

BroadcastMed | Making Decisions with not for patients

SELMA Greetings. I'm Doctor Selma Mohammed, Advanced Cardiology Fellow at Mayo Clinic. During today's trending
MOHAMMED: talks video we'll be discussing shared decision-making. I'm joined by my colleague, Dr. Victor Montori, Professor of Medicine and Director, Knowledge and Evaluation Research Unit at Mayo Clinic. Victor specializes in how knowledge is produced, disseminated, and taken up in practice, and how this leads to optimal health care delivery of patient outcomes. Welcome, Victor.

VICTOR Thank you very much, Selma.
MONTORI:

SELMA We'll start with the definition of shared decision-making. What's shared decision-making? Why do we care as
MOHAMMED: providers, patient, and the society at large?

VICTOR Yeah, well shared decision-making is an approach to care by which patients are helped to recognize that there
MONTORI: may be more than one reasonable way of proceeding, of going forward, with treatment or tests, and how to choose between those reasonable approaches.

And it would depend-- which one is the best for this patient-- it would depend on the situation of the patient and what they value. And clinicians-- we can't be experts on everyone's situation and everyone's values. But the patient is the expert on their situation and values. And the clinician can be the expert about the nature of those options-- the nature of those strategies and approaches, what are the pros and cons, the relative merits.

So we have two experts coming together, and having a conversation, and deliberating together about what is the best course of action, eventually coming to a consensus about how to proceed. That describes shared decision-making.

And why should we care about it? Because we don't want to make a mistake. And the mistake we will make here is to give people tests and treatments that they wouldn't choose if they had our expertise, given their situation, given their values. It helps us prevent that error. It's the right thing to do. It's the ethically correct thing to do. Because at the end of the day, patients will live with the consequences of these choices. And it will be difficult to then impose those consequences to them without their input.

SELMA So it is critical for patients because we empower them. But what about the society?
MOHAMMED:

VICTOR Yeah, well the value for society of having patients have a voice about what treatments they want, is similar to the
MONTORI: value of society that society gets at large when people are involved in decision-making. So the large scale version of shared decision-making would be democracy.

And so deliberative democracy, where people are activated to choose the best course of action for their communities at the level of the individual patient, takes the form of shared decision-making.

SELMA And are we not doing it right now? Are we not doing shared decision-making?
MOHAMMED:

VICTOR
MONTORI: We have thousands of video recordings at Mayo Clinic and elsewhere, of patients and clinicians having discussions about treatments. And we have ways of using checklists to determine the extent to which patients and clinicians are engaged in shared decision-making. And I have to say that it is a very rare situation where we see shared decision-making in full representation. Patients and clinicians are trying sometimes to engage each other in making decisions together, but they lack the tools, and the skills, and the opportunities to do it properly.

SELMA
MOHAMMED: It is a new science to us, and it isn't really taught in medical school.

VICTOR
MONTORI: No, even when there are courses about how to communicate better with patients, a lot of effort is set up in setting the agenda ahead of time and then providing explanation and education. But there is very little education about how might we engage patients as a partner in making decisions together, and also in learning to what extent should we engage patients for this decision of this circumstance. Not everyone will be interested in a full participation. And the clinician has to be very empathic with the patient to figure out what is the maximum level of participation that is appropriate and desirable for this decision at this time.

SELMA
MOHAMMED: It's actually one of the questions that I was about to ask you, is do we know how much participation in decision-making patients want? And how can we tell or get an idea on how much they want?

VICTOR
MONTORI: There are surveys that are around-- they've been done for a number of years now-- that tell that patients want a lot of information-- that 99%, 98% of patients will want information about the options. But a much smaller proportion want to be involved in decision-making.

The problem with those services, as we discussed just now, is that most patients have not had an experience of shared decision-making. So you're almost like asking people about pistachio ice cream, would you like more of it? And you've never had it. You have no idea what you're talking about. The same actually applies to clinicians.

So surveys now are beginning to appear where patients have been given an opportunity to, for instance, watch a video of shared decision-making and then say, have you had that? And the proportion of people reporting that they've had it is low, maybe like 20% or so. Would you like it? The proportion goes way up.

In our studies after we've exposed people to shared decision-making experiences, we asked them, would you like shared decision-making? And the proportion that are saying yes exceeds 70% to 90%, depending on the decision that we've facilitated.

And the same have actually happened for clinicians. 70% to 90% of clinicians endorse the idea of having more decisions, like the one I just had, which happened to be a shared decision-making exercise for future patients.

