

Rachel A. Greenup and Jeffrey Peppercorn

- Shared decision-making, a fundamental component of “patient-centered care,” should include a two-way exchange of information between the doctor and patient in which both parties have the opportunity to express treatment p and arrive at treatment decisions that are both medically sound and consistent with the goals and preferences of a well-informed patient.
- Shared decision-making is meant to respect patient autonomy, consider patient comfort and satisfaction with medical care, and honestly convey information about the costs and trade-offs of treatment decisions for patients and their families.
- Patients retaining autonomy over their healthcare decisions has been shown to have several benefits including improved patient satisfaction with medical decisions, improved patient satisfaction with consequences related to those decisions, greater adherence to medical therapy, and improved long-term clinical outcomes

- Issues such as the patient’s desire to delegate decision-making back to the provider, the provider’s unwillingness to share treatment decisions, the complex nature of a medical condition, an overwhelming volume of potentially relevant medical information, demographic characteristics of the patient, and time constraints associated with a busy clinical practice may complicate the process of shared decision-making.
- In situations where there is a clear “best” clinical practice for a given scenario, patients may benefit from learning information about their diagnosis, making a choice as to whether or not to participate in the decision to undergo therapy, but ultimately delegate the specific treatment decision and planning to their physician. However, in more complex medical situations, where two treatment options have relatively equal clinical value, shared decision-making may be most useful.

R.A. Greenup (✉) · J. Peppercorn
Duke University Medical Center, Durham, NC, USA
e-mail: rachel.greenup@duke.edu

J. Peppercorn
e-mail: jpeppercorn@mgh.harvard.edu

Background

Shared decision-making is defined as the process in which patients act in partnership with their healthcare providers to make treatment decisions

(Emanuel and Emanuel 1992). In its optimal form, it involves a collaborative relationship between patient and provider, through which available evidence-based healthcare recommendations offered by providers are considered and pursued in the context of patient preferences and values (Edwards and Elwyn 2009).

The concept of shared decision-making is a fundamental component of “patient-centered care,” which focuses on the goals and values of individual patients, as opposed to care based mainly on consideration of the pathophysiology of disease and clinical data, with a view to optimizing standard clinical outcomes such as survival, response to therapy, and tolerability. Implicit in this model is the recognition that individual patients will have different preferences for the outcomes of medical care, differing expectations and tolerance for the components of care, and different risk/benefit thresholds that will impact decision-making. This concept gained traction in 2001, when the U.S. Institute of Medicine officially endorsed and promoted a culture of “patient-centered care” and included it as a quality metric in its landmark report “Crossing the Quality Chasm.” Since that time, the importance of incorporating the patient’s perspective into medical decision-making, and supporting the process of shared decision-making, has been recognized as a component of quality health care (Woolf et al. 2005; Epstein et al. 2004). In an era of decreasing medical paternalism, increasing patient autonomy, and ready access to medical information, shared decision-making has become both more important and more complex. This chapter outlines the promise of shared decision-making and the challenges in implementing this process in clinical practice, including issues facing patients, providers, and the medical system as a whole.

The Promise of Shared Decision-Making

The ultimate promise of shared decision-making is that doctors and patients together will discuss and arrive at treatment decisions that are both medically sound and consistent with the goals

and preferences of a well-informed patient. The “right” decision should include treatment plans that are acceptable to the patient, a risk/benefit ratio that matches the patient’s risk tolerance and considers their satisfaction with their current state of health and the potential consequences of receiving or forgoing a given test, intervention, or plan of care. The underlying assumption is that shared decision-making includes a two-way exchange of information between the doctor and patient in which both players have the opportunity to express treatment preferences and to be involved in the decision-making process (Charles et al. 1999; Sheridan et al. 2004). Physicians are expected to communicate comprehensive medical information regarding diagnosis and treatment options. In turn, patients are expected to communicate their informed preferences, values, and goals. This exchange presumably reviews standard medical approaches and alternatives, risks and benefits, and costs of pursuing or failing to pursue a given care plan. Ideally, the patient and provider will then concur on the plan of action (Barratt 2008; Barry and Edgman-Levitan 2012).

