



# Shared Decision Making in Primary Care: An Overview

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The notion of Shared Decision Making (SDM) has been evolving for a number of years. It appears to be growing in favour as patients become increasingly empowered and informed about their health conditions and options and health professionals are urged to promote patients' engagement in their care. In fact, SDM is reflective of patient centered care at its best, because it necessitates awareness by the provider of the patient's preferences and values. The purpose of this review article is to provide a broad overview of SDM that examines 1) definitions and models, 2) its relationship to the new paradigm of patient-centered care, 3) barriers to its implementation, 4) training methods for providers, 5) tools for measuring SDM, and 6) research findings of SDM's influence on patient outcomes.

## Shared Decision Making: Definitions and Models

### Definitions

Shared decision making (SDM) is a "collaborative process that allows patients and their providers to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences" [1].

A partnership between patient and provider is the essence of SDM. As Hain & Sandy [2] explain, communication and collaboration are also the hallmarks of SDM [2]. In this model of health care, treatment options that are appropriate to patient needs, preferences and values are examined, and medical recommendations are supported by best practices. This approach ideally will not only shape the future state of health care, but just as importantly, will likely empower patients and their loved ones in their decision making process. Barratt [3] asserts that SDM is, in fact, founded on the ethical notion of autonomy or self-determination. As a consequence, the likelihood of patient adherence to a mutually agreed upon treatment approach is increased, which can positively affect patient outcomes.

It should be noted, however, that participation necessitates the provider's awareness of the patient as a unique individual. A strong therapeutic relationship between the patient and provider will likely support the patient in conveying thoughts as the decision making process unfolds [4]. SDM fosters patient engagement via

questions from patient to provider, risk/benefit analysis of treatment options and, finally, a guided, yet shared, treatment choice. Trust, another element of SDM, facilitates communication twofold: patients and their loved ones trust their provider's expertise and willingness to respect their preferences, and the provider trusts that their patients will be forthcoming in sharing "their concerns, strengths, and limitations in carrying out the plan of care" [2]. To this end, SDM can be said to be both a process and an outcome [4].

If patients and their providers are able to agree upon the definition of SDM, then consideration of how patient contributions will be valued is necessary. In their article that examines this, Rise et al. [5] use a qualitative method to highlight what matters most to patients versus providers and administrators in the SDM transaction [5]. Respect, for example, is necessary in that the patients need to feel as though their voices are being heard, and that their subjective contribution is equally weighed to the provider's objective valuation. The dialogue that ensues, hence, should entail a balanced exchange of knowledge and ideas between patient and provider [5]. While ideas or belief systems of health may diverge at this point, ultimately a treatment goal must be agreed upon, which can only be attained via mutual effort from both patient and provider. Additionally, the likelihood of patient satisfaction, as an extension of positive psychosocial outcomes, may be increased because of productive encounters with the provider, "from which patients feel known, validated...reassured, and comforted" [6].

### Models

Montori et al. [7] consider a model developed by Charles and colleagues in their discussion that considers one approach to increasing patient adherence to the agreed treatment plan. The authors note that chronic illnesses mandate patient's taking an active role in the SDM process, although there also exists a longer timeline and/or window of opportunity to make decisions and to revisit them when compared with decisions made in the throes of an acute exacerbation of illness [7]. The authors identify four phases to SDM that entail: 1) establishing the partnership dynamic; 2) sharing of information; 3) reflecting on options; 4) making the decision and acting upon it [7]. The partnership aspect, they elaborate, is especially important when the patient struggles with

maintaining a decision. Re-establishing the partnership, or perhaps redefining it, may be needed when a new or different decision has to be made. Furthermore, the establishment of trust and mutual respect are necessary in order to enable the patient to attain self-management, which is needed in the management of chronic diseases [7]. Interestingly, the authors also point out that the level of trust should be such that the “patient should be able to acknowledge failures and shortcomings without fear of disappointing the clinician or damaging the relationship” [7]. Moreover, the patient should also be able to verbalize the provider’s misunderstanding or underestimating the influence of the patient’s context, as it relates to his/her ability to carry out agreed upon decisions.