SELMA
MOHAMMED: It's amazing. So both sides are really looking into it and want to learn more about it, and maybe--

VICTOR
MONTORI: If they have tools designed for them to do it efficiently and effectively in practice, which is a development that only has appeared recently.

SELMA
MOHAMMED: Absolutely. So then which patient should we offer it to? Is it appropriate for all patients and under all circumstances?

VICTOR I think the biggest mistake we can make is to assume that someone who has difficulty speaking the language, or
MONTORI: is of low socioeconomic status, or has had limited education-- these people will probably not be appropriate for shared decision-making. I think that would be a mistake.

In Hennepin County, north of us in inner city Minneapolis, homeless patients have been given the opportunity to participate in shared decision-making, for instance, about choosing their diabetes medication. And they've been able to effectively participate.

In a meta-analysis of ten years of work that we've done here at Mayo Clinic, we've noticed that patients that come in with low socioeconomic status benefit the most from their exposure to shared decision-making tools. So there is an opportunity to, instead of introduce disparities in care by offering shared decision-making to only those who we think are going to be able to partner, is to advance the notion of equity in health care by actually using these tools as an equalizer of the opportunities for engagement that patients with different socioeconomic status bring to the table.

SELMA So we really shouldn't limit it. It should be [INAUDIBLE] applicable.

MOHAMMED:

VICTOR Yeah, at least not from a-- not using socioeconomic, for instance, for that. But what about illness? So if
MONTORI: somebody is very sick, or very emotionally distraught, it would be abusive for the clinician to say, you need to make this decision. I just present you the evidence, you decide. That's not caring. So we actually do not offer or do not advocate for shared decision-making, what we advocate is for empathic decision-making. The clinician constantly reading the patient and deciding with the patient how much or how little involvement is right for this patient right now.

And of course, many patients bring family with them that make decisions. So that skill needs to be expanded, not only for including the patient, but also appropriately including other family members-- a big challenge.

SELMA It is. And it's more than science. It looks like it's science and art, and it just really requires a lot of experience and
MOHAMMED: expertise.

VICTOR Yes, and it all starts by caring enough to engage the patient in the decision-making. Many people argue that we
MONTORI: don't have time for this in the consultation. I'd rather just tell people what I think is best for them, and then they can decide whether they want it or not. Well, that's not very caring. This might be efficient, but it does not reflect the best that we can offer.

SELMA If it was more practice we'll be able to integrate it in our limited time for patient encounter?

MOHAMMED:

VICTOR Yeah we've tested this-- again, over a decade of work. And most of our tools which are designed for the context
MONTORI: in which they're going to be used-- most of our tools take around two to three more minutes, or add two to three more minutes to the consultation as is.

So they are efficient. They can be used. But they're not something you can just give to the patient and have the patient decide on their own. This is something that requires our investment of those two or three minutes of being present in the consultation and engaging the patient in doing that.

But the tools that we've designed are efficient and can be used. And we've used them in the emergency room-- that's a pretty fast paced environment-- and in primary care, and specialty care, and in the hospital. So we've been able-- but they're not the same. Each one is designed for the context in which it will be used, by the professionals that they will be used.

SELMA So it's time worth spending--

MOHAMMED:

VICTOR Yes.

MONTORI:

SELMA --of high value to get into it during our clinical encounters. Do you think a blank shared decision-making would
MOHAMMED: make clinicians less likely to adhere to the guidelines?

VICTOR One of the things that we've discovered with these tools is that clinicians are able to perceive, very effectively,
MONTORI: that maybe adhering to the guidelines may not be the right thing to do for this patient, because of the patient's situation, because of what the patient values at this point in time.

So the tools almost always will make the clinician more patient-centered. The question is what happens when patient-centeredness is in contradiction with being adherent to the guidelines. And those are issues that need to be resolved.

We are working with guideline development teams for them to begin to appreciate those issues and recognize that where it may have been a class one indication for anything, there are some patients for which this is not a class one indication. This is one situation in which patients might want to be involved in shared decision-making. And that should be the class one indication in that particular case. In other words, a strong recommendation should be for shared decision-making in that particular case.

And we've seen this all the way from staffing use to, for instance, atrial fibrillation, anticoagulation treatment, to whether a stent is appropriate for the management of my stable angina.

SELMA Actually, some of our recent guidelines are emphasizing team approach to decision-making. Or perhaps an
MOHAMMED: integral part of this team should be the patient, and that would be shared decision-making.

