

MASTERING SHARED DECISION MAKING

The When, Why and How



Overview

One of the problems with the growing interest in shared decision making is that it is not very well understood. The goal of this article is twofold: first, to be very clear about what shared decision making is and what it isn't; and second, to explain the enormous potential of shared decision making, yet only if it is done well [1]. The challenge we face is that the interest in shared decision making might vanish, unless we prove that it makes a significant contribution.

Shared decision making is not about...

- Letting patients have whatever they want
- Wasting time when it is already clear what is best for the patient
- Abandoning patients to make decisions on their own
- Just "being nice" to patients

These are common misconceptions [2], and we will dig deeper into many of them. Clinicians often say that they are already doing shared decision making, but when researchers examine recordings of conversations between clinicians and patients, there is little evidence of shared decision making [3]. This is the problem: how can we realize the benefits of shared decision making when it is rarely done well?

SO, WHAT IS SHARED DECISION MAKING?

At a very basic level, shared decision making is simply helping another person make an informed decision, whatever choice or behavior change they face [4]. That does not sound too difficult, but the process itself can be complex. This is especially true in situations where patients and clinicians have significantly different levels of knowledge, experience and expertise. Healthcare is a prime example where options available are very unfamiliar and filled with uncertainty. Buying a house, planning a vacation, or dealing with money or legal issues can all be difficult to navigate, which is why we look for advice from people such as agents, accountants or lawyers. These comparisons, however, are of limited help. People are familiar at least with some of the issues they face with these types of decisions and have clear views about what they want to achieve. Facing decisions in healthcare can often be like entering a new country, where the language is different and where people have not experienced any of the options available. Individuals need help to understand the possibilities and what might suit them; they essentially need information to compare one option against another. One way to think about shared decision making is to categorize decisions into those that need deliberation versus those where that level of investment might not be needed [5].

Shared Decision Making:

An approach where health professionals and patients make decisions together, using the best available evidence about the likely benefits and harms of each option, and where patients are supported to arrive at informed preferences. [6]

Box 1: Definition of shared decision making

DELIBERATION SOUNDS LIKE HARD WORK. WHEN IS IT WORTH IT?

If everyone were to deliberate about every possible choice, no one could get dressed in the morning. What shall I wear today? Do I need socks? Which ones? And so on. We all make hundreds of choices every day, many without being aware that we could have considered an alternative, given that we all follow routines and form habits. Some decisions, however, do rise to a different level. Typically, these decisions are situations where the stakes are higher. These are situations where making the wrong choice could be costly, painful, irritating, or lead to regret. Decisions in healthcare are often of this type and especially where there are tests or treatments to be considered. However, the problem is that most people are often blind to two important issues.

First, people are generally not aware that reasonable alternatives exist or no one tells them that options exist. How can anyone work out whether to weigh available options – to deliberate – if they are unaware that alternatives exist? Healthcare professionals and healthcare organizations in general are not good at making people aware that options exist. Second, if people do become aware that options exist, often after searching the internet, there tends to be a reluctance among healthcare professionals to support a process of deliberation. People who bring their own research to clinic visits are often met with skepticism.

There are many possible reasons for this reluctance. It is typically faster to suggest one way of doing things, and it takes less effort to explain a recommendation than to undertake a process of comparing two options. The culture

of healthcare has been wedded to this approach. Clinicians are taught to diagnose, to make clear authoritative recommendations, and to explain those recommendations to patients. Research efforts are also used to reinforce this way of thinking. For many decades now, clinical practice guidelines have been developed to provide summaries of the medical literature. These guidelines make recommendations — literally best practice statements — and clinicians are strongly encouraged to follow the recommendations. Rarely do clinical practice guidelines make it clear that there is a range of reasonable alternatives available to patients [7][8].

There are other reasons why some organizations and clinicians do not offer alternatives. Tests are often suggested even when the benefit of having the extra information is very limited. Yet doing the test is viewed as defense against a possible claim that every diagnosis was not excluded, irrespective of the cost. This is known as defensive medicine [9]. This is partly why costs in the United States are so high. Procedures are sometimes suggested because organizations or individuals benefit financially. It is difficult to know how much such a financial interest leads to offering procedures that are not appropriate. We do know that financial interests do not encourage the frank and full disclosure of reasonable other alternatives which patients might choose if given the option.