The conversation may start with a review of multiple evidence-based options and concludes with identification of the choice that best matches the patient’s goals and preferences. From the provider perspective, shared decision-making is meant to respect patient autonomy, consider patient comfort, and satisfaction with medical care, and honestly convey information about the costs and trade-offs of treatment decisions for patients and their families. Additionally, patients and physicians should jointly consider the severity of disease, the morbidity associated with treatments, and the barriers to patient adherence to medical recommendations (Charles et al. 1997). According to this model, then, the appropriate medical decision will be the one that is right for the individual patient and his or her circumstances, rather than one that is based on consideration of clinical factors alone. For example, in the treatment of many cancers the benefit of postoperative (adjuvant) radiation therapy may be considered differently by different patients. A 5-10 % reduction in the risk of

breast cancer recurrence may be deemed worthwhile by a patient who lives in close geographic proximity to a radiation treatment facility where daily, short treatment sessions add minimal interference to daily life. In contrast, for a patient who is required to temporarily relocate to a new city or to drive an hour each day for 6 weeks of radiation therapy, this real but small reduction in recurrence risk may be deemed insufficient to justify the substantial investment of time and finances required for daily radiation treatments. Similarly, in the same clinical scenario, some patients may be unwilling to undergo the discomfort of radiation (which while transient, can be severe) or to accept the rare risks of complications such as lung injury in exchange for modest absolute risk reduction, particularly, if it is in the setting of a relatively low baseline risk of cancer recurrence. The physician may feel that the benefits outweigh the risks and recommend radiation as the starting point for conversation, but based on discussion of the patient's preferences the doctor and patient may reach an informed decision to forgo this intervention.

Although this model is compelling, it raises a number of issues. First and foremost, there is the issue of how much information should be discussed, what level of detail is appropriate, what form the information should take, and whether the goal is simply to present information and/or to ensure that patients understand the information provided. Charles et al. define the process for shared decision making as follows: "At a minimum, the physician must inform the patient of all information that is *relevant* to making the decision," while the patient "needs to provide information to the physician on issues raised... values, preferences, lifestyles, beliefs" (Charles et al. 1999). This definition helps to focus the interchange on what constitutes relevant information, and provides some boundaries on what can and should be discussed. Ideally, all relevant treatment options are communicated to the patient, and treatment decisions are then considered in the context of that individual. However, as we

explore in greater detail below, physicians and patients may have different standards and goals for what level of evidence should be considered regarding options for treatment.

Benefits of Shared Decision-Making

Most patients express a desire to obtain more information about their diagnoses and treatment options, and wish to participate in medical decisions affecting them or their family members (Tariman et al. 2010). A growing body of the literature suggests that patients informed of their treatment options have greater knowledge of their medical condition, gain improved understanding of potential treatment risks and benefits, and express increased satisfaction with care (Woolf et al. 2005).

Shared decision making has been shown to have several benefits including improved patient satisfaction with medical decisions, improved patient satisfaction with consequences related to those decisions, and improved long-term clinical outcomes. Woolf et al. demonstrated that patients informed of their treatment choices demonstrated greater adherence to medical therapy. Improved adherence can in turn lead to improved disease outcomes.

