Making diabetes care fit: insights, strategies and support

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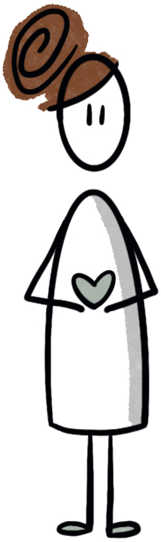

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Shared Decision Making as a method of care

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ABSTRACT

Care happens in interaction between the patient and the clinician, in conversation. Within this conversation, the patient and clinician uncover or develop a shared understanding of the problematic situation of the patient and identify, discover, or invent ways to make that situation better, given what each patient prioritizes and seeks(1). Thus, to get the right care for each patient, patient and clinician collaborate and deliberate together to figure out what to do(2).

Anytime a patient and clinician figure out together what to do about the patient's situation, they are doing shared decision making (SDM). Although there are multiple models and accounts of what SDM is and is not(2-6), in practice, SDM starts by determining the nature of the problematic situation the patient is experiencing. This often requires considering insights that only the patient and perhaps their family can share, insights about both the patient's biology and biography. This diagnostic process goes beyond identifying, classifying, and naming, e.g., "you have mild type 2 diabetes mellitus". Rather they must uncover how medical conditions manifest in daily life and how treatments fit into daily routines, and how, in turn, symptoms and treatments affect living.

After developing a shared and useful formulation of the problem, clinicians must mobilize their competence and compassion to work with patients to develop a sensible care plan that responds to the situation as understood, is based on relevant evidence, attends to the emotional aspects of the problem, and is feasible and sustainable for the patient(7,8).

Therefore, SDM is not about eliciting and documenting patient preferences in the medical record, distributing educational pamphlets or decision aids for patients to come prepared to the consultation, or leaving clinical decisions for patients to make on their own after receiving a clinician's recommendation. Rather, SDM is as central to the clinician's art as history taking, the physical examination, the selection and interpretation of diagnostic tests, and patient education and counseling. This makes SDM not "another thing clinicians must do", not just an expression of patient-centered care or a way of involving patients, or a mere antidote to medical paternalism or low-value care. Rather, SDM is a method of care.

The practical method to implement SDM as a method of care proposed below seeks to make as few demands as possible of both patients, who are taxed by the demands of self-care and of navigating a labyrinthine healthcare system while responding to the demands of living(9-12), and of clinicians, who, despite some evidence of the contrary(13,14), often express their worries about SDM adding time to their encounters(15,16).

HOW TO IMPLEMENT SDM IN PRACTICE

Here we propose a simple four-step method to implement SDM in practice (**table 1**).

Table 1. Steps for shared decision making in practice

(1) Foster a conversation
(2) Purposefully select and adapt the shared decision making (SDM) process
(3) Support SDM
Protect the space
Make the most of participation
Deploy useful tools
Advocate for care
(4) Evaluate and learn SDM
Evaluate beyond outcomes
Share the evaluation
Seek joint improvement

(1) Foster a conversation

The first step in implementing SDM in practice is to foster conversations that invite patients and clinicians to collaborate, support their collaboration, and lead to the formulation of a co-developed care plan.

In this conversation, the clinician curiously works to understand which aspect of the patient's problematic human situation requires action(5). This could be an unaddressed medical problem, such as a new symptom, concern, sign, or complication. It could also be a change in life circumstances that affects how the medical condition manifests or that affects the practicality of the existing plan to address it. It could be signs that the plan of care in place is not helping, or even hurting, or that it has become impractical or unfeasible. The patient and clinician must collaborate to arrive at a useful formulation of the problem. For example, will the change in insurance coverage change the patient's ability to afford the treatment prescribed given their income and other expenses they must cover? Is the increase in pain in the feet impairing living? The inquiry then seeks to uncover the action that the situation requires(1). It may be necessary to conduct new tests, change the care plan, or provide additional support.

