Beyond Informed Consent: The Shared Decision Making Process

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Abstract

Informed consent is more than a signature on a piece of paper. True informed consent involves helping patients make an informed choice through shared decision making. Although shared decision making has been shown to improve adherence and increase satisfaction, it is not widely used. In this article, a 3-step model for engaging in shared decision making is presented. According to this model, there are 2 core physician communication skills involved in facilitating shared decision making: inquiring, or asking about the patient's existing information, values, beliefs, preferences, and understanding; and informing, or providing the patient with information about clinical evidence, options, risks, and benefits, as well as about the clinician's values and beliefs. Example dialogues illustrate use of the model in practice.

For physicians providing a treatment or performing a procedure, it is an ethical and legal obligation to obtain the patient's informed consent [1]. Informed consent is not a signature on a piece of paper. It is a process of communication between a patient and a physician that results in the patient's agreement to undergo a specific medical intervention [1]. From a legal perspective, valid informed consent includes the receipt of information about the nature and purpose of the proposed procedure or treatment; the expected outcome of the proposed procedure and likelihood of achieving that outcome; the reasonable alternatives, including no treatment, to the proposed procedure and the likelihood of achieving a successful outcome; and the inherent material risks of the proposed procedure and the reasonable alternatives thereto, including no treatment [2].

While some describe informed consent as a risk management tool used by professionals to limit their liability, it is also a process to assist patients in choosing a course of action. True informed consent involves helping patients make an informed choice through shared decision making. In this paper, we describe effective communication strategies for implementing a shared decision making model in a busy clinical practice.

The Shared Decision Making Model

In the shared decision making model, the clinician and patient interact as partners in a relationship in which the opinions, information, and values of both parties are introduced and utilized to make a decision [3–7]. The choice of treatment is based on evidence and preference rather than persuasion. The decisions emerging from such a conversation between partners are informed, consistent with personal values, and mutually acted upon [8,9].

Benefits of Shared Decision Making

Empirical evidence about the benefits of shared medical decision making is beginning to accrue [10–12]. Shared decision making has been shown to improve adherence [13,14] and to lead to better health outcomes [15–19]. Informed patients are more likely to be more satisfied and less anxious [20,21]. A more active role in decision making decreases decisional conflict for patients and increases their satisfaction with the decision [22]. Deductively, we believe an informed choice will reduce the risk of a malpractice allegation against the clinician [21]. Despite its benefits, shared decision making is a rare phenomenon in primary, specialty, and surgical care [23–25].

Barriers to Shared Decision Making

Many clinicians think they are already doing a good job educating patients and involving them in decision making. However, clinicians have traditionally underestimated how much information patients want [26–28]. Ziegler and colleagues [29] found that 83% of patients wanted to hear of any serious side effect of medication “no matter how rare.” 73% felt that a clinician is never justified in withholding information about side effects and adverse effects. Yet, in a survey of clinicians asked to rate their own estimates of patients’ desires to share in decision making, the clinicians gave only modest support for readiness of patients to share in decision making [30]. Generally, physicians perceived that patients wanted their clinician to take responsibility for their medical
problems. A number of clinicians report the concern that giving too much information might create undue anxiety in patients. In one study of surgery patients [10], the patient group provided detailed information about surgical risks were not found to be more anxious, and they had the opportunity to make a fully informed choice.

Other barriers to shared decision making include lack of time [30] and physician attitudes. Sainio and colleagues found some clinicians did not even recognize the definition of shared decision making and when they did, they thought shared decision making was impossible [31].

Communication Skills Necessary for Shared Decision Making

To pursue informed choice and engage in shared decision making, the clinician needs effective communication strategies [32,33]. In our model, there are 2 core physician communication skills involved in facilitating shared decision making (Table). The first skill is inquiring, or asking about the patient’s existing information, values, beliefs, and preferences. The second skill, informing, involves closing the information gaps by providing the patient with information about clinical evidence, options, risks, and benefits, as well as about the clinician’s values, beliefs, and preferences.

Inquire—Assess Current Understanding and Desired Level of Involvement

The communication process required for shared decision making begins with respect for the patient. Behaviorally, it calls for an assessment of the patient’s current knowledge, expectations, preferred level of involvement, and preferred format or style for receiving and processing information.

Inquiry begins with an implicit or explicit invitation for involvement of the patient in an active role in the decision making process [33–35].

