

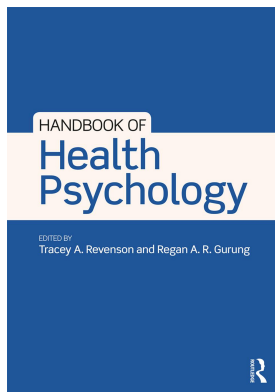
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SHARED DECISION MAKING IN HEALTHCARE

Michael A. Diefenbach and Sara Fleszar

Over the last several decades, the United States has witnessed considerable advancements in healthcare, initiating a paradigm shift in medical decision making. Traditional medical decision making, practiced up until the 1970s, was based on a paternalistic physician-patient relationship. Patients assumed a passive decision role and placed authority on all aspects of their diagnosis and treatment in the hands of the physician (Hoving, Visser, Mullen, & van den Borne, 2010; Meadows, 2017). A cultural shift to increasing patient autonomy, coupled with increasingly complex treatment modalities, resulted in an emphasis on knowledge transfer from physician to patient on the risks and benefits of treatments (Charles, Gafni, & Whelan, 1999). This development led to the formation of the first scientific journal focusing on patient education, *Patient Education and Counseling* in 1976. As a consequence, accessibility to studies of physician-patient communication increased, stimulating research on improving patient education (Hoving et al., 2010). With attention concentrated on new models of patient education, patient advocacy organizations and healthcare professionals began focusing on patient's rights, education, and self-efficacy.

Over time, physicians' dominance over decision making shifted to a more collaborative model and, in 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research coined the term *shared decision making* (SDM). The president's commission redirected "the discussion toward how to foster a relationship between patients and professionals characterized by mutual participation and respect and by sharing decision-making" (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982, p. 36). Physicians, healthcare providers, and patient advocacy groups began to encourage patients to take an active role not only in the shared treatment selection process but also in the process of improving their health in general. Although it was always recognized that patients' behaviors outside their interactions with their physicians were important to health outcomes, it was not until the 1990s that incorporating health behaviors into patient education programs became a primary focus (Hoving et al., 2010).

Today, SDM is the dominant model for prevention and medical treatment decisions. Policy makers are incentivizing and integrating the shared decision-making process into quality payment models, making it a required practice for all U.S. clinicians receiving government payments ("Beneficiary engagement and incentives models: General information", March 28, 2017). With the increased attention focusing on SDM, many organizations in the U.S. and abroad (the Agency for Healthcare Research Quality, the U.S. Preventive Services Task Force, the Institute of Medicine, and the World

Health Organization) advocate for shared decision making when making preventative and treatment recommendations (Berwick, 2002; Sheridan, Harris, Woolf, & Force, 2004).

This chapter provides a current review of the literature addressing SDM, beginning by describing the most prevalent models and frameworks, and the barriers to implementation. The common instruments used to measure SDM are presented, followed by a brief discussion on the extent to which patients want to be involved in their healthcare decisions and the degree of participation by physicians. The chapter also covers the effectiveness of interventions to improve the adoption of SDM, and finishes with a discussion of the future directions of SDM focusing on missing pieces of how we study SDM and with whom.

Models of Shared Decision Making

Although there are several models of shared decision making (see Table 12.1), there is no agreed upon definition. The most commonly used definition is: “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010). Charles, Gafni, and Whelan (1997) describe four minimal necessary characteristics of SDM: Both the physician and patient (1) are involved in the treatment decision-making process, (2) share information with each other, (3) take steps to participate in the decision-making process by expressing treatment preferences, and (4) are involved in making a treatment decision.