Elwyn et al. [8] has developed a model for clinician use that translates conceptual descriptions into action steps. The three step model includes 1) introducing choice for the patient’s role, 2) describing care options available in the situation, and 3) helping patients explore preferences, clarify information, and make decisions. The article contains specific dialog the clinician can use in each of the steps to promote SDM.

Evans, Sharp and Shaw also explore a decision making model for patients considering the use of complementary therapy as an adjunct to cancer treatment. The authors employed a multi-faceted approach entailing both observation and interviews to assess exchanges between patient and health care professionals at cancer treatment facilities where complementary approaches were available. These “holistic assessments” revealed that, while patients may exhibit varying levels of interest in their decision making involvement, it is equally as important to recognize their preferences as to how much or little they want to be involved, although this is likely to be influenced by the acuity of their disease process. Furthermore, it is likely for non-traditional treatment methods were considered, as opposed to standard therapies, it was more feasible to give priority to patient preferences.

## Patient Centered Care and SDM

Paradigm shifts, by their inherent nature, entail a whole new way of thinking. Patient centered care with its commitment to begin with the patient and to meaningfully engage the patient in his care is an example of a paradigm shift away from the well-established and heavily engrained paternalistic approach in which the well-meaning provider chooses and recommends all treatment options. One should not underestimate how profound this shift is in healthcare. It could be equated to Copernicus’ discovery that the planets revolved around the sun (think patient) rather than revolving around the earth (think provider). To this end, evidence based practice embraces new approaches to patient care, creating paradigm shifts [3]. Furthermore, because substantial and quality evidence must be used as benchmarks for excellence in patient care, SDM is an example of evidence-based practice. SDM remains an evolving approach within patient centered care efforts to personalize health care.

In addition to epitomizing quality in health care, patient centered care offers the foundation for SDM, as it compels the

provider to see and treat the patient as an individual, and not simply a disease process or health concern [9].

The Institute of Medicine describes the aim of patient-centered care as: “providing care that is respectful and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” [10].

On a wide scale, providing patient centered care is an important goal when considering needed improvements of any health system [11]. As described by Lusk and Fater [12], patient centered care encompasses specific, important elements that must be present to attain quality patient care. The authors identify additional recommendations by the Institutes of Medicine, which address the recognition and respect of varying experiences, inclinations and needs of each patient, in addition to the provision of care and health and wellness preservation. In essence, excellent and quality patient care are the goals of patient centered care [12], and this speaks directly to the process of SDM.

As Moreau et al. [13] state, SDM accentuates patient centered care since meaningful and effective communication is necessary. This sets the foundation for a treatment method that incorporates the patient’s preferences and participation in the decision making process. The authors identify six components of patient centered care: disease exploration, seeing the patient as a biopsychosocial being, finding common ground, creating a therapeutic partnership, being realistic, and disease prevention/health promotion. However, the providers’ beliefs about shared involvement by the patient will also come into play. The establishment of a constructive patient-provider relationship, the provider’s experience and expertise and interest in and respect for the patient as the subjective expert then come together to foster information sharing and discussion of choices [13]. Trust on the patient’s part can also promote their “self-confidence and self-efficacy”, thus facilitating involvement in the decision making process as a fully involved participant in the agreed upon treatment plan [13].

Of the six components outlined, finding common ground is the element that highlights the essence of SDM, although it does not speak to its totality [13]. Beyond the already discussed defining attributes of SDM, shared participation can only be attained where there is a “high-quality relational process” and resulting intervention that respects the patient’s values where information and treatment decisions are concerned [13]. Ferrer and Gill also ascertain that a sign of patient-centered care is that important choices are made through SDM [14]. The authors elaborate that SDM combines important aspects of patient care such as “patient preferences, scientific evidence on outcomes, and clinicians’ expertise in integrating clinical circumstances, values and evidence” [14].