Dr: Mrs. Smith, I’d like to find out first what you think is going on, then I’ll do an exam, and we’ll see if we can get to the bottom of this together. Is that OK with you?

Pt: Yes, sounds great, because I do have some ideas.

The clinician then provides an opportunity for the patient to express ideas, fears, and expectations around the problem and the treatment [36–40]. The questions listed in the Table can be used to elicit this information. Most patients enter the clinical encounter with some ideas about what is happening to them and what should be done. There is no point in using valuable time to repeat what the patient already knows. Further, learning what the patient thinks also provides an opportunity for the clinician to clarify any misunderstandings.

Dr: Good, then why don’t we begin with you telling me what you think is going on, what are your biggest concerns, and do you have any ideas so far about a treatment plan?

Pt: Yes, well, what I think is that I have the same infection as my husband, and they had a hard time figuring out how to get rid of his. Finally, after 2 weeks they prescribed prednisone and a strong antibiotic for him and things cleared up very quickly but not until after a lot of suffering. I was hoping you could do the same things but not waste time. I cannot afford to be out for a week like he was.

Dr: Sounds like your husband had a rough go of it and it’s important for you that you not miss any work like he did.

Pt: Yes, I just have way too much to do and I’m sure it’s the same thing.

### Table. Clinical Skills Involved In Shared Decision Making

<table>
<thead>
<tr>
<th>Inquire</th>
<th>Inform</th>
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</thead>
<tbody>
<tr>
<td>Provide an explicit or implicit invitation to participate in shared decision making</td>
<td>Clearly inform the patient about the clinical definition of the problem in language and pictures the patient can understand</td>
</tr>
<tr>
<td>Ask:</td>
<td>Present the available options for treatment, including doing nothing, using qualitative language based upon current evidence</td>
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<tr>
<td>What do you think is going on?</td>
<td>Present the pros and cons for each treatment option</td>
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<tr>
<td>What do you think is wrong (ideas about diagnosis)?</td>
<td>Discuss uncertainties that exist for each treatment option</td>
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<tr>
<td>What concerns you the most (fears) about this problem?</td>
<td>Ask permission to present the clinician’s preferences for treatment</td>
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<tr>
<td>How is this problem affecting your ability to function in your day-to-day activities?</td>
<td>Ask: Of the options we’ve discussed, which do you feel would be best for you?</td>
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<tr>
<td>How is this illness affecting your life, family, relationships, work, etc. (context)?</td>
<td>How committed are you to following through with the plan?</td>
</tr>
<tr>
<td>Do you have any expectations regarding treatment?</td>
<td>How involved do you like to be in discussing options and making treatment decisions?</td>
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Dr: Is there anything else you are worried about or concerns about how this is affecting your day-to-day life?
Pt: No, I just want to get rid of it as soon as possible.
Dr: OK, tell me about what your husband had and how your symptoms are similar.

In regard to presenting information, it is important to negotiate both format of information and amount of information desired [34,35].

Dr: Mrs. Jones, we all process information differently. I’m interested in knowing if you have a particular preference. For example, when you are trying to learn something, do you prefer pictures, statistics, time on the internet, or some other method that facilitates your learning? I want to make sure you fully understand what we are facing and what the pros and cons are for each treatment option.
Pt: Well, I’m a very concrete person, so pictures and simple are good for me. I don’t much understand statistics. In fact, they just confuse me more.

A patient who arrives with a list of printouts from various internet sites probably has a high need for information, as compared with the patient who says, “Whatever you think doctor, I don’t need to understand. I’ll do what ever you say.” Each requires different approaches. One cannot assume that if there is high need for information, there will be high desire for involvement in the decision-making process. Again, it is important to explore and learn how involved a patient wants to be.

Dr: It seems like you have done quite a bit of research here. Do you have a specific idea about how you want to proceed or would you like to hear my thoughts about the options and come to a conclusion together?

Once the clinician has a good grasp of what the patient believes, how much information the patient wants, and how that patient wants to receive information, she or he may then move on to the next step and provide the information to close the gaps and facilitate shared decision making.

Inform—Provide Information
We believe a position of equipoise is essential in the delivery of health care information and achieving true shared decision making. Equipoise is defined by Elwyn and colleagues [34] as “stating a position of equal balance.” In the context of consultation, equipoise occurs when a clinician uses phrases to indicate to the patient that there is more than one management possibility available. The clinician is explicit about the fact that there is no fixed professional view and that it is legitimate to discuss choices in more detail because each has clear pros and cons [34].