The Three-Step Model

Achieving SDM is contingent on creating an environment where individuals can act independently to make choices. To create this environment, patients must be provided with information and support through the decision-making process. The three-step model (Elwyn et al., 2012) illustrates the process of moving from initial to informed preferences. In the first step, choice talk, the physician provides quality information and assesses the patient’s knowledge of options. Supporting patients’ deliberations about their options, physicians can help patients understand that reasonable options exist, correct any misinformation, and check the patient’s reaction. In the second step, option talk, patients are informed about treatment options in detail, the harms and benefits of each option, and provided with decision support. During the last step, decision talk, patients are supported to explore what matters most to them and aided in moving toward a decision. Elwyn et al. suggest that this model should be used in conjunction with decisions support tools such as decision aids, booklets, and websites. This model is concise and easily integrated into routine clinical settings.

Despite the strengths of Elwyn et al.’s (2012) model, Stiggelbout, Pieterse, and De Haes (2015) argued that the third step, decision talk, should be split into two distinct steps. The resulting model consists of four distinct phases: The physician (1) informs the patient that a decision is to be made and that the patient’s opinion is important, (2) explains the options and the benefits and side effects of each option, (3) discusses the patient’s preferences and supports the patient in deliberation, and (4) discusses the patient’s decisional role preference. After this, a decision is made or deferred, and follow-up is planned. When applied to clinical settings, this model effectively facilitates patient-physician communication without adding to the appointment length (Stacey et al., 2017).

Collaborative Deliberation Model

Most theoretical decision frameworks focus only on the patient as an “individual”; the contribution of others outside the healthcare system is rarely considered. Elwyn and colleagues (2014) assert that

Table 12.1 Models of Shared Decision Making

Charles et al. (1997)	Physician and patient <ul style="list-style-type: none"> • are both involved in treatment decision-making process • share information with each other • express treatment preferences • make a decision and agree upon a treatment
Charles et al. (1999)	Information exchange: (a) physician informs the patient of situational relevant information; (b) patient provides values, preferences, lifestyle, beliefs, and knowledge about illness and treatment Deliberation: (a) physician gives treatment recommendations; (b) patient provides physician with preferences Agreement: physician and patient reach an agreed course of action
Makoul and Clayman (2006)	<ul style="list-style-type: none"> • Define and explain the problem • Physician explains options, benefits, risks, and side effects • Physician elicits patient's values and preferences, concerns, and outcome expectations • Discussion of patient's ability, or self-efficacy • Arrange subsequent interactions to track the outcome of the decision and reach a resolution
Elwyn et al. (2012)	Choice Talk: conveys awareness that a choice exists Option Talk: patients are informed about treatment options in detail Decision Talk: patients are supported to explore what matters most to them
Stigglebout et al. (2015)	<ul style="list-style-type: none"> • Professional informs patient that a decision is to be made and patient's opinion is important • Professional discusses options and pros and cons • Patient's preferences are elicited and is supported through deliberation • Professional and patient discuss patient's preferred role in decision-making process, make or defer the decision, and discuss possible follow-up
AHRQ's SHARE Approach	S eek your patient's participation H elp your patient explore and compare treatment options A ssess your patient's values and preferences R each a decision with your patient E valuate your patient's decision
Elwyn et al. (2014)	Collaborative deliberation takes place when interactions between participants: <ol style="list-style-type: none"> 1. Are characterized by curiosity, respect, and empathy 2. Recognize the existence of relevant, alternative potential courses of action 3. Compare alternative courses of action 4. Consider, construct, and elicit presences in relation to alternative courses of action 5. Integrate individual preferences in determining the subsequent courses of action

the dominant view of decision making has overlooked the reality that patients turn to others for help and support. As a result, they created a more specific conceptual model, the Collaborative Deliberation Model (CD), which contains five propositions as a foundation for clinical communication processes. The first proposition takes place under constructive engagement, which occurs when two or more people explicitly engage in dialog in which interactions are characterized by curiosity, respect, and empathy. The second proposition, recognition of alternative actions, occurs when alternative courses of action, including no change or no intervention, are available and acknowledged. The third proposition, comparative learning, posits that individuals engaged in CD should compare alternative sources of action. The fourth proposition, preference construction and elicitation, occurs when

interaction between individuals, consider, construct, and elicit preferences in relation to alternative course of action. The final proposition, preference integration, emerges when individuals integrate preferences in determining the subsequent courses of action.