The process of shared decision-making is particularly relevant to what are termed "preference-based" decisions, where medical treatment options lead to equivalent clinical outcomes, and patients truly have a choice that does not compromise survival or disease control. For example, among patients with early stage breast cancer, treatment decisions depend largely on the patient's decision-making metrics related to personal preferences, values, and goals when choosing between breast-conserving surgeries followed by radiation therapy versus mastectomy alone. While scientific data suggests the two options are equivalent in terms of overall survival (Hwang et al. 2013; Fisher et al. 2002), numerous medical details and personal implications

influence choice of therapy for any individual patient. The majority of patients with early stage breast cancer will survive the disease and live for decades with the consequences of initial treatment decisions. Keating and colleagues found that among 1000 women with breast cancer, roughly half reported that their actual level of participation in surgical decision-making matched their preferred involvement in the decision-making process. Among these individuals, patients who were able to participate in decision-making at a level that matched their preference demonstrated greater satisfaction with the type of breast surgery they received (Keating et al. 2002). Additional research in this area suggests that providing patients with more treatment choices and promoting patient involvement in treatment decisions reduces the risk of regret they might experience later about healthcare choices (Caldon et al. 2008).

In addition to improving satisfaction, the process of shared decision making may also serve to remind patients that although providers navigate patients and their families through complex medical decisions, patients ultimately retain autonomy over their healthcare decisions (Charles et al. 1997). Increasing knowledge and sense of control can translate into improved health behaviors and outcomes. Further benefits may include improvement in patient's ability to cope with illness. In a study of 256 cancer patients, Cassileth et al. reported that patients who were actively involved in decision-making remained more hopeful during treatment, and less likely to experience unrealistic fears about their health outcomes (Cassileth et al. 1980). Schroy et al. (2012) found that a shared decision making model increased colorectal cancer screening, albeit modestly, at an urban academic medical center. In their randomized trial involving 825 patients, a decision-aid based intervention in which patients were informed of their individual risks and asked their preferences for screening was deployed, resulted in a 10 % higher rate of completing colorectal cancer screening compared to a control arm in which patients received general information about colon

cancer and routine referral for screening from their doctor alone.

The promise of shared decision-making requires that patients and their providers engage in an equal exchange that meets the needs of both invested parties. Though shared decision-making is desired by patients and doctors alike, implementing this process can be difficult in a real-time clinical setting. Issues related to the patient, the provider, or the clinical situation may complicate the process of shared decision-making. These include the patient's desire to delegate decision-making back to the provider, the provider's unwillingness to share treatment decisions, the complex nature of a medical condition, an overwhelming volume of potentially relevant medical information, and time constraints associated with a busy clinical practice. In addition, there may not always be consensus among clinicians, let alone between a patient and their physician, on what constitutes relevant evidence or reasonable treatment options to consider. (Peppercorn et al. 2008)

Challenges of Shared Decision-Making

The potential promise of shared decision making is clear; promoting improved medical decisions that match patient values and preferences, leading to greater patient satisfaction, improving treatment compliance, and clinical outcomes. The challenges to this process are considerable. As noted above, patients vary in their preferences for information, desired involvement in decision-making, and in their ability to clearly elicit these preferences. In addition, many clinical encounters occur in a narrow time frame with multiple components competing for patient and physician attention. In this context, shared decision-making can easily become a neglected priority. Furthermore, in some settings, important decisions need to be made quickly and both conveying information and allowing time for an informed decision can be challenging. Cost can also be a factor both in terms of reimbursement

for the shared decision-making process, and in terms of the financial impact of resulting medical decisions. Implicit and explicit costs resulting from the shared decision-making process may not be recognized by doctors and patients at the time of decision making.

While shared decision-making ideally leads to care that matches patient's informed preferences, doctors and patients may disagree about what constitutes an acceptable option for a given clinical scenario. Ethical conflicts may emerge between the physicians obligation to respect patient autonomy and their obligation to the principle of beneficence which requires the physicians to try to improve the patients health (Peppercorn 2012). We explore some of these challenges and available data on the complexity of shared decision-making below.