VICTOR Yeah, the guidelines are beginning to talk like that. And they're also beginning to specifically ask for shared
MONTORI: decision-making. But what is, unfortunately, lacking in those guidelines is the support that is necessary for patients and clinicians to actually do it. So it is assumed I think, still today, that if you say shared decision-making, it will be a conversation that any clinician can do. And what we're seeing is that it's actually quite hard to convey the evidence to the patient in a way that will not overwhelm the patient and will invite the patient to participate.

SELMA Fascinating. And what tools are available today for shared decision-making. Can you maybe elaborate on this?
MOHAMMED:

VICTOR There are probably more than 500 different tools out there to support decision-making across all relevant
MONTORI: decisions that are common in practice. However, the majority of those tools have not been tested in the clinical encounter to help those conversations.

The majority of those tools are, in fact, patient education materials that are given to the patient with the assumption that if the patient were to be in the know, they'll come to the consultation more prepared to have a discussion. Turns out that that doesn't work.

The consultations are still scary places and patients can read everything, but when they come to the consultation their minds will be blank. So it's better to support the conversation as it happens during the visit.

In terms of tools for the visit, there are actually quite few. And many of them are, in fact, beginning to appear in cardiology for cardiovascular medicine. And the kinds of tools are in general, two categories. One are tools that help us understand what are the issues that matter to you, and then decide which interventions are more consistent with those interests.

And there are tools that are communicating risk and deciding with the patient how we might reduce those risks. Let me show you the tool that we've developed for, for instance, deciding whether a statin is right for you. And in this particular tool, we can see here that it is for a 67-year-old man with no cardiovascular risk factors, relatively benign lipid profile and blood pressure risk.

And the way we would use it is we will say, Mr. Jones, you're in a room with 100 people like you. As you can see, if we close a door for 10 years, and we open it 10 years later, and we count we will see 78 people here in green, that during the ten year mark would not have had any coronary events, or cerebrovascular events-- any cardiovascular events.

And you'll see here there will be 22 here in orange, that during that 10 year period would have experienced a cardiovascular event. Now, this is very important. We'll say Mr. Jones, we do not know if you're one of the green ones or one of the orange ones.

If we were to give a statin to 100 of you, what we will see-- and close the door, and open the door 10 years later, and count-- we will see that 78 people that were not destined to have a cardiovascular event would have taken a statin. They would have had their cholesterol go down and all that-- but they would not benefit, because they were not destined to have an event that would be preventable by statins.

And of the 22 folks that were at risk of-- or they were destined to have a cardiovascular event-- five, here in light blue. These five would avoid their destiny by taking a statin regularly. And then there'll be 17 here in orange that will still get their cardiovascular event, despite taking statins.

Now, as you can imagine, many clinicians will look at this and say, well, there must be something wrong. Statins are much more effective than this, when in fact, this is the 25% risk reduction that is seen across the board for cardiovascular events with regular dose-- primary prevention doses-- of statins. And we will tell Mr. Jones, we do not know if you're one of the green ones, one of the light blue ones, or one of the orange ones.

And so, this is actually-- now we have 10 years of experience with this tool, and now its use is picking up because the guidelines finally became risk guidelines, rather than LDL target guidelines. This tool is being used at a rate of about 10,000 users a month from all over the world-- most of it the United States.

And we have video recording and clinical trial data that shows that these tools help clinicians and patients have discussions. Patients can participate in discussion about this, which they cannot if you tell them-- Mr. Jones, your LDL cholesterol is 101 milligrams per deciliter, and according to the guidelines you should be 100 milligrams per deciliter. We're going to start medicine and check in three months whether your cholesterol is lower than 101 milligrams per deciliter, or less than 100 if that's your target.

Well, the patient can only say, whatever you say, Doc. And then we'll come back and see what the cholesterol level is. And if it's lower, they're going to say, I'm benefitting from statins, which of course, as we have seen from the decision aid, is actually not the case for the majority of people that take it for prevention.

So we add transparency, we add clarity, we calibrate risk information for the patient, and I think we calibrate also risk information for the clinician. And as a result, people are making now informed choices. And the dogmatism-- you must take a statin, your cholesterol must be this-- has been eliminated, and patients can participate in choice.

SELMA Fascinating. I think it's taking the discussion to a whole different level about patient preferences, values, and
MOHAMMED: goals, and involving them in their own decisions.

VICTOR Um-hmm. And the hope is that they will improve adherence and improve outcomes. And unfortunately, we are
MONTORI: yet to demonstrate that that is true. But more studies are being done at the moment about that.

SELMA Absolutely. Thanks, Victor, for these very important insights. And thanks to our viewers here on theheart.org. at
MOHAMMED: Medscape Cardiology.