Barriers to Shared Decision Making

Both patients and healthcare providers report barriers to SDM. Most patient-reported barriers are a result of situational factors rather than patients' unwillingness to participate in SDM. (However, the unwillingness of patients to participate in SDM is a common, albeit unsubstantiated view shared by many healthcare providers; Légaré & Thompson-Leduc, 2014). The most prevalent patient-reported barriers to SDM are time, relationship with the healthcare team, the type of clinical setting, power imbalances, and lack of disease or treatment knowledge (Joseph-Williams, Elwyn, & Edwards, 2014). These factors should be considered along with healthcare providers' perceived barriers to SDM: Time, lack of agreement with aspects of SDM, and lack of familiarity with SDM (Gravel, Légaré, & Graham, 2006).

Time

Time is the most reported perceived barrier for both patients and providers. Many patients, sensitive to the demanding workload of their providers, feel there is not enough time during clinical consultations for SDM (Fraenkel & McGraw, 2007; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Patients reported feeling guilty about monopolizing their providers' time and often end clinical visits short when waiting rooms are full (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Beaver et al., 2005). Similarly, providers across many different cultural and organizational contexts reported time constraint as the largest barrier for implementing SDM (Ford, Schofield, & Hope, 2003; Graham et al., 2003). However, to date there is no conclusive evidence supporting the claim that SDM takes additional time (Stacey et al., 2017). A study of medical residents found that most predictors of SDM, including physician's gender, lost statistical significance after controlling for consultation duration, showing the important of length of time in an SBM discussion (Pellerin et al., 2011).

Relationship With Healthcare Team

Some patients believe that if they do not have a personal, trusting relationship with their provider, they cannot engage in SDM. Many patients feel uncomfortable discussing sensitive information with a new provider (Doherty & Doherty, 2005). Patients are more willing to ask questions, share personal information, and discuss concerns if they have a trusting relationship with their provider (Fraenkel & McGraw, 2007; Peek et al., 2010). However, it is not this simple, as trust can also act as a barrier to SDM. Patients who trust their providers may engage in passive behaviors, letting the professional make the decisions; patients who distrust their providers may ask additional questions and encourage SDM (Belcher, Fried, Agostini, & Tinetti, 2006). As the U.S. healthcare system moves towards integrative care across multiple providers, many patients report poor communication with and between providers, which can decrease SDM (Larsson, Sahlsten, Segesten, & Plos, 2011).

Clinical Setting

Patients report that a perceived lack of privacy, noisy environments, and feeling uncomfortable during a physical examination all act as barriers to SDM (Légaré, Ratté, Gravel, & Graham, 2008). For example, for patients suffering from hearing loss, a noisy environment may prevent participating actively in a decision consultation. Additional environmental barriers reported were poorly lit rooms and uncomfortable room temperatures.

Power Imbalance

Authoritarian or dismissive healthcare providers who dominate decision-making encounters, do not listen to or respect patients' concerns, or use negative verbal or non-verbal behavior, impede SDM (Eldh, Ekman, & Ehnfors, 2006). Some patients perceived being a "good" patient as a passive one, who allows the provider to make the decisions on their behalf. Some patients worry that by asking questions they will be labeled as "difficult" and receive poor quality of care (Clover, Browne, McErlain, & Vandenberg, 2004).

Lack of Knowledge

Many patients feel that they have insufficient information about their condition and are unprepared to choose between options; therefore they cannot be involved in shared healthcare decisions (Beaver et al., 2005). Additionally, the use of medical terminology by healthcare providers can be a barrier to SDM. Patients often feel that providers are "talking another language" (Nordgren & Fridlund, 2001) leading patients to sometimes misinterpret or not fully comprehend the information being shared.