Challenges that Affect Patient Preferences

Though current medical culture encourages physicians and patients to engage in shared decision-making, it is not clear that a given patient actually wants to participate in their care and if so, to what degree. Patient-related factors correlates with desired involvement in shared decision-making. Arora and McHorney surveyed 2197 patients with chronic medical illnesses, including cardiovascular disease, diabetes, and depression, and found that 69 % preferred to leave medical decision-making to their physicians (Arora and McHorney 2000). Desired level of participation varied with patient characteristics. Female gender, younger age, and increased level of education were associated with an increased desire to actively participate in clinical decisions. Among advanced cancer patients, high levels of information were more likely preferred by younger, more educated, and more hopeful patients (Cassileth et al. 1980). Younger age also predicted an increased level of desired participation in decision-making among healthy volunteers surveyed to determine predictors of shared decision-making (Swenson et al. 2004). While demographic characteristics, such as

income, social support, marital status, and health distress seem to correlate reliably with interest in shared decision making, it is important to identify the individual patient's preferences for information and involvement in decisions (Barry and Edgman-Levitan 2012). As Miller has documented, patients with cancer do best from a psychological and behavioral perspective when there is a match between their personal coping style, which may call for more or less information and more or less involvement, and way shared decision making is approached by the clinician (Miller 1995).

Degner et al. surveyed breast cancer patients to determine whether patients' desired level of participation in shared decision-making matched their perceived level of participation (Degner et al. 1997). Results reflected that patients vary in terms of their preferences: 22 % of women expressed a preference for an active role in shared decision-making, while 44 % preferred a collaborative role (sharing the responsibility of decision-making with their physicians), and 34 % expressed interest in entirely delegating decision-making to their providers. Further, only 42 % of patients believed they had achieved their desired level of participation in treatment decisions (Degner et al. 1997). This study highlights the common discrepancy between attained and desired level of participation in medical decisions.

Since patients vary in terms of the level, type, and role they desire to play in medical decision-making, it is important that providers be able to assess and address these subtypes of patient preferences. At one extreme, the data suggest that few patients desire complete autonomy. For these individuals, efforts at shared decision-making can devolve to presenting patients with a menu of options without providing sufficient clinical guidance.

In a study involving outpatients with varied diagnoses (breast cancer, prostate disease, orthopedic injuries, multiple sclerosis to name a few), patients were surveyed regarding their preferred participation in treatment decisions. The investigators used the problem-solving decision-making scale based on patient

scenarios describing options for making treatment decisions (Deber et al. 2007). Participants were queried regarding their beliefs on who should lead different aspects of the patient–doctor encounter including diagnosis, treatment options, prediction of risks and benefits, and ultimately treatment decisions. Over 2500 outpatients with chronic and acute medical issues, only 1 % of patients expressed interest in independently making healthcare treatment decisions without input from their providers (Deber et al. 2007). 77.8 % of patients in this study preferred a shared decision-making approach, and only 20 % preferred a passive role, delegating decision-making entirely to their physicians. Greater familiarity with the diagnosis, increased education, and younger age correlated with a desire for increased participation in shared decision-making (Deber et al. 2007).

A further challenge is that physicians may not be able to accurately estimate their patients' desired level of participation in sharing medical decisions. Strull et al. revealed this discrepancy through a survey of 200 hypertensive patients and their caring providers (Strull et al. 1984). In this study, after consultation with their physician, 41 % of patients still wanted more information about their diagnosis. However, only 53 % of patients preferred to participate in shared decision-making as opposed to being given a clear medical recommendation. In contrast, clinicians estimated that 78 % of patients desired to participate in treatment decisions. The authors concluded that physicians generally underestimate a patient's desire for medical information, but overestimate their desire to participate in shared decision-making. As a result, physicians may expect patients and their families to make independent medical decisions in the face of limited presented medical information.

It is challenging to identify an individual patient's preferences for the amount and type of medical information, and the patient's desired level of participation in decision-making. Though few patients want to entirely delegate treatment decisions to their doctors, even fewer appear to want to make decisions independently. Specifically, fewer patients may wish to

participate in medical decision-making less often than expected. Although the literature suggests subsets of patients who may be more likely to prefer shared decision-making, there may be patients that fail to fit the mold: a younger well-educated patient who wants a clear treatment decision directed by the clinician and an older less well-educated patient for whom participation in decision-making is both desired and critical for treatment satisfaction and compliance.