Munthe et al. offer the concept of the patient narrative as a tool to guide the provider’s thought process in care provision and treatment approaches [15]. The collaborative method by which treatment options are agreed upon as well as how this further incorporates the patient’s story underscores that the ongoing nature of patient centered care is inherent within SDM [15]. This, in effect, individualizes the patient’s care.

Additionally, Lein and Willis suggest patient-centered interviewing methods as an approach to fostering “long-term therapeutic relationships with complex patients” [16]. Factoring in time constraints inherent to most outpatient visits, the authors describe patient-centered interviewing as “a skill that requires an optimal balance between completeness and efficiency” [16].

Finally, Robinson et al. maintain that adherence is increased when patient centered approaches are used [9]. The elements of communication, SDM, and self-management are explored, and specifically correlate understanding of the patient’s goals or desires of treatment with the likelihood of adherence [9]. The process of SDM should reveal any barriers to adherence, the authors elaborate, creating an opportunity for exploration of alternative options that align with the patient’s values. However, evidence based practice should still be incorporated, which can be accomplished by recognition of effective interventions and consideration of the risks/benefits of each treatment options, all the while keeping in mind and incorporating patient preferences [9].

As a tangible example of patient engagement, which requires SDM and effective communication, the Agency for Health Care Research and Quality (AHRQ) offers a toolkit titled, “Taking Charge of Your Healthcare: Your Path to Being an Empowered Patient.” This material addresses patient discharge needs after a hospitalization. A user friendly printout, lists crucial details for patients to be aware of, such as making a follow up appointment, having a list of medications and obtaining hospital records [17]. It can be located at <http://www.consumersadvancingpatientsafety.org/caps/wp-content/uploads/2013/03/EmpoweredPatientBooklet.pdf>

An important addition to the literature is the 2018 Cochrane review: “interventions for increasing the use of shared decision making by healthcare professionals” [18]. The purpose of the meta-analysis was to determine the effectiveness of interventions used by healthcare providers intended to increase shared decision making. They concluded that at this time there is insufficient evidence to be supportive of any such interventions because evidence of effectiveness is low or very low.

## Obstacles and Solutions

If SDM is such a needed approach to achieving excellence and effective patient care, why does it seem to be so infrequently used by American health care providers? Friedberg et al. found that treatment recommendations and care delivery are still taking place without sufficient explanation of treatment options or inclusion of patients’ input [11]. This may be attributed to providers lacking the communication skills or competencies needed to achieve SDM [11]. In addition, a problem of non-adherence may lie in the “bureaucratic approach” to healthcare management on behalf of health care providers for their patients. That is to say, a focus on managing costs, outcomes, and efficiency may inadvertently inhibit patients from choosing to be accountable for their health, at least to the best of their capability [2].

Legare and Witteman [19] evaluated a number of studies to explore perceived barriers to SDM. Time constraints, patient characteristics, and greater need for data supporting positive patient outcomes were the most reported by providers [19]. Interestingly, they found that time has been the most often listed barrier to any change in clinical practice, although the authors suggest this could likely be minimized through provider training in SDM. Providers were also found to inaccurately assume whether or which patients would be interested in participating in SDM: the roles were minimized for older adults, immigrants, or those with lower education or literacy levels [19]. The authors suggest that these vulnerable populations can be empowered to take a more active role in decision making by learning communication skills that might facilitate SDM, which by extension would empower them enough to participate in making health care related choices. Furthermore, this aligns with knowing patients’ needs and preferences.

Politi et al. also address why SDM isn’t more popular among providers at this time [20]. In their discussion of how scientific uncertainty can affect providers’ interest in using SDM, the authors looked at what provider characteristics made them more or less likely to incorporate SDM into their current practice. Provider responses to questionnaires examined patient encounters that employed SDM methods before and after providers attended SDM training sessions. Respondents were largely physicians, and the authors established correlations between having additional educational training (in addition to a medical doctorate degree), being male, established providers (as opposed to residents) and lower reported rates of anxiety from uncertainty as well as lower reported rates of reluctance to verbalize uncertainty.