Providers have reported a lack of agreement with some aspects of SDM, an unfamiliarity with SDM, or that SDM is not applicable in certain clinical situations or with specific patient populations (Cohen & Britten, 2003). Some providers felt their lack of familiarity with SDM was a barrier to implementation of SDM, suggesting that interventions to train providers in SDM may be needed (see later section).

How Is SDM Measured?

Since the development of the Krantz Health Opinion Survey (Krantz, Baum, & Wideman, 1980), there have been over 30 instruments developed to assess SDM (Bouniols, Leclère, & Moret, 2016; Scholl et al., 2011; Simon, Loh, & Härter, 2007). SDM is most often assessed through an individual's perspective (i.e., external observer, the patient, or the physician), with most instruments being self-report scales that assess patient perspectives. Instruments can be further categorized into tools that measure role preference, assess the decision process, and focus on the decision (Scholl et al., 2011). Shay and Lafata's (2015) review of SDM and patient outcomes found that 85% of studies measured SDM through patient self-report, most often using the Control Preference Scale (Degner, Sloan, & Venkatesh, 1997). The Observing Patient Involvement in Decision Making (OPTION) instrument is the most frequently used for measuring patient involvement from an observer's viewpoint (Elwyn et al., 2003).

More recently, research has focused on a dyadic approach as a way to capture the interdependence between the patient and healthcare provider when making a healthcare decision (Scholl et al., 2011). Several previously developed scales have been revised to become dyadic approaches. This has several advantages. First, obtaining measures from both patients and health providers simultaneously produces the information necessary to move to a more equitable model of healthcare. Second, a dyadic approach avoids results reflecting the biases of providers or patients (Légaré, Leblanc, Robitaille, & Turcotte, 2012). However, most existing scales do not include a dyadic component. Brief descriptions of the most commonly used scales, along with some psychometric data, are presented next, in the chronological order in which they appeared.

The Decisional Conflict Scale

One of the earliest scales, the Decisional Conflict Scale (DCS), was developed and validated by O'Connor (1995) in response to the dearth of instruments available to evaluate decision aids and

decision-supporting interventions. The DCS was developed using items derived from the decisional conflict construct that assess uncertainty, factors contributing to uncertainty, and perceptions of effective decision making. The DCS is a 16-item self-administered questionnaire with five subscales: certainty, information, clarification of values, support or pressure from others, and the respondent's perception of the quality of the decision process. The scale has been adapted and tested among health professionals and is widely used (Légaré et al., 2012).

Control Preference Scale

In its original form, the Control Preference Scale (CPS) was developed to measure how treatment decisions and decisional control preferences are made among people with life-threatening illnesses (Degner et al., 1997). The CPS presents patients with five alternative decisional roles and asks them to select the option which most closely reflects their perceptions of their involvement, from patient-only through shared decision making to physician-only, i.e., "I made my decision alone", "I made my decision alone considering what my doctor said", "I shared the decision with my doctor", "My doctor decided considering my preferences", and "My doctor made the decision" (Kasper, Heesen, Köpke, Fulcher, & Geiger, 2011). Although the CPS is commonly used, the patient or physician's cultural expectations for what patients' involvement should be might affect responses (Henrikson, Davison, & Berry, 2011).

Observing Patient Involvement in Decision Making

This observer rated instrument, abbreviated as OPTION, measures the extent to which clinicians involve patients in the decision-making process (Elwyn et al., 2003, 2005). Although many other observer instruments now exist, OPTION is still the only instrument that focuses on behaviors initiated by the healthcare provider. Nicolai et al. (2012) published a systematic review of studies using OPTION, finding psychometric and methodical limitations of the scale, including the fact the majority of studies found it to have multiple factors and that inter-rater reliability was overestimated and varied greatly across studies (Nicolai, Moshagen, Eich, & Bieber, 2012). Because of these criticisms, Elwyn, Tsulukidze, Edwards, Légaré, and Newcombe (2013) created a short version, the OPTION-5, with improved reliability and construct validity. OPTION-5 is based on a more robust conceptual model, and offers the ability to give "credit" to providers who make efforts to engage patients in decision making over multiple encounters (Barr et al., 2015; Elwyn et al., 2013). OPTION 5 is able to differentiate between various levels of patient involvement (Stubenrouch et al., 2016).