Patient preferences for involvement in shared decision-making have consistently demonstrated generational differences (“older versus younger”) across several studies. It remains unclear whether these patterns hold true due to temporal changes in the way medical care is approached (i.e., we have moved from a period of greater emphasis on paternalism to a period of greater emphasis on autonomy), or whether they reflect something relatively constant in the way age cohorts of patients approach medical decisions. Older patients may be more likely to defer to the physicians medical authority or believe that they are not qualified to make treatment decisions. In contrast, younger patients consistently express interest in taking ownership of their health care, and participating in shared decision-making (Cassileth et al. 1980). It is unclear whether these patterns will persist over time, with today's young patients developing less of a preference for shared decision making as they get older, or if this reflects cultural changes such that soon all patients, of any age, will be interested in (or feel compelled to exert) shared decision making. Given changes of the role of medicine in society over time, it seems likely that older patients will be increasingly be interested in shared decision-making. Clinicians and research must be aware of large variation in this area and account for individual preferences in clinical practice and future studies.

Challenges Based on Disease Chronicity and Setting

Although the theoretical benefits and importance of shared decision-making are equally relevant to

the acute and chronic disease settings, there are principled distinctions that mediate the effects of patient-provider interactions. In chronic diseases such as hypertension, diabetes, and cardiovascular disease, patient input into managing their long-term medical conditions is critical. On a day-to-day basis, the patient either may or may not choose to take their medication or adhere to their diet and other aspects of self-care. Patient participation in the treatment decision-making process can encourage compliance, communication about treatment failures and successes, and support an open long-term relationship between patients and providers. In this setting, shared decision-making often consists of many nonurgent but ultimately important decisions made between patients and their physicians over time.

One potential challenge in chronic care management of patients is the increasingly fragmented nature of the healthcare system, where patients may switch providers frequently due to insurance and other issues. In addition, multiple providers caring for patients complicate both coordination of care and communication as patients move from clinic to clinic and between the inpatient and outpatient setting. Decisions to pursue therapy for chronic conditions may be made or medications may be adjusted with little communication among providers. While theoretically, there is potential for a long-term relationship between a patient and a physician and time to make nonurgent decisions within a shared decision-making framework for chronic conditions, actual management of chronic conditions occurs over many encounters and fidelity to this process may be variable based on the setting and the clinicians involved.

In contrast, in the acute context, certain illnesses require that treatment decisions be made urgently between patients and physicians, often without a prior relationship. Decisions in the setting of the emergency department, intensive care unit, or in any setting where acute symptoms and rapidly evolving disease conditions are managed can have both acute life and death consequences and dramatic long-term impact on the patients' health and morbidity. (Sheridan et al. 2004). Need for rapid establishment of

trust, high volumes of information delivered to overwhelmed patients, and pressured decision-making can complicate the process of shared decision making in the acute setting. Patients' preference for knowledge of their disease and preferences for decision-making will not necessarily translate into an ability to make an informed decision under these conditions. Coping with the shock of a recent diagnosis may also render patients less able or even unable to participate in treatment decisions. Challenges in these settings do not diminish the importance of considering shared decision-making, but these limitations and challenges must be acknowledged and more research is needed to develop better methods for decision making in urgent and high-risk settings.

Cost Implications of Shared Decision-Making

It is difficult to adequately discuss models for decision-making without considering the resources required to support these models or the impact of medical decisions on both the patient's expenses and societal costs of care. Health care spending is increasingly becoming unsustainable, leading to pressure to explicitly consider the costs of care involved in medical decision-making. The US currently spends roughly 18 % of the gross domestic product on health care, and without changes to the system it is projected that health care spending will soon account for 1/5 of every dollar spent in the US economy. Given these circumstances, physicians are required to consider the costs of care in decision-making and to review costs with patients. The American Society of Clinical Oncology has suggested that discussions of costs of cancer care should be considered a component of high quality care delivery (Meropol et al. 2009).