For all of these reasons, helping patients compare reasonable alternatives so they can make a decision that fits best with their circumstances, goals and preferences — otherwise known as shared decision making — is rare. Is this because there are few situations where reasonable options exist?

IS IT RARE FOR REASONABLE ALTERNATIVES TO EXIST?

It is more common for reasonable options to be available than not. In fact, there are relatively few situations in medicine where there is only one effective way to deal with a problem. Figure 1 illustrates that shared decision making is the overlap between evidence-based medicine and where patient preferences are relevant and appropriate. It is important to describe some examples, so that we can agree on those situations where it would be unnecessary, maybe unhelpful, to suggest the need for careful deliberation.

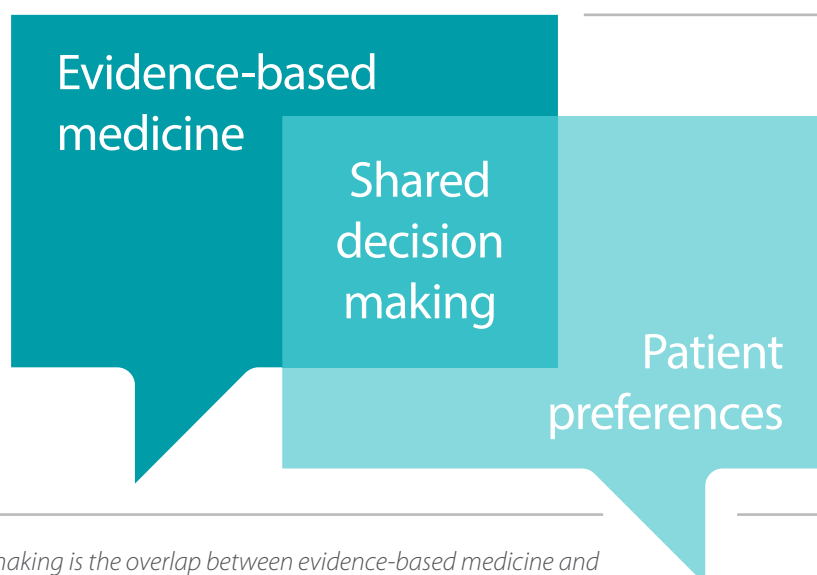


Figure 1: Shared decision making is the overlap between evidence-based medicine and patient preferences.

WHEN DOES ACTION TAKE PRECEDENCE OVER DELIBERATION?

Urgent situations, where life is at stake, are clearly where action takes precedence over deliberation. These can be after trauma or in other life-threatening situations, such as meningococcal infection, myocardial infarction, acute aortic aneurysm, and other similar emergency circumstances. In these situations, there are proven effective treatments. It would be unethical and unhelpful to waste time by suggesting a need to consider illogical alternatives such as taking no action. However, there is a caveat. Even in urgent situations, there is a need to obtain consent [10], however efficiently, by explaining the need to intervene. Gaining consent could be considered as a legitimate but limited form of shared decision making in these kinds of situations.

WHEN DO PATIENT PREFERENCES MAKE A DIFFERENCE?

For other situations in medicine, the goals, concerns and informed preferences of patients should play a significant part in decisions. There are many reasons why this is so. First and foremost, it is an ethical imperative to respect a patient's right to self-determine the best course of action for themselves. Clinicians have high status and occupy powerful positions because of their qualifications and role. Such power can stifle the views of patients, and professionals may be unaware that patients might not share the same views or care goals [11]. Secondly, patients may not be aware of the possible balance between harms and benefits that accompany all treatments, nor the fact that these harms and benefits vary across alternative treatments. To recommend only one treatment is to deny the patient the opportunity to understand the tradeoffs and to consider what might best fit their own situation. Thirdly, the costs of care are relevant to patients, whether these are financial or the extra burden that some treatments bring with them. For instance, some treatments require long recovery times or the extra time of additional appointments or having tests [12]. In short then, shared decision making is not something extra, and it is not a luxury. It is at the heart of practicing medicine proficiently. Shared decision making is about paying attention to the things that matter to patients. It is the true expression of being kind and careful, by showing respect to the views of patients.