SDM-Q and SDM-Q DOC

With the increased attention on SDM, the a consortium organized by the German Ministry of Health reached the conclusion that no theory-driven, psychometrically sound self-assessment tool existed to measure the process of SDM from the patient's perspective (Simon et al., 2006). To close this gap, two parallel instruments were developed, the Shared Decision Making Questionnaire SDM-Q, for patients and the Shared Decision Making Questionnaire for Physicians (SDM-Q-DOC). The instruments were tested in a German primary care sample of 2351 patient, yielding high internal consistency (Cronbach's $\alpha > .90$) and factorial validity (Kriston et al., 2010).

A systematic review of intervention studies found that using a shortened nine-item version of the SDM-Q (SDM-Q-9) could be used successfully to investigate the effectiveness of interventions aimed at the implementation of SDM and as a quality indicator in health services assessments (Doherr, Christalle, Kriston, Härter, & Scholl, 2017). Subsequently, the SDM-Q-9 was translated into

English (Kriston et al., 2010; Scholl, Kriston, Dirmaier, Buchholz, & Härter, 2012) and tested in the U.S. with a stratified primary care sample, which confirmed its unidimensional structure and high internal consistency.

CollaboRATE

The CollaboRATE scale was developed to be a brief (three-question) measure that could easily integrate a SDM measurement into any clinical setting (Elwyn, Barr, et al., 2013). Additionally, aggregation of large numbers of responses can be used as a performance metric or feedback tool within a hospitals or clinic and to make comparisons (Barr et al., 2014). Patients rate the extent to which three core SDM dimensions are present in a specific clinical encounter (“how much effort was made to help you understand your health issue”, “how much effort was made to listen to the things that matter most to you about your health issue”, and “how much effort was made to include what matters most to you in choosing what to do next?”). CollaboRATE has been used successfully in diverse primary care settings (Forcino et al., 2017). A recent intervention, “OpenComm”, aiming to increase patients and primary care physician’s communication, found that compared with visits in the usual care clinic, patients in the “OpenComm” condition had 1.52 times higher odds of giving their primary care providers the highest possible CollaboRATE score (Tai-Seale et al., 2016).

Are Physicians Using SDM?

It is difficult to assess the overall use of SDM by physicians. In a systematic review of 33 studies, physicians’ efforts to involve their patients in SDM was generally low (Couët et al., 2015). Interventions to increase SDM, however, did result in significant improvements in the use of SDM. Conversely, without interventions to implement SDM, most healthcare providers did not involve their patients in SDM with any consistency. Behaviors that required tailoring care to patient preferences were attempted even less consistently across studies. The two least observed behaviors were “assessing the patient’s preferred approach” and “eliciting preferred involvement”, both of which require the healthcare provider to probe the patient about their preferences. Longer consultations usually coincided with greater likelihood that SDM was used. In another study, Menear et al. (2017) found that primary care physicians performed only minimal behaviors to involve patients in decisions about their care

Efforts have been made to increase healthcare provider’s training in and acceptance of SDM. A study of general practitioners trained in SDM showed a 13% increase in SDM behaviors as measured by the OPTION scale; however, overall observed levels of SDM remained low. Another intervention study trained general practitioners in SDM and to positively reinforce a patient’s treatment decision; compared with untrained practitioners, trained practitioners engaged in SDM and positively reinforced decisions significantly more (Sanders et al., 2017). Additionally, the duration of the consultation was strongly correlated with SDM performance, confirming the findings in Couët et al.’s (2015) review. However, during consultations, practitioners rarely questioned patients about the preferred information format or their concerns or understanding of information. The authors conclude that SDM training sessions for practitioners might be more effective at changing behavior (i.e., using communication tools) rather than increasing attempts to elicit patient’s treatment preferences and understanding of information. And, despite Medicare’s reimbursement for documented use of SDM, barely half of U.S. primary care physicians indicate that SDM is important and feel more comfortable endorsing a discussion of benefits than a discussion of risks (Elston Lafata, Brown, Pignone, Ratliff, & Shay, 2017).