Physicians view costs as an important part of medical decisions, but are frequently unsure of the costs of care or how to address this with patients in the clinic (Neumann et al. 2010). For their part, patients express a high degree of interest in being informed of costs of care, but differ in their belief that costs should influence

decision-making and as to whether discussions of cost should include only direct costs to the patient, or also societal/payer costs of care (Irwin et al. 2013).

Shared decision-making has potential to add costs to the increasingly burdened healthcare system, and is most cost-effective for decisions that are highly sensitive to patient values (Ubel and Arnold 1995). Timely exchanges of information, expressed need for additional work-up and return visits to fully communicate risks and benefits of treatment can add to the cost of this process. On the other hand, decisions that better match patient preferences can lead to better adherence and improved outcomes (such as preventing disease recurrence in the setting of cancer, or stroke in the setting of hypertension) as noted above, which can translate into downstream cost savings for both the patient and society. In addition, literature on end-of-life care suggests that many patients will forgo expensive futile care when physicians provide them with adequate information about their prognosis and discuss their preferences for care (Peppercorn et al. 2011).

Challenges of Shared Decision-Making for Patients

Ideally anyone making a complex decision would be poised to gather and process information they need and would be able to consider their options without time pressure or coercion from any source. The actual experience of patients faced with medical decisions falls far short of this ideal. Physical strain of illness may be anticipated to impact patient's desire or ability to be involved in their treatment decisions.

In addition, active participation in medical decision-making may impose a greater burden and responsibility on patients than the process of delegating decision-making to the provider. Specifically, when unexpected negative outcomes occur, it may be that having engaged in shared decision making increases the burden experienced by patients. Complications from treatments, treatment failures or side effects may prompt some patients to reflect on and question treatment decisions. Struggling through medical

failures takes a significant emotional and physical toll on both patients and providers. Patients who are directly suffering the adverse consequences of treatment (i.e. side effects of chemotherapy, surgical complications like poor wound healing, prolonged hospital stays, time off of work, etc.) may not always find that participating in the treatment decision makes these burdens easier to bear.

While above we have highlighted the potentially beneficial effects of shared decision-making in terms of greater patient satisfaction and adherence with a plan of care, there is also potential for exaggerated negative consequences if undesired outcomes occur. Little attention has been given to this issue in the literature. Consequences resulting from shared decisions, including morbidity and mortality, may not be shared with equal responsibility between doctor and patient. In addition, adverse outcomes resulting from shared decision-making often lead to psychological, as well as physical consequences from treatment decisions. Though the medical decision was "shared" the patient carries the majority of the physical burden related to treatment decisions, and providers can carry significant psychological burden related to treatment consequences. There has been little exploration in the literature of the consequences of poor outcomes and whether they differ based on decision-making process. Physicians should evaluate for additional burdens experienced as a result of treatment decision-making and address both the physical and psychological consequences of adverse events, regardless of whether the patient participated in decision making or not.

Challenges of Shared Decision-Making for Providers

While modern medicine is characterized by greater respect for patient autonomy and less paternalism than was the norm 50 years earlier, many practitioners work under the assumption that medical training teaches us to "know what is best" for patients and their families. Even though providers may be less likely to dictate a care plan and expect that patients will accept their recommendations unquestionably, physicians still hold

tremendous influence over medical decisions based both on the power of their recommendations and their ability to bias the presentation of information, intentionally or not. Patients can be biased toward medical treatments that the physician has predetermined to be in their best interest. There is not consensus among physicians regarding how and when shared decision making should occur, and differences in practice and skills in this areas have been inadequately evaluated to date. Additionally, physician bias against shared decision-making may negatively impact engaging patients in this process. Even when providers are motivated to involve patients in treatment decisions, barriers to realizing this balance exist.