EXAMPLES WHERE SHARED DECISION MAKING MIGHT MAKE A HUGE DIFFERENCE.

Let's consider a few cases to illustrate the unrealized potential of shared decision making [13], and what might have happened if more discussion had occurred.

Case 1 describes Mary, a 70-year-old with early stage breast cancer who was under the false belief that she was being recommended a treatment that would lead to improved long-term survival.

Case 2 describes Anthony who has knee osteoarthritis. Anthony was under the impression that having a knee replacement was a fast and effective cure to the problem. His surgeon outlined the procedure but did not spend time explaining the possible drawbacks.

Case 3 describes Joseph who suffers chest pain and has been diagnosed with angina. He believes that the best way for him to avoid a heart attack in the future is to have an operation to put a small tube, called a stent, to keep open an artery in his heart.

MARY: Lives on her own, a few hours away from the hospital and does not drive.

| | No shared decision making | Excellent shared decision making |
|-----------------|---------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|
| Belief | Had the misconception that lumpectomy with radiotherapy was the best treatment for long-term survival. | Correctly understood there was no difference in survival between mastectomy and lumpectomy. |
| Decision | Had lumpectomy, followed by radiotherapy every week for two months, plus delayed breast reconstruction. | After discussion, she preferred mastectomy, avoided radiotherapy and decided against breast reconstruction. |
| Outcomes | High costs, wound infection, tiredness, breast tenderness and 6 months of misery. | Less disruption to her life, less cost, faster recovery. Less misery. |

Case 1: Mary: 70-year-old with early stage breast cancer

ANTHONY: Retired and overweight, he struggles to get around the golf course.

| | No shared decision making | Excellent shared decision making |
|-----------------|-----------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Belief | Had the misconception that he would be pain-free and back to playing golf a few weeks after a knee replacement. | Correctly understood that his pain would be reduced but might not be gone, and that it would be a few months before he could get back to his usual activities. |
| Decision | Total knee replacement. | Wait before seeking knee surgery, while reducing weight, using pain relievers and exercising. |
| Outcomes | Tough recovery period after surgery, some residual pain and stiffness. Stops playing golf. | Some improvement and is able to continue playing some golf periodically. |

Case 2: Anthony: Retiree who suffers from knee pain

JOSEPH: Married and coping with two teenagers.

| | No shared decision making | Excellent shared decision making |
|-----------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Belief | Had the misconception that the operation was going to prevent future heart attacks and was far superior to using medication for angina. Despite wanting to avoid surgery, he was offered urgent angioplasty (stenting). | Correctly understood that stenting does not reduce the risk of having heart attacks. Realized the benefit of medication and graduated exercise and decided to adopt medical therapy. |
| Decision | Angioplasty (cardiac stent). | Lifestyle changes and medication. |
| Outcomes | Developed pulmonary embolus. Died 7 days later. | Tolerated medical therapy and increased his tolerance for exercise. No respite from unruly teenagers. |

Case 3: Joseph: 63-year-old diagnosed with stable angina

WHAT KIND OF BENEFITS COULD SHARED DECISION MAKING DELIVER?

The range of potential benefits that could come about because of shared decision making are substantial. As is clear from these cases, individual patients could benefit immediately from decisions that are much better aligned with the issues that matter most to them and that fit into their personal situations. It is also possible that in some situations the costs of healthcare might be reduced, where patients choose to take less risky operations [14], or use their medication more effectively [15]. It is also possible that shared decision making would have benefits at other levels, such as reduce professional stress and burnout levels [16]. These kinds of potential benefits have not been proven but could be an important future direction for research [1].

CAN SHARED DECISION MAKING BE OF HELP TO PEOPLE WHO HAVE LOW LITERACY?

The short answer is yes [17,18]. In fact, if health professionals can communicate effectively and use tools that have been designed specifically for low-literate populations, the benefit is greater than for those who are better educated. However, it takes special effort to design effective communication tools and strategies, and there is not enough research in this area.