The process of noticing and responding is iterative(1,17), and continues until a response emerges that makes intellectual sense (i.e., it is an evidence-based response(18) to the situation as understood), practical sense (i.e., it is feasible and minimally disruptive of personal and social routines), and emotional sense (i.e., it accounts for the emotional dimensions of the situation and feels like the right thing to do now) to patients and clinicians(8). Confronting the actions available to respond to the situation may lead to reframing the situation itself and reformulating the problem to address. For example, a patient facing a cancer with a very poor prognosis and seeking a cure may discover that the treatments have a low likelihood of success and a high likelihood of harm. The unattractiveness of these options may lead to a recasting of the situation as one in which the patient is facing death because of cancer and now seeks ways to die well. The options identified in the first instance fail to be a sensible response to this new formulation of the situation and new options must be identified, uncovered, or invented.

As plans are co-created and implemented, it is the patient as care-receiver who is in the best position to provide feedback about the plan's adequacy as a response to their situation, its acceptability in relation to the burdens and costs it imposes by itself and in interaction with other treatments and daily routines, and in its efficacy in improving the situation.

It may be helpful to be aware of some stumbling blocks to fostering SDM conversations:

- In some cases, patients may not be aware that SDM is an appropriate method of care since there is no one technically correct solution to their problem. Clinicians can helpfully state so and invite the patient into the process of figuring out together what to do(19,20). This renders irrelevant that the patient "did not go to medical school," creating the space and momentum for collaboration.
- An eager desire to be helpful may compel clinicians to curtail the conversation by prematurely making a recommendation(19). Rarely, patients may open the conversation by making a demand(21). The clinician's recommendation and the patient's demand act as anchors reducing the responsiveness of the clinician to new insights and complicating the patient-clinician relationship if the action recommended or demanded proves inadequate. A desire to avoid conflict may lead to either party acquiescing, which is why policies (e.g., guidelines, pathways, formulary restrictions, pre-authorizations) and marketing campaigns (e.g., detailing to clinicians, direct-to-consumer advertising and "ask your doctor about…" ads) can unduly shape care(22,23).

The conversation is, therefore, the workshop in which patients and clinicians co-create plans of care together. Fostering these conversations is the first step in doing SDM in practice. The next step is to determine the method used to jointly arrive at a sensible response.

(2) Purposefully select and adapt the shared decision making process
The second step to implement SDM in practice is for patients and clinicians to purposefully select the appropriate SDM process. There are four distinct ways in which they can work together to address the patient's problematic situation: (a) focusing on matching preferences, (b) reconciling conflicts, (c) problem solving, or (d) meaning making.[5] Each of these forms of SDM is best suited to address one of four different kinds of problematic situations **(tables 2A and 2B**). Clinicians need to be aware of these forms of SDM to intentionally select the form best suitable to respond to the situation at hand, avoid selecting the wrong one, and nimbly switching to a different form when the situation becomes clearer or changes(24).

In our observations, clinicians and patients who do SDM well, work within a form of SDM until a better one becomes apparent and they flexibly, gracefully, and perhaps intuitively switch according to the challenges uncovered during the conversation(24). For example, a conflict requiring reconciliation ("I will never use insulin because I am not allowed to use needles at my job") can become a problem requiring solving ("Is there a way to use insulin such that it is only administered at home?"). A problem can be solved by recognizing that there are several reasonable options ("There are several insulin preparations that are longer acting and can be used once or twice a day"), and the selection of those options may call for matching preferences ("I rather use a once-a-night insulin because my mornings are hectic, and I often forget my morning medicines"). Perhaps the best option selected is not readily available or affordable, and this problem is solved by implementing the second best, while resources are mobilized to access and afford the best one ("Let's start with the twice-a-day insulin while we work with your insurance to gain access to the once-a-day preparation.").