Identification of patient preferences for shared decision making and the skills of using preferences to guide treatment decision-making is a distinct skill set from the core competencies that are typically the focus of medical training and practice. Not all providers are equally skilled in the art of medicine, such that they can balance medical recommendations with facilitation of shared decisionmaking. Physicians may lack training to facilitate shared decision-making or be unable to provide information that is accessible and comprehensible to a given patient (Sheridan et al. 2004). Consistent with this attitude, physicians may expect patients to understand complex and sophisticated medical evidence and to have the skills to make individual treatment decisions based on the population-based data that are presented to them (McNutt 2004). When clear and well-organized evidence is unavailable, the process of shared decision-making becomes complex, confusing and may be ultimately detrimental to patients.

In situations where there is a clear “best” clinical practice for a given scenario, patients may benefit from learning information about their diagnosis, making a choice as to whether or not to participate in the decision to undergo therapy, but ultimately delegate the specific treatment decision and planning to their physician. However, in more complex medical situations, where two treatment options have

relatively equal clinical value, or clinical “equipoise,” shared decision-making may be most useful (De Haes 2006). Determining how to apply shared decision making under different medical conditions, in addition to accounting for different preferences among patients is a distinct medical skill. There is a clear need clinical training to focus on development of this skill and a need for research to define optimal patients communication techniques.

Deliberation is an integral part of shared decision-making. As described by Charles et al., deliberation is a two-way exchange of information between patient and physician that requires an often time-consuming exchange of information to build trust and reach conclusions (Sheridan et al. 2004). In attempts to minimize unrealistic time investments by busy practitioners, and to eliminate decision-making in a pressured setting, shared decision-making tools have been developed and advocated. Shared decision-making tools offer treatment choices to patients, presenting equal treatment efficacy with different side effect, quality of life, and risk profiles. These tools describe the patient experience from the patient perspective, including convenience, recovery time, and treatment side effects.

Despite the potential advantages of these adjunct clinical tools, Holmes-Rovner et al. demonstrated low patient referral to shared decision-making programs by physicians due to perceived time and productivity pressures (Holmes-Rovner et al. 2000). Physicians in this study were reluctant to introduce a process that could slow the time to decision and treatment intervention. In a literature review by Gravel et al., including 31 publications on physician perception of shared decision-making, the most commonly cited physician-perceived barriers to sharing treatment decisions included time constraints, lack of applicability based on patient characteristics, and lack of applicability to the clinical situation (Gravel et al. 2006). Physicians in this study cited additional barriers to shared decision-making including the perception that some patients did not want to participate in

treatment decisions, and not agreeing with asking patients about their preferred role in decision-making.

Physicians wishing to engage patients in shared decision-making require fundamental interpersonal skills, knowledge, and communication skills. Elwyn et al. reviewed the complex set of competencies required by providers in preparation for shared decision-making. These include: developing a partnerships with patients, establishing and reviewing patient preferences for information, reviewing patient preferences for their role in decision-making, responding to patient expectations, identifying choices, presenting evidence-based treatment options, helping the patient reflect upon the anticipated impact of treatment decisions, negotiating a decision in partnership, and agreeing upon an action plan (Elwyn et al. 2000). Though acquiring these skills and utilizing them with patients is medically appropriate, it is labor-intensive in the context of most clinical practices.

The authors surveyed general practitioners through focus group interviews to review opinions about shared decision-making, and to determine challenges to implementation as key informants. Despite positive attitudes about shared decision-making, and an overall desire to include patients in treatment decisions, physicians relayed that interpersonal skills and knowledge about all treatment choices remained practical barriers to implementing shared decision-making (Elwyn et al. 2000). Risk communication, managing a difference of opinion between patient and doctor, conflict resolution, and difficulty in eliciting patient preferences have been previously described as critical interpersonal skills for doctors participating in shared decision-making (Say and Thomson 2003; Godolphin et al. 2001). Although physicians typically strive to engage patients in the process of shared decision-making, providers continue to perceive clinical barriers that prevent them to make this a clinical reality for every patient.