Dr: The exercise electrocardiogram shows that some of your heart muscle doesn’t get enough blood when you exercise. This would explain your shortness of breath. Because of the size and location of the problem, it could involve more than one coronary artery, but it is unlikely to be severe or critical at this time. I want to emphasize that there is no permanent damage to the heart at this time.
Pt: Wow, that all sounds pretty scary.
Dr: Yes, I’m sure it does. What scares you the most?
Pt: Well, everything. I mean, it’s my heart … isn’t this serious?
Dr: It could be, but let’s start with you telling me what you know about coronary artery disease.
Pt: Well, not much. I know it’s not a good thing. What should I know?
Dr: You’re right, it’s not a good thing, but the good news is it is treatable. However, there are a number of ways to approach it in your case and there is no clear evidence that any one way is the best. It depends on what you are comfortable with.
Pt: OK, what are they?
Dr: One option is we could do a procedure called coronary angiography, in which we take x-rays of the arteries around your heart to see how much blockage there is and where. And then if needed we can do a procedure called angioplasty, which uses a tiny balloon to push open the blocked arteries. Another approach is to start you on a medication such as a beta blocker or calcium blocker to improve symptoms and protect the heart. Or we could simply wait and keep an eye on it. You may be able to do a lot through exercise and diet.
Pt: OK, what does that really mean?
Dr: Well, one of the important things we need to do is talk about choosing the best treatment approach for you. I’d like to discuss the options available to you in further detail. Maybe the best place to start is for you to tell me if you have any thoughts about these different choices—having an angiogram now and fixing blockages if they warrant it versus reducing your symptoms and the risk of heart damage with medications, or just waiting and watching.
Pt: Doctor, I’m glad we can talk about it. My friend’s father had an angiogram last year and his kidneys stopped working. He was in the hospital for almost a week. I think about that, and I’m happy to keep taking aspirin and nitros, and just stop trying to keep up with everyone at the gym.
Dr: I can understand that. I think that is very unlikely in your situation but it is a remote risk. Given your health and current situation, I am not at all worried about that. Are you open to hearing about the pros and cons of each option?
Pt: Yeah, sure. Let’s hear it.

Care should be taken when describing risks. How the clinician presents or frames risk information can have significant effects on patient outcomes, such as utilization of tests and procedures [41,42]. Edwards and Elwyn describe different framing techniques and their potential impact. For example, the risk of major osteoporotic fractures is 12% in women who take hormone replacement therapy (HRT) for over 5 years and 15% for those who don’t. This could be framed as a 3% reduction (absolute risk) or that fractures are 20% less common in women who take HRT (relative risk). Other ways to frame this include 3% more people remain free of fractures with HRT (positive framing) and 3% more people suffer fractures if not taking HRT (negative framing). In this example, relative risk reduction is the most likely format to persuade patients to agree to a specific treatment. Persuasion is increased when emphasis is placed on the positive aspects of a course of action [43,44]. In general, however, it has been found that patients have a greater understanding of risks when they are stated in qualitative terms (high, medium, low) rather than as rates and proportions [45].

Dr: One alternative is to have the angiogram. The risks of problems occurring during the procedure are low—less than 1%. And if we see an important blockage we can often open it right then and there, with only a slight increase in risk from the procedure. We talked about the risk before and I know you’ve done some reading. Would it be helpful to go over them again?
Pt: No, that’s fine. OK, what else?
Dr: Well, on the other hand, your test results could easily mean that we caught this pretty early, too early to expect to find such a blockage. So the alternative is to start a medicine to reduce your symptoms and improve blood flow to your heart and stay vigilant for any evidence of worsening disease.
Pt: What about side effects of medicines? I saw some information about beta blocker drugs. It looks like they have lots of side effects, like fatigue, that I wouldn’t want. And it said they can increase your cholesterol.
Dr: You’re right. Most medicines have some side effects. But we can work to find the right medicine at the right dose for you. On the other hand, if you have an important blockage, we could take care of it now before it causes permanent damage to your heart. It’s hard to know how to balance these choices and to predict what will happen with your heart disease. If you want, you can take some time to discuss this with your family before we make the final decision.

The patient often wants and deserves to hear your opinion after the facts have been presented. We suggest clinicians ask the patient’s permission before stating an opinion and preferences.