The issues of uncertainty as they relate to the risks and benefits, or even a diagnosis, can quickly surface as a consequence of closely involving patients in their decision process. O’Riordan et al. [21] consider the skills needed to cope with uncertainty (as it relates to diagnosis) as a challenge within general medicine [21]. The authors outline how the provider’s thought process could play out, and this could provide useful traits that might make one provider engage in SDM with his/her patients versus another. The use of evidence-based medicine is considered as an example, although not always used, when providers must choose the appropriate diagnostics to order. The notion of pattern seeking is also differentiated in the practice of primary care providers, as this may alleviate or reduce the possibility for uncertainty when making a diagnosis. Additionally, the challenge of how the patient presents his symptomology can also confound efforts, although an experienced or expert provider is suggested to be more able to hone in on important details that might be embedded within the patient’s “story of illness”. To this end, the use of closed ended questions is provided as a means to ascertain an initial diagnosis.

As Politi and Street [20] state, “collaborative decision making assumes that the uncertainty that complicates medical decisions” is communicated with patients, and this is where decision aids or tools can be used to facilitate the patient’s decision making

process [20]. Elwyn et al. [22] consider the use of option grids or summary tables that patients can review during their provider office visit. The FAQ formatting allows the patient to quickly hone in on possible topics of discussion as a guide. The patient can also print the table ahead of time. The format was borrowed from the web tool Bresdex, a website designed for patients diagnosed with breast cancer. One must also consider that, while providers may have struggled with the possibility of more than one possible treatment option, a decision still needs to be made [19]. This is where a discussion may take place about what role patient/provider will make in the decision-making process.

Finally, Elwyn et al. [8] assert that providers have received a lack of guidance about how to accomplish SDM in their practices. They propose that having clearly stated guidelines and steps as presented in their model will result in increased use of SDM strategies. While this assertion is understandable and may be true, guidelines alone may not be sufficient to overcome the many barriers that exist in a clinical practice.

In their examination of fibromyalgia treatment that used SDM, Bieber et al. [23] established that effective treatment methods are best accomplished via partnership. In fact, the patient is enabled and supported to the extent that greater responsibility can be assumed on their part for medical choices, which underscores the importance of autonomy for this dynamic to exist [23]. The process in itself surfaces as provider's employ specifically needed capabilities, "such as inviting patients explicitly in the decision-making process, checking patients' role preference, explaining the notion of medical equipoise (to have more than one valid medical option), available options, checking patients' understanding, identifying and responding to any expectations and fears, and, finally, negotiating a treatment decision" [23].

However, Shortus et al. also point out the distinction of the patient's clinical context, such as being in imminent danger versus management of chronic diseases. In other words, providers can safely and appropriately promote and employ SDM to improve implementation of patient care to achieve mutually agreed upon goals where decisions are flexible, and this tends to exist in management of chronic diseases [24].

Recently, SDM was evaluated in a study of lung cancer screening discussions and decisions [25]. Such discussions between physicians and patients averaged less than one minute and potential harms of the procedure were never mentioned even though there can be a false positive rate of 98%. CMS provides guidelines to promote SDM in situations in which lung cancer screening is being considered and these were clearly not implemented.

Implementation science experts have begun to address the realities of how the health care system could more effectively begin to implement SDM [26]. They engaged with several stakeholders to better identify the issues and challenges involved in using SDM in clinical practice. One of their key findings was that "...translating SDM into practice is complex and requires ... attention to multilevel contextual factors" (page 11). Many levels of stakeholders must be involved to continue to develop the required approaches.

## Training Health Professions

Having the capacity to establish an effective patient-provider dynamic requires good communication skills from the provider, in addition to genuinely listen to what the patient is saying, or not saying; even non-verbal cues can offer insight as to what are the patient's values and preferences [2]. Providers can emulate the tenets of SDM by first trying to elicit the patient's understanding of their disease process or condition, what the treatment goals are and their understanding of the risks involved of treatment options or no treatment at all [27]. Only then should the provider go into an explanation of the patient's condition, in addition to self-management approaches, and finally conclude with treatment options. Outcome goals can then be mutually agreed upon [27].