Patient Involvement in Shared Decision Making

SDM is associated with many positive outcomes for both patients and healthcare providers. SDM enhances patient-physician relationships through improved communication, increases discussions about treatment options and improves patient's readiness to actively participate in one's care. SDM affects mutual trust, agreement between treatment team and patient, by giving responsibility to patients, and empowers patients to take ownership of their care (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014).

A meta-analysis compiled of 3,491 patients from six U.S. cancer centers (Singh et al., 2010) found that roughly half of the patients preferred a collaborative decision approach with their clinician (based on the Control Preference Scale), whereas the remaining half were split almost equally between preferring entirely active vs. passive roles. Overall, older patients (> 60 years old) tended to assume a more passive decision-making role than younger patients. Men were more assertive than women in treatment decision making about tumors unrelated to the reproductive system, whereas women, in contrast, were more assertive than men about reproductive system tumors. Most patients experienced a role in treatment decision making that was consistent with their preferences. However, 39% of patients experienced discordance and 6% experienced extreme discordance between their preferred and actual roles in treatment decision making.

Interventions Promoting Shared Decision Making

Relatively few evaluations have been conducted between SDM and patient outcomes when both the decision-making process and patient outcome have been measured. Although there are strong ethical reasons to advocate for SDM, there is continued uncertainty surrounding SDM as a mechanism to improve patient outcomes (Shay & Lafata, 2015). Studies that show increases in SDM as a result of SDM promoting interventions indicate improvements in decisional satisfaction, treatment adherence, and indices of well-being, including depressive symptoms (Durand et al., 2014; Flynn et al., 2012). It is important to note that studies of successful interventions involved patients making longer-term decisions and/or having chronic diseases, whereas most of the studies that did not show significant outcomes involved a single decision (Joosten et al., 2008).

Although discussing specific interventions to employ and encourage SDM is beyond the scope of this chapter, we briefly review the conclusions of Légaré and colleagues' (2018) systematic review on the effectiveness of interventions to improve the adoption of SDM. First, interventions targeting health professionals may have better overall outcomes than interventions targeting patients. Second, interventions targeting patient/healthcare professional dyads were more likely to be effective than those targeting only the patient or healthcare provider. Third, there are few studies assessing SDM in healthcare team-based approaches to care, which are increasing as the standard of care. Fourth, although the study of SDM in healthcare has grown, most studies do not involve low income countries. The last and most significant finding of the review involves the variable effectiveness of interventions to improve the adoption of SDM, partially a result because of the heterogeneity of interventions and outcomes, and the generally low quality of the research evidence. Légaré and colleagues' review clearly demonstrates major gaps in knowledge regarding the effectiveness of interventions focused on improving the adoption of SDM and suggests the need to consistently measure of SDM across interventions

Underserved Populations: LGBT and LGBT Racial/Ethnic Patient Populations

Despite strong recommendations for SDM in clinical settings, minority populations, such as LGBT patients, often receive poor quality of care and have negative healthcare experiences (Sánchez,

Sánchez, Lunn, Yehia, & Callahan, 2014). LGBT patients frequently delay or avoid seeking care, or feel uncomfortable disclosing sexual orientation or gender identity to their physician, because of anticipated stigma, preventing them from having open and honest communication about their health and decreasing their chances for preventive care and accurate diagnoses (Chin, Lopez, Nathan, & Cook, 2016). In a study by Foglia and Fredriksen-Goldsen (2014), 15% of participants who identified as belonging to the LGBT community reported that they were fearful about accessing healthcare services outside of the LGBT community; furthermore, 13% reported that they were denied healthcare services or provided with inferior care as a result of their sexual orientation. Prior experiences with discrimination may influence how willing patients may be to fully disclose sexual orientation for fear of additional discrimination. Compounding these issues, LGBT patients who are also racial and ethnic minorities have an even higher risk of poor health outcomes, and many face more complicated challenges than white LGBT patients (Baig et al., 2016).