Table 2A. Forms of shared decision making

SDM form method description	Situations in which this form will be preferred
Matching preferences	
Patients and clinicians compare features (i.e., efficacy, burdens, side effects) of the available options and match them with the patient's values, preferences, goals, and priorities. They may use an SDM tool to share information about the options. Patient and clinician deliberate until the best match is identified.	Deciding whether participating in a screening program is a desirable way to address the threat of breast cancer. Selecting which of the available diabetes medications to use to achieve glycemic control.
Reconciling conflicts	
Using a collaborative process, the clinician helps the patient articulate the reasons for their position while reconciling those reasons with the varying possibilities ahead.	Opting to take an antidepressant or not for mild depression in a patient who, up to now, thinks that psychoactive medications must be avoided. Determining whether to curtail driving privileges in an elderly patient with potentially dangerous levels of visual and cognitive impairments.
Problem solving	
Potential solutions are tested – in conversation or therapeutic trials – and become justified based on the extent to which these can demonstrably and successfully address the problem and improve the patient's situation.	Determining how far to reduce blood pressure in a patient with hypertension and frailty with a tendency to fall and a history of taking medications erratically. Deciding when to discharge a patient home from the hospital, figuring out what accommodations and ongoing support and care will be needed and who will ensure the patient receives it.
Meaning making	
Using conversations, patient and clinician develop insight into what the patient's situation means, at a deep level, to the patient and their community and to find the reasons within that process for pursuing a particular approach.	Deciding how the dying patient will transition off life-support technologies in preparation for death. Planning the extent, type, and timing of gender affirming therapies in individuals transitioning to a different gender.

Table 2B. Practical differences between the forms of shared decision making

What is the problem?	You and your patient are talking about…	The conversation or the decision is difficult because…	The patient may be feeling…	You and your patient can use this form of SDM to…
Matching preferences				
The problem is clearly defined and can often be established ahead of the conversation. Its solution is in one of the options presented.	The likely positive and negative effects of a specific illness and its treatment options.	It is uncertain what will happen, and hence which option is preferable.	Uncertain, fearful of what could happen, and worried about making a wrong choice.	Address uncertainty by matching the threat of what could happen to the benefits, harms, and burdens that the patient prefers to take.
Reconciling conflicts				
The problem involves an internal (two values or goals in tension) or external (disagreements with important others or with the clinician) conflict.	The stance on an issue (e.g., disease, diagnosis, treatment, guidelines, relationships) taken by the patient, clinician, or others.	There is conflict or tension within the patient or between the patient and other parties.	Disoriented, pulled in multiple directions, torn, guilty, ashamed, adamant, indecisive, not knowing who or what to trust, relationally hurt.	Reconcile conflicts within the patient or between parties so that an acceptable, honest, comfortable, self-aware, or committed position on next steps is found.
Problem solving				
The problem is not clearly understood prior to the conversation. The problem comes into sharper focus as it is used to find reasons to proceed in one way or another.	A difficult situation	The situation is practically and emotionally troubling, due to multiple, often unclear, competing or limiting factors with limited capacity to rectify.	Stuck, incapacitated, diminished, trapped, threatened, hopeless.	Change the situation by problem solving–uncovering the actionable factors contributing to the situation, generate ideas for changing them, and experimenting with them in the conversation.
Meaning making				
The problem involves an existential threat or transition.	A person's or community's meaning or identity and what ultimately matters in the situation.	Who the person and their community is in the face of life changes is in question or threatened.	Splintered, lost, no longer themselves, resigned, fearful, not at peace, deprived of what makes them whole and gives life meaning.	Work with the patient and their community to make meaning and find a way to feel at peace or whole again, secure in the knowledge of what ultimately matters in the situation

Also in our observations, the situations adverse to care emerge when clinicians use an unhelpful SDM form or inflexibly insist on using a particular SDM form after it has proven unsuitable. This can be observed when a clinician offers distressed patients and family members a menu of life-sustaining therapies and demand they select what they would prefer from it; or when a clinician insists on reviewing the pros and cons of insulin without addressing the patient's inaccurate understanding that starting insulin causes amputations or dialysis. Selecting the right approach requires clinicians to be present, competent, flexible, and attuned to whether the conversation is helping the patient with what they are struggling.