Legare et al. [19] offer a review of existing SDM training programs for health care providers. They noted foremost the novelty of these programs, suggesting perhaps that greater and wider scale efforts are now being implemented. The authors found that physicians tended to be the focus of skill development in SDM, although they also offer that an interdisciplinary approach might increase its frequency in health care settings.

Legare et al. [19] also maintain that patients making decisions in the primary care setting usually work with more than one type of health care provider, and hence SDM models should reflect this multi-faceted perspective. Training of various types of health care providers, whether via educational intervention or continuing education certification, is one approach to help increase patient participation, as well as the likelihood of adherence to the agreed decision [28]. In fact, Lown and colleagues developed their own continuing education training tool to teach and encourage needed skills to achieve SDM for health care providers at the interdisciplinary level.

Communication skills, as identified by this interprofessional decision support tool include listening and exploring varying perspectives, clarifying responsibilities, recognition of one's limits, asking for/offering/receiving feedback, reflection of group process, discussion of possible options and identification of whom will offer the interdisciplinary group's opinion or thoughts to the patient/family members [28].

<ul style="list-style-type: none"><li>• Is the patient passively listening, or are they asking questions as the treatment plan is discussed?</li></ul>
<ul style="list-style-type: none"><li>• Have they shared any meaningful information about their life or beliefs that could create obstacles to upholding an agreed upon treatment plan?</li></ul>
<ul style="list-style-type: none"><li>• Are several approaches to a treatment plan feasible? Has the patient even verbalized agreement to the treatment plan?</li></ul>
<ul style="list-style-type: none"><li>• Has the patient opted not to have or implement any treatment at all?</li></ul>

<ul style="list-style-type: none"><li>• Has the patient expressed interest or had previous experience with complementary therapies, and if so, would it be possible to include these as an approach to improve adherence to a treatment plan?</li></ul>
<ul style="list-style-type: none"><li>• Have printed or written materials been offered?</li></ul>

**Table 1:** SDM questions providers may want to consider.

## Tools to Measure SDM

Also useful are tools that measure SDM from the patient’s perspective, in addition to attributes that may be needed from the patient and/or provider to achieve SDM. What is essentially being measured here is the quality or efficacy of communication [29]. Hibbard and Greene discuss the quantification and outcomes of patient activation as it relates to health outcomes and patient experience [30]. Named the Patient Activation Measure (PAM), this tool was designed to assess the patient’s self-understanding and capacity to manage their own health care. The authors state findings that established patients scoring higher Patient Activation Measure with regular provider visits, screenings, immunizations, and improved outcomes such as BMI, HgA1C, blood pressure and cholesterol within normal ranges [30]. Furthermore, the authors found evidence indicating that being highly activated as a patient was linked to more positive patient care experiences. Indeed, “highly activated patients may have the skills and confidence to elicit what they need from their providers” [30]. While the PAM does not measure SDM, it would be a useful tool to correlate with a SDM tool.

The OPTION scale (abbreviated for “observing patient involvement”) has also been developed as a method to determine the level of patient participation [3]. Developed by Elwyn and colleagues, it provides a determination of whether or not patient participation in SDM is an option, and if so, at what point of care or level of treatment this may be possible. The existence of this tool lays the necessary foundation for open communication, so that patients are enabled to understand the “nature of the problem, that there are uncertainties and different likelihoods of harms and benefits and that the patient can... influence the decision itself” [31].

Elwyn and colleagues are also refining another measurement that assesses SDM from the patient’s perspective called CollaboRATE [8]. Based on SDM, this patient-reported measurement tool also seeks to establish its barriers in the patient-provider dynamic. The very use of the term “decision” was found to be problematic where patients were unaware of how or whether they were making decisions. Hence, confusion sets in and patients may not feel cognitively equipped to participate in making choices. It was established that using specific terms such as “what matters most” and “choosing what to do next” were more patient-friendly [8].