HOW DO CLINICIANS DO SHARED DECISION MAKING?

Achieving shared decision making requires paying attention to those situations where reasonable options exist and where patient preferences will be relevant. For the purposes of teaching shared decision making, a model has been developed called the three-talk model. This model is based on a theoretical approach that describes collaborative

deliberation [5]. The three-talk model describes three broad steps that form the core elements of shared decision making. Initially described in 2012, it has been widely cited and used as a basis for teaching shared decision making [6]. Because of feedback, changes have occurred, and the most recent version is presented here (Figure 2).

“Team talk” is the first and most important step. It involves reassuring patients that although there are decisions to be made, there will be support as they learn about, compare and consider alternatives. Patients fear being abandoned to face decisions on their own [19]. It helps to identify goals and ask about what matters most to patients as a way of emphasizing the relevance of their concerns and preferences to decisions.

“Option talk” is the more obvious step where information about options is provided to patients. It is just as challenging to do well as team talk. Giving the right amount of information is key. Too much and patients will be overwhelmed. Too little and it is impossible to compare the harms and benefits of options. Tools such as patient decision aids can help if they have been well designed and offer balanced evidence-based information [20]. However, they are not a substitute; patient decision aids alone do not achieve shared decision making [21].

“Decision talk” follows option talk and is based on trying to align the goals of care with the patient’s informed preferences.

The three-talk model is designed to be brief and stepwise. It could be viewed as a recipe that, if followed, would lead to effective shared decision making. This is not true, of course; human interactions are complex and dynamic. These steps merely provide a scaffold for the task of comparing options in a way that respects patients’ views. Accomplishing shared decision making rests much more on having a positive attitude toward eliciting and respecting the views of patients and their families.