Dr: Would you like to hear what I’d do if I were in your shoes?
Pt: Sure, what’s your suggestion?
Dr: This is a tough call. Personally I lean more toward starting another medicine and having you continue whatever level of exercise you want. The test results and the tempo of your symptoms make me think that you have coronary disease but not severe enough at this point to find and fix a blockage. That’s not to say you won’t need it in the future, if your symptoms or tests worsen. If that happens, we might make a different decision. Ultimately, it’s your choice and we can go whichever way you feel comfortable with. Some people are not comfortable waiting, they want definitive answers about the problems and a fix if possible. And others are happy not to have additional invasive procedures that may not be absolutely necessary.
Pt: Thank you, Doctor. I have to say, this is tough. Thanks for your ideas, though. Let me talk with my husband and I’ll call you soon for another appointment.
Dr: That sounds good. If you’d like for me to talk with you further or with you and your husband to discuss the options, please let me know.

A lot of information is lost by patients during consultations due to lack of understanding or forgetfulness [46]. For example, even if patients can recall the percentage of risk, they may not actually understand what the risk is. For example, what does “heart attack” mean to a patient [47]? By asking the patient to provide his or her understanding and conclusions, communication gaps can be explored and eliminated.

Dr: Before you go, I’d like to make sure you are clear about the 3 options. Can you tell me what you plan to tell your husband?
Pt: Sure. There are 3 options…

Decision aids and patient information pamphlets can supplement the information delivered by the clinician. Decision aids are interventions designed to help patients make choices for treatment on the basis of their personal values and preferences for different outcomes. One critique of
decision aids is that the patient and clinician may not actually have the opportunity to review the information together in a true exchange [5]. Some decision aids require equipment such as computers and videos that may not be easily accessible in a small private practice. Pamphlets may fail to give a balanced view and omit information about choices, risks, and effect of no treatment [48]. Literacy is also an issue that needs to be considered when using decision aids and written material.

Inquire—Assess Understanding, Reactions to Information, and Choice

Once information is delivered to the patient, it is important to provide for an opportunity to enter into a decision-making process. It is necessary to ask what the patient thinks is best for him or her or what he or she can live with. The final step is to review arrangements and commitment to the plan [49].

Dr: Well, I see you have done quite a bit of investigation on the different options we discussed. Are there any other questions you have or can I help explain some of what you have found?
Pt: Yes, you are right, I've looked at everything I could get my hands on. I think I understand everything fairly well. And I weighed all the pros and cons and have come up with a decision.
Dr: Sounds like this has been difficult and you feel like you know what you are getting into now.
Pt: Yes. There is so much to consider. Anyway, I think I'd like to go with the medication but monitor it for side effects that I am worried about.
Dr: So, you have done your homework and now you think you want to try medication and monitoring, especially to make sure there are no unwanted side effects. What side effects are you most concerned about?
Pt: Well, being tired and increasing my cholesterol and then having to take another medication for that and having side effects from it.
Dr: So, if we are able to find a medication that is helpful in protecting your heart but does not have either of the side effects you mentioned, how confident are you that you can take a pill every day?
Pt: I'm not wild about it but it beats the alternative, so I'd say 9 on a scale of 1 to 10.
Dr: Great, so you are pretty confident you can do this. One more question if I may?
Pt: Sure.
Dr: Using that same scale of 1 to 10, how convinced are you that you need to take this pill every day?
Pt: Again, I’m not wild about it but I’m convinced it’s the best alternative I have right now given the problems I’m having with shortness of breath and concerns of doing any heart damage if I do nothing.
Dr: Sounds like we have a plan then. Let’s talk about the different medicines.

Summary

Without choice, true consent is impossible. Thus, clinicians must move their thinking beyond the construct of consent in its narrow frame and adopt a flexibility of response that addresses the patient as a unique individual. Frequently, this will lead to a collaborative discussion in which the focus is on a decision to be made and the responsibility for that decision is shared. Barriers to this discussion exist but are not insurmountable. The rewards for clinician and patient are significant. As Bogardus et al [50] state,

Fundamentally, the dialogue necessary to achieve truly informed consent is more rewarding than time consuming. It improves trust between doctor and patient, it makes both feel more secure and, should complications arise, communication is already properly established and can be maintained [50].

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References

SHARED DECISION MAKING