(3) Support SDM

The third step to implement SDM in practice is to find useful, usable, and desirable ways to support SDM in each encounter.

Protect the space

Shared decision making is work for both patients and clinicians(25). The conversation is the workspace within which this work takes place. The space for the conversation must be set up to be supportive of this work(26-28). Clinical spaces can be cluttered with visual (posters behind office doors, clinical equipment) and auditory (overhead announcements, ringtones) distractions. Demands for entries from the medical record system can interrupt conversations. Thus, clinicians must be deliberate about protecting the space and the time allocated for these conversations. This is less about new investments in interior design and more about securing agreements and arrangements (e.g., team policy to avoid interrupting clinicians when in consultation with patients; minimize pop-up alerts and mandatory data entry in the design of medical records) that eliminate distractions, disruptions, and interruptions. The setup should clearly signal the intention: the clinician and patient are here to have an unhurried conversation – not necessarily a long one – to work through what to do about the patient's problems today and going forward.

Make the most of participation

Having set the stage for an unhurried conversation(29), it is necessary to determine who should participate in that conversation. Patients and clinicians in continuous relationships of care may be optimally situated to have unhurried conversations. When the issue requires specialized technical knowledge, or access to educational materials, longer consultations, and decision-making tools, it may be optimal to bring into the conversation clinicians specialized in the matter, either to co-create the plan of care with the patient or to assist the established patient-clinician dyad in their decision-making process. A similar choice needs to be made about the participation of informal caregivers, who in their roles at the patient’s side, often have expertise about and experience with the patient and may be responsible for the plan’s implementation.

Deploy useful tools

Clinicians and patients may want to thoughtfully consider which tools are allowed into the conversation, including specialized tools designed to support specific SDM forms that have shown to be useful, usable, and desirable. Given the situation at hand, different tools can support the decision-making process:

Self-management logs, patient-reported outcome trends, results from ancillary laboratory and imaging tests can all support the problem-solving mode of SDM.

Patients and clinicians could consider using home visits, photographs, narrative accounts of daily living, the “My Healthcare, My Life” conversation tool(30,31), and other ways to develop a joint understanding of the social and economic challenges the patient faces routinely, and how these conditions promote or hinder health and the implementation of treatments.

Tools to support SDM conversations can help patients and clinicians select together which treatments to implement to reduce the risk of adverse disease outcomes(32,33). These tools should be easy to use, use helpful ways to communicate pertinent evidence and numerical risk information(33,34), and should support the conversation without intruding. Some tools which have been found to be useful in randomized trials are available free of use(35).

Teach-back could be used to verify that patients and clinicians understood the information shared by each other(36).

Stories and accounts of how patients lived their lives may be helpful to their family and clinicians in determining together whether and for how long to implement intensive life-support interventions in the care of a critically ill patient.

Advocate for care

Access and efficiency imperatives abbreviate and accelerate consultations to the point that SDM and other forms of care cannot be adequately implemented. Algorithms and guidelines may enable bypassing the messy process of co-creation, offering a right answer for “patients like this” which may or may not fit “this patient”. SDM may get outsourced to third parties, offered to privileged patients (and less to those who need interpreters, racialized patients, patients with cognitive and sensorial challenges, and those seen in high-volume or understaffed clinics), or reduced to the distribution of SDM tools(37).

Like careful and kind care(37-40), SDM is not a luxury. And yet, it often seems as if high-quality SDM is a method of care that healthcare cannot afford to offer everyone. Clinicians and patients must play an active role in advocating and working toward healthcare that enables and supports SDM. This work can focus on reprioritizing care over efficiency, advancing unhurried care conversations(29,37), reorienting healthcare innovations to advance rather than replace SDM, and on ensuring SDM for all patients(41).