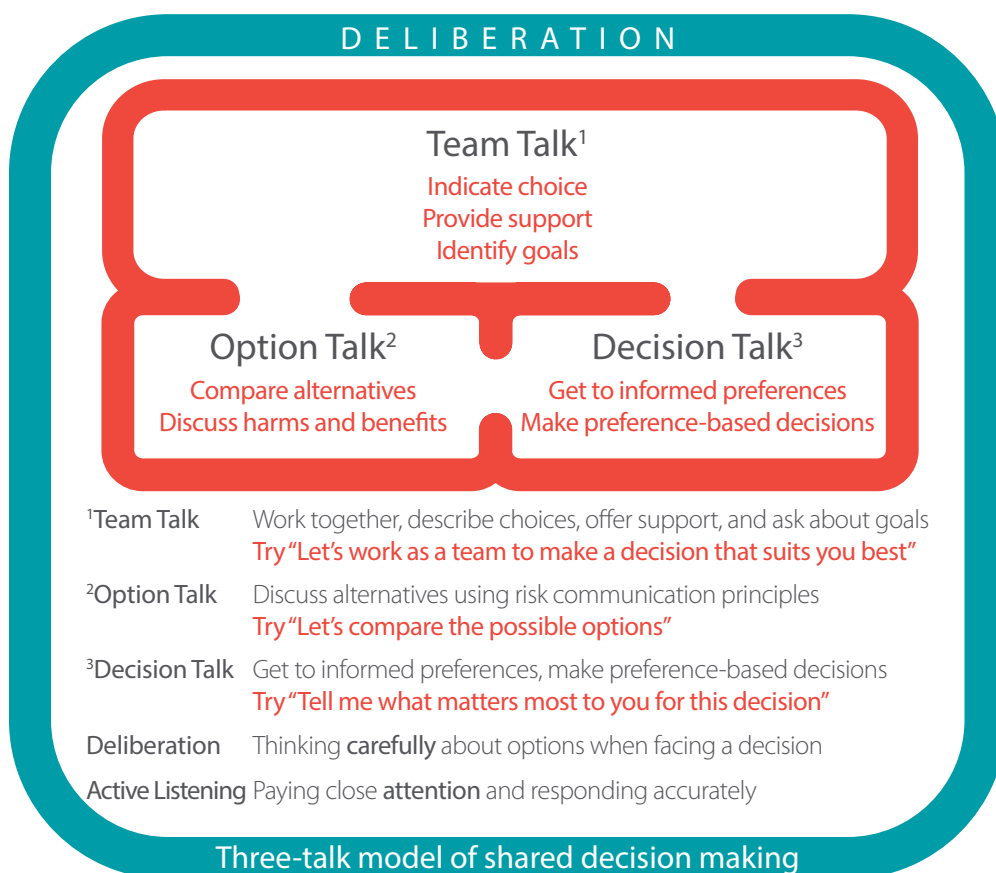


Figure 2: The three-talk model of shared decision making

WHAT CAN HELP FACILITATE SHARED DECISION MAKING?


There has been a lot of interest in tools that have been called patient decision aids [22]. These tools contain information that has been specifically created to help patients compare options, and there has been significant research on how to make sure they contain accurate evidence-based information, provide balanced descriptions of options, and are free of competing interests [23]. Most studies involved patient decision aids that were designed to be used by patients before meeting their clinician and have been called pre-encounter decision aids [21]. Although these tools have been shown to help patients gain knowledge, there is almost no evidence to show that they help patients and clinicians do shared decision making.

Another type of patient decision aid has also appeared, and it has been suggested that these be called 'conversation' tools, or encounter decision aids [24][21]. There is good evidence that these tools help support shared decision making. The design of encounter-based tools is different because they are meant to trigger discussions between clinicians and patients. They are brief, and the content is deliberately designed to be quickly understood by patients, even if literacy levels are low [25].

One example of this type of tool is *Option Grid*[™] decision aids. These are tables that help people compare alternatives and provide answers to patients' frequently asked questions. This way of presenting information provides a fast way for patients to prioritize concerns that are of highest relevance to them, especially if the content is written in language that is easy to read [26–28]. *Option Grid* decision aids are written at a reading age of approximately 12 years old. To ensure the information provided in the *Option Grid* decision aids is current and accurate, a rigorous process of search, appraisal, and summarization is used, based on the very best studies and checked by clinical experts. The search system checks the research evidence daily, and the *Option Grid* decision aids are updated immediately, if there is new relevant data.

When *Option Grid* decision aids are used, it helps to explain the tabular layout to patients so that they understand how the information is displayed. Figure 3 shows part of an *Option Grid* decision aid for spinal stenosis. Studies have shown that these tools help patients gain knowledge quickly, compare alternatives, ask relevant questions, and make efficient use of time in clinical encounters [26–28].

Spinal Stenosis: Treatment Options

EBSCO Health | option grid 

- Spinal stenosis is a narrowing of the space where nerves are in your back. It can cause back and leg pain or numbness and tingling in the legs. It might limit what you can do. This decision aid is not for people with back or leg pain from other causes. For PDF suitable for printing, [click here](#).

| | Treatment Without Surgery | Shots in Your Back (Epidural Injections) | Surgery |
|-----------------------|-----------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------|
| What does it involve? | Options include exercise, physical therapy, support brace, and pain relievers. | A steroid shot is injected into your back to try to reduce swelling. This may take about an hour. Discuss costs. | You will have surgery to reduce pressure on nerves in your back. You may stay in the hospital up to 3 days. Discuss costs. |
| Will it help my pain? | There may be less pain as soon as 2 weeks. Up to 70 out of 100 people (70%) will have less pain for many years. | There may be less pain in 2 weeks or so. Pain will not lessen in the long term compared to not having shots. | Most people have less pain. It is hard to know if this is because of surgery or for other reasons. |

Figure 3: EBSCO Health Option Grid for Spinal Stenosis

SITUATIONS THAT ARE DIFFICULT, EVEN FOR SHARED DECISION MAKING.

