weiss, B. D. (2002). The role of health literacy in patient-physician communication. *Family Medicine, 34*, 383–389.

Williamson, W. K., Nicoloff, A. D., Taylor, L. M, Jr., Moneta, G. L., Landry, G. J., & Porter, J. M. (2001). Functional outcome after open repair of abdominal aortic aneurysm. *Journal of Vascular Surgery, 33*, 913–920.

Zikmund-Fisher, B. J., Couper, M. P., Singer, E., Levin, C. A., Fowler, F. J, Jr., et al. (2010a). The DECISIONS study: A nationwide survey of United States adults regarding 9 common medical decisions. *Medical Decision Making, 30*, 20S–34S.

Zikmund-Fisher, B. J., Couper, M. P., Singer, E., Ubel, P. A., Ziniel, S., et al. (2010b). Deficits and variations in patients' experience with making 9 common medical decisions: The DECISIONS survey. *Medical Decision Making, 30*, 85S–95S.

Zikmund-Fisher, B. J., Sarr, B., Fagerlin, A., & Ubel, P. A. (2006). A matter of perspective: Choosing for others differs from choosing for yourself in making treatment decisions. *Journal of General Internal Medicine, 21*, 618–622.