Evaluate and learn SDM

The fourth step to implement SDM in practice is to evaluate how well SDM is happening and learn how and to what extent SDM as practiced is contributing to care.

When done well, SDM should contribute to improve the patient's problematic situation. Being able to co-create and jointly revise plans of care may reduce the risk of a poor-quality decision, that is, one that does not respond sensibly to the problem, fails to support patient goals and priorities, and maximally disrupts patient lives and loves(17). Doing SDM can deepen the relationship between patient and clinician and this relationship can offer resilience to adverse patient outcomes(42). In turn, joint evaluation of how well the patient and clinician are doing SDM can motivate improvement of SDM skills and further their partnership. In this way, care and learning to care are intertwined, and are both reliant on unhurried conversations and SDM.

Evaluate beyond outcomes

It is not adequate to judge the quality of the SDM process by patient outcomes, as the link between decisions and outcomes is weak as many outcomes result from highly complex interactions, multiple decisions over time, and chance. Short of general patient satisfaction questions, to our knowledge, there are no practical means available for external evaluators to assess how well a healthcare system, a clinician, and a patient implemented SDM and how well this process contributed to advance the patient's problematic situation.

A way forward may require defining a good decision by the way it was produced (evidence-based, co-created), by the goals that animated the decision-making process (advancing the patient situation in a sensible way), and by the nature of the care plan that emerged from it (maximally supportive of the patient situation and goals, minimally disruptive of the live routines of patients and their community (17)).

Share the evaluation

Beyond external assessments, the most important evaluation needs to take place within the patient-clinician relationship. The patient and clinician may want to ask each other how well the conversation went and to seek feedback from each other about how they went about working out what to do, i.e., how well they did SDM. This may be particularly necessary early in the dyad's decision-making experience so that their performance can improve over time and be increasingly readier to face more difficult situations. By seeking feedback, clinicians exercise their humble commitment to meet the patient where they are and to care well for, about, and with the patient.

Seek shared improvement

The shared work of SDM demands that both parties learn from their experience. Since clinicians and patients with chronic conditions face a lifetime of decisions, this learning is life long and ongoing. Few opportunities exist to improve together. Clinicians can access courses in communication, but often these courses pay limited attention to the co-creation of a plan of care, instead focusing on explaining the plan to the patient. Patients are often trained to ask questions (e.g., what are my options, what are their pros and cons, how likely are these pros and cons to happen(43)), but there is little training about the different ways in which they can contribute depending on the forms of SDM used. Resources to improve the performance of both patients and clinicians, including joint skill building opportunities, need to be made available to promote high quality SDM(36,44).

CONCLUSION

The number of tasks assigned to clinicians seem to increase in inverse proportion to the time allotted to execute them. In this context, SDM may seem like just one more box to tick, or a skill clinicians have no time to learn or use. But SDM is not an add-on. Clinicians are already engaging patients in conversations to work through a plan of action because that is what is required to formulate the best plan.

As with every other aspect of caring for patients, this method of care must continue to be subject of innovation and improvement(45), including the preparation of both patients and clinicians (and the healthcare systems within which they meet)(38) to better contribute to the joint work of making care fit(17).

The ubiquitous nature of SDM means that every conversation with a patient is an opportunity to get care right—intellectually, practically, and emotionally – for that person. In these conversations, patients and clinicians can find problems that matter along with possible ways of addressing them, deciding amongst the possibilities, and putting it all together in a plan that the patient wants, is likely to help, and is feasible and sustainable.

Within the constraints of any situation, including systemic constraints, SDM is a method of creating the best care, it is also the human, kind, and caring thing to do—the sort of thing that breathes life, joy, and purpose into the practice of medicine.

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