Individual preferences are bound to differ, and this is also the case when considering healthcare options. There are also situations where it is difficult to find agreement. Compared to the clear majority of clinical decisions, these kinds of examples are relatively rare, though they often dominate debate about shared decision making. We discuss a few of those situations below

1. *Patients who say, "Tell me what to do. You are the expert."*

As soon as you begin to do shared decision making, you will hear patients say: "You are the expert. I want you to tell me what to do." This can be a genuine request for help and guidance; and in which case, it is best to give advice. Often, however, the patient has not understood why their opinion is important to you or has not understood why their preferences are important, even if you, as the clinician, find yourself making a recommendation. If a clinician has done 'team' talk well and has explained that the informed views of patients are vital to choose the right action and that their treatment goals will help the decision-making process, then it is rare for a patient to withdraw entirely from the decision-making process. Patients worry most about being abandoned to make difficult decisions alone [19]. Clinicians who are skilled at 'team' talk find that it is much less likely that the patients will say, "Tell me what to do." They are more likely to say, "Given what I now understand, I think option A is best for me. Do you agree?"

2. *Disagreement, such as an inappropriate demand for antibiotics.*

There are many clinical situations of this nature [29]. Viral conjunctivitis, an upper respiratory infection, mild otitis media, and many other conditions typically resolve in a few days without the need for antibiotics. Yet, the patient, or maybe the parent of a child, may be adamant that antibiotics are required, and there is refusal to accept advice to the contrary. This is a situation where it is probably impossible for easy agreement to emerge. We must accept that sometimes decisions are going to be 'un-shared' [30]. The practitioner can correctly decline antibiotics, and the patient (or parent) may have to accept such a decision. However, clinicians often negotiate in these kinds of situations and deploy beneficial persuasion, explaining their rationale, and educating the patient about their position to be a responsible prescriber [30]. Sometimes, clinicians compromise and provide antibiotics or a delayed prescription for antibiotics, accepting that, on this occasion, preserving the relationship or reducing overall stress levels will achieve more in the long term than frank disagreement. Whatever the strategy, the chances of achieving a genuinely agreed as well as shared decision are low.

3. *Coercion, such as an inappropriate demand for drugs for addiction.*

Providing support for addiction within a negotiated contract with agreed limits and regular review can easily fit into a shared decision making approach. However, demands that violate such agreements are among the most difficult situations to manage, especially where the possibility of verbal or physical violence exists. There is no chance of a genuinely shared decision under situations of duress or threats of harm.

4. *Conflicting values, such as a refusal to accept vaccination.*

In some healthcare systems, clinicians are rewarded for achieving high rates of vaccination. The incentives arise from a public health imperative to prevent infectious outbreaks, typically to help achieve vaccination rates that

generate herd-immunity. Some individuals do not accept, or do not trust, scientific evidence that vaccination provides more benefit than harm. Some individuals fear conspiracy. Whatever the reason, individuals decline vaccination, either for themselves or their children. In some situations, where the benefit of vaccination is small or uncertain, it is not difficult to respect a decision to decline vaccination. In others, the weight of evidence is strong, which is particularly the case for childhood illnesses such as diphtheria, rubella or mumps – infections that are known to cause significant problems if they spread. These are situations where health professionals often adopt a public health viewpoint and risk feeling conflicted if, at the same time, they wish to be viewed as the patient's advocate. Most clinicians adopt a stance of beneficial persuasion, sharing information with the goal of overcoming resistance. In a shared decision making approach, there would be respect for the values and preferences of individuals on the proviso that there had been an effort to ensure that their views were well-informed and that the professional perspective of benefit outweighing harm was made clear.

5. *Unproven interventions, such as a demand for therapy that is unproven.*

Patients do make requests for treatment or referral where there is very little evidence of effectiveness. These situations test the borders of professional obligation and responsibility. It is often possible to offer to discuss the claims made, draw attention to different information, and, in this way, arrive at an agreement about balance of potential harms and benefits on an unproven intervention. Unrelenting demands for treatments that are not licensed or not considered safe or effective are unlikely to lead to shared decisions.

Conclusion

Patient centered care was first described in the 1970s [31]. It took a few decades before the significance of that concept became clear and attention was focused on decisions and the power relationships around decisions. Patients have views and goals that must be considered when decisions are being made. At a rudimentary level, decisions could be viewed as obtaining consent; but shared decision making goes much further, and the opportunity to inform patients about tradeoffs in medicine, and to seek their views about what is likely to best fit their situation, has untapped potential to improve healthcare.

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