Additionally, the SDM-Q-9 was designed to address the patient’s perspective of the SDM process in the primary care setting, a tool that was generated from a German federally funded research team [32]. The questionnaire starts with identification of the chief complaint and treatment decision. Nine statements then

follow, and are presented on a Likert scale where the patient rates answer from “completely disagree” to “completely agree”. The total raw score can range from 0, which would indicate the lowest level or no SDM occurring, to 100, meaning that the highest level of SDM [32].

Finally, Kasper et al. compared four instruments purporting to measure SDM. They concluded that existing measures do not refer to a single construct and that a gold standard is not present to judge current SDM tools.

## Research Findings of SDM’s Influence on Patient Outcomes

Nurses are involved with SDM on two levels. Nurses are part of interdisciplinary teams who collaboratively work together with patients to reach treatment decisions. Nurses are also individual providers who work with patients to make choices about treatment and delivery choices that are wholly within nursing care. Research conducted by nurse researchers in the context of SDM exclusively in nursing practice is still in its infancy. Most research around SDM includes nurses as part of the interdisciplinary team providing care to a target population, but is not exclusively about SDM only in nursing practice.

Research conducted by and about nursing practice in SDM has been frequently qualitative and studies the nurses’ perceptions regarding SDM. Often the dilemmas surround end-of-life decisions. Kryworuchko et al. have provided a thorough review of extant literature on interventions used in SDM in end-of-life for nursing literature, but the trials are much broader than nursing practice alone [33]. Frank also has provided a review of qualitative studies focused on end-of-life decision making which involve nurses in various roles [34]. Kahveci produced a qualitative study since then that describes SDM in paediatric intensive care units in Turkey [35]. Oliver et al. [36] evaluated the shared decisions between hospice nurses, patients, and family members. They concluded that hospice staff can benefit from a more purposeful process which includes more focus on patient and family understanding and ability to implement a plan of care. Allen et al. [37] studied the effectiveness of an intervention supporting shared decision making on patient decision quality and concordance between stated values and actual treatment received. The intervention modestly improved patient decision quality, but did not affect concordance.

Outside of end-of-life decisions, Upton and colleagues produced a qualitative study describing how primary care asthma nurses share decision making with patients regarding inhaler device selection. Truglio-Londrigan is the only author from the US to publish a study, also qualitative, which describes their experiences with SDM. She interviewed home care nurses to describe their experiences in SDM [38]. The contribution of this study is its focus on the process and understanding of SDM that is more generic in nature and not focused on critical end-of-life decisions. Smith et al. [39] conducted qualitative interviews with patients to discover whether or not patients had discussed out of pocket medication costs as part of the decision making process around a specific

pharmacologic agent for their form of congestive heart failure. Few patients could recall ever having had a discussion around out of pocket costs and all shared that cost played a considerable role in their ability to adhere to the agreed upon plan of care.

So there is research, as well as clinical practice opportunities, for nurses to participate in SDM with patients as part of a team and in direct practice as individual nurses caring for a patient or family. Nursing research on SDM seems to focus primarily on the experience of the nurse in SDM, thus, descriptive and qualitative in nature. Nurses have yet to use the quantitative tools described earlier in this manuscript to describe their practice of SDM [40].

Physicians have recently demonstrated in a small study that they are not using a SDM approach in conversations with their patients about lung cancer screening [25]. It is unclear what other choices regarding screening patients may have made had SDM been used to inform them of benefits versus harms in this screening.

## Conclusion

As one can appreciate, SDM, while certainly no longer a novel concept, still remains an evolving effort towards quality based patient care. As a process from the provider's assessment, it starts with a willingness to believe that patients are capable of directing their care when fully informed. As an outcome from the patient's experience, it obliges not only active participation in one's health care, but also implies self-management, which can exist in varying degrees. This discussion of SDM demonstrates its complexity, particularly because effective communication between patients and providers, among other elements of SDM, is often lacking. Another challenge is that SDM, which has inherently intuitive elements, necessitates provider training and for many providers, this translates into an entirely new approach to patient care. However, the use of decision aids, as briefly discussed, can provide an excellent avenue for opening the door to communication, and also serve as educational opportunities that can be reinforced or revisited.

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