Although there is a plethora of evidence of health disparities among people identified as LGBT, there is sparse translational research into the improvement of these health disparities (Baig et al., 2016; Bonvicini, 2017; Fredriksen-Goldsen, Kim, McKenzie, Krinsky, & Emler, 2017). For example, a recent systematic review to identify key construct for understanding SDM among African American LGBT persons identified only six studies, all focused on HIV infection (Peek et al., 2016). None involved African American women who identified as sexual minorities or African American transgender men, nor did any report that clinical tools, such as decision aids were used to assist in SDM. However, the March 2017 issue of the *Journal of General Internal Medicine* published several articles on improving shared decision making among underserved ethnic and sexual minority patient populations (Chin et al., 2016).

How can we increase SDM among underserved populations and their practitioners? Most efforts to improve SDM focus on patient-provider communication, rather than improving the context in which healthcare is received. DeMeester, Lopez, Moore, Cook, and Chin (2016) proposed a conceptual model for how organizations can reshape their operations to support SDM among minorities, including changes that establish a safe environment, increase trust, and decrease stigma. These changes involve workflow, health information technology, organizational structure and culture, resources and clinic environment, training and education, and incentives and disincentives. These factors are hypothesized to operate through four mechanisms: continuity and coordination, ease of SDM, knowledge and skills, and attitudes and beliefs, all of which improve clinician and patient activation of SDM. Activation occurs when both parties have the knowledge, skills, confidence, and motivation that ultimately leads to shared decision making (DeMeester et al., 2016).

Another model, labeled “the environment”, addresses important overlooked factors in previous SDM frameworks (Peek et al., 2016). “The environment” includes both physical and social contexts that shape people’s experiences and expectations. Specifically, the model assumes that social identity, structural inequities, and past experiences and beliefs about physician and healthcare delivery all inform SDM. In addition, this model incorporates interactions within patients’ healthcare environment and communications with their physician, allowing for the examination of more intersectional factors.

Fundamental Problems With the Shared Decision-Making Paradigm

Although the idea that patient and providers should collaborate on decisions about a patient’s care seems intuitively appealing, there are a number of fundamental difficulties that can easily derail the process. Developments in clinical practice, such as integrative practice settings that include multiple providers of different specialties, provide new challenges for the shared decision paradigm.

In addition to the identified barriers to shared decision making, such as lack of time, low health literacy, and lack of provider education or skill in shared decision making, a power differential exists

between patient and provider that could undermine SDM. Yet three basic assumptions that are essential to SDM are often not considered. First is the assumption that patients need to have all available information to make an informed decision; second, is that patients are rational decision makers; and third, that patients make decisions without emotions.

Assumption 1: Patients Need to Have All Available Information to Make an Informed Decision

It seems logical that one can only make a decision about a situation when one is well informed. However, this assumption elevates one type of information, specifically medical risks and benefits, over any other type of information. As Leventhal and colleagues have argued in their common sense, self-regulation framework, patients often value their own experiential knowledge more than expert knowledge when making health behavior choices (Leventhal, Brissette & Leventhal, 2003). Examples range from patients who decide not to take their medication because their body doesn't need it to the reflexive response of cancer patients who say that they would never have surgery. In these cases more information may not change a person's mind; rather, different experiential and culturally appropriate information needs to be considered for SDM.