Challenges When Patients and Physicians Disagree About Shared Decision-Making

A premise of shared decision making is that physicians should not pursue what on strict clinical terms they deem the “best” treatment, and instead pursue what they deem an “adequate” care plan that best matches the patient’s preferences, after careful exchange of the pros and cons of different treatment options. An inherent risk of not relying on medical judgment alone is that patients who hold strong but nonevidence-based opinions may be more likely to experience negative medical outcomes when judged by conventional standards. It is therefore critically important to distinguish between patient preferences for outcomes and patient preferences for treatments. For example, a patient with early stage breast cancer may have a weak preference to avoid mastectomy as a treatment but a strong preference for the outcome of a good cosmetic result from surgery. In some cases, the best cosmetic outcome might be achieved by mastectomy with reconstruction, and the patient will be best served by a decision-making process that identifies the cosmetic outcome as a priority and then discusses which treatment will be most likely to achieve that outcome, instead of focusing on the preferences for type of treatment alone. Patient preferences for outcomes may be different from the physicians preferences and as a result lead to changes in treatment plan (for example, a patient with advanced cancer who prefers to focus on palliative care alone vs. a physicians desire for further disease directed therapy, or vice versa). If the patients has a strong preference to die at home and/or to forgo an intervention and its immediate side effects and chooses a path that shortens their survival but allows them to meet their quality of life goals, this decision should not be deemed a “bad outcome” by the clinician, even if the patient foregoes prolonged survival.

In contrast, if the physician and the patients both wish to prioritize the same outcome, such as cure of early stage breast cancer, but the patient has a strong belief in the power of diet alone to prevent cancer recurrence and/or believes that evidence-based options such as chemotherapy or radiation therapy are harmful, it may not be possible to arrive at true consensus for a shared treatment decision. Clinicians need to consider the potential for patients to make decisions that are viewed as medically unwise, or even dangerous {Peppercorn 2012}. In such cases, evidence may suggest that the option preferred by the patient will actually increase the likelihood of an outcome that the patient wishes to avoid. For example, a patient with bulky lymph node involvement of breast cancer may wish to forgo radiation out of fear of the potential risk of nerve damage and resulting loss of arm function, but in doing so, place herself at greater risk of loss function due to cancer recurrence. It is important for clinicians to identify the patients goals and to make an evidence-based recommendation on how they can best achieve those goals, but this will not always change the patients preferred treatment plan. In some cases, even an adequately informed patient will still wish to pursue a plan that matches their preferences (for example, avoiding radiation therapy) but that the clinician believes is inconsistent with their expressed goals (such as survival).

These circumstances highlight an important limitation of the shared decision making model. Physician support for shared decision making requires an assessment of the patients goals and preferences but does not mean that the physician must ultimately defer all medical judgment or agree to participate in a plan that they believe is harmful or nonevidence based. Good communication regarding the reasons for strong differences in opinion between patients and physicians is essential. In some, but not all cases, efforts to understand the basis for differences in opinion or care preferences may result in better outcomes for the patient.¹

Conclusion

Despite the ideal of shared decision-making in which physician and patient act in partnership through evidence-based and informed decisions, challenges to realizing this ideal remain in the clinical setting. The U.S. Preventive Services Task Force encourages clinicians to participate in shared decision-making [D]. The recommendation for physicians is to provide patients with “balanced, evidence-based information” when clear benefit exists, and to discuss other options of high-visibility of particular importance to the individual patient’s clinical situation [D]. Patients should be informed of their opportunity to participate in medical treatment decisions, and directed toward decision-making tools and resources. Physicians should be trained to assess a patient’s level of interest in participating in treatment decisions, and be provided with the resources to engage patients in this process. Considerable challenges will likely remain, but awareness of such challenges, and of the desire for shared decision-making on the part of many patients, should make it more likely for the potential benefits of shared decision-making to be achieved in clinical practice.

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