How much information do individuals need to make a decision? Proponents of the shared decision paradigm argue that patients should be "fully" informed. It is unclear what this really means, but what we can safely say is that there will be great variation in the amount of information that patients can process. Take the decision for prostate cancer treatment as an example. When diagnosed early, men have the choice between active surveillance, (i.e., actively and regularly monitoring the slow progress of disease), surgery, and radiation treatment (external beam radiation or radiation through implanted radioactive seeds). Each treatment option has multiple pros and cons that influence future quality of life. Patients become overwhelmed by the sheer number of factors to consider in making a decision, (mis)understanding the statistical presentation of risk and the uncertainty of outcomes. Often, patients end up asking the physician "What would you do in my place?" Whatever the circumstances, patients' bring both their knowledge and information processing capabilities (often termed health literacy) to the situation. When these factors are not queried in a decision-making encounter and only the standard discussion of medical pros and cons is presented, the medical information becomes much less influential in the final decision.

Assumption 2: Patients Are Rational Decision Makers

Tversky's and Kahneman (1974) seminal paper on heuristics and biases identified the pitfalls of rational decision making. Similar processes operate with medical information processing. Decisions are shaped by previous experiences, social norms, contextual factors, and cognitive biases. Biases and heuristics that have been identified are the anchoring effect, loss aversion bias, social norms bias, and action-oriented bias (Beckmann & Kuhl, 1984; Furnham, 1986; Kahneman & Tversky, 1986; Strack & Mussweiler, 1997). None of these biases or heuristics is considered in the usual presentation of information, yet they influence decisions (Chapman & Coups, 2006; Peters, Lipkus, & Diefenbach, 2006).

Cultural norms and experiences influence decisions, as well as lived or witnessed experiences. Lived experience is particularly powerful, especially when the consequences are considered painful or harmful. A man with prostate cancer might not consider surgery because a close family member who had surgery experienced persistent urinary and sexual dysfunction. This real-life experience is so powerful that it overrides "rational" arguments. In the age of social media and the Internet, lived experiences might not even be necessary any more to shape opinions; witnessed or vicarious experiences could be just as powerful in shaping opinions.

Assumption 3: Patients Make Decisions Without Emotions

Medical decisions are distressing and anxiety provoking, especially for serious or life-threatening diseases. The literature is filled with reports from patients who report that a cancer diagnosis, for example, is “like a blow to the head” and that patients are filled with an existential dread, unlike anything they have experienced before (Meyerowitz, Williams, & Gessner, 1987). Although most clinicians postpone a serious discussion of treatment options to a later date, under the assumption that patients would be less distressed, the knowledge that the disease is present is a constant source of distress. It is therefore unavoidable that important decisions are made in an emotion-laden environment.

A case in point is mammography screening among a group of women at high risk for breast cancer. In one study (Diefenbach, Miller, & Daly, 1999), women with a first degree relative diagnosed with breast cancer received genetic counseling and the recommendation to obtain a mammogram within a year. At study entry, participants were asked how worried they were about breast cancer and how likely it would be that they would be diagnosed with breast cancer in their lifetime. Mammography uptake a year later was predicted by age, education, risk perception, and worry; without worry in the model, higher risk perceptions of breast cancer were predictive of greater uptake. However with worry in the model, risk perception became non-significant, indicating that worry about cancer was the stronger predictor. Hence, the mammography decision was driven by the “hot” emotional fear of cancer and not the “cold” cognitive risk perception. Clearly, emotions influence decisions, but they are not part of any SDM model.

Conclusions

The move from a paternalistic to a shared decision making model is clearly a positive development. However, the exclusive focus on increasing patient knowledge as the single most important factor in decision making appears misguided. Many heuristics and biases impact information processing, as do cultural and experiential factors as well as the emotional context of the disease and its treatment. All exert powerful influences in the decision-making process. We challenge researchers working in the science of medical decision making to develop and evaluate new comprehensive theoretical models to guide the next iteration of interventions.

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