Building patient trust to support medication adherence

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Medication adherence is a growing concern for physicians and health care systems. There is increasing evidence of noncompliance among patients and correlated adverse outcomes that follow.

In an episode of the “AMA Moving Medicine” podcast, AMA Chief Experience Officer Todd Unger is joined by Marie T. Brown, MD, a geriatric and internal medicine specialist at Rush University Medical Center, in Chicago, to talk about creating connections with patients to support medication adherence.

Below is a lightly edited full transcript of their conversation. You can tune in on Apple Podcasts, Google Play or Spotify.

Unger: Thank you so much for being with us today.

Dr. Brown: Thanks, Todd. It's really fun to be here.

Unger: What is medication adherence and why is it so important to assess?

Dr. Brown: Great question. As a practicing internist here in Chicago, I face talking to my patients about whether they're taking their medicine every single day. We know that, if the patients don't take their medicine, they're never going to get their blood pressure, their diabetes, their depression, so many chronic conditions under control, and medication adherence is, by definition, taking at least 80% of your medicine. So, we're not talking about perfection. A person can miss once a week, even five days out of 30, and we still consider them adherent.

Some people call it compliance, some people call it adherence, persistence, but what we're really talking about is the individual patient taking behavior, and it's going to vary for many patients.

The World Health Organization stated that improving medication adherence would have a greater impact on the health of the population than any new treatments or inventions that we have. Because we have good treatment, but we know that our patients aren't taking their medicine.

Unger: What should a physician do if a patient's condition isn't under control?

Dr. Brown: Well, the first thing that a physician should do when you see that the A1C isn't under control or the blood pressure isn't under control, is have a heart-to-heart with the patient, and really try to understand if they're taking their medicine. That is easier said than done, and I found that the challenge was that we physicians don't ask in a way that uncovers the true medication-taking behavior of the patient in front of us.

In fact, our patients really have been encouraged to hide their non-adherence from us, which was a big surprise to me, and only after I began becoming interested in this topic and read about it, did I understand why patients weren't taking their medicine.

Unger: You're saying that patients are hiding it. Why are they doing that?

Dr. Brown: Well, much to my surprise, patients often conceal what they're doing. They're not taking their medicine, but for a variety of reasons they're afraid to tell me that they're not taking their medicine. And once I tried to understand why that would be, I realized that I was part of the problem.

About 10 years ago, when I went on this journey, and read about it, I recognized that my experience in my day-to-day life was so different from my patients'. I would wake up in the morning, take my children to school, I would stop at the hospital, and I would see maybe three or four patients who had a preventable condition, had they been taking their medicine for the past 10 years.

So, it might've been somebody who had a stroke, might be family that I'm going to meet with, that I'm going to say, "We're going to have to amputate a toe." We might have to have a conversation about starting dialysis on somebody who wasn't taking their diabetes or their blood pressure medicine for the past 10 or 15 years, and it was very frustrating because I knew, had they been compliant, had they been adherent to their medicine, they wouldn't be losing their toe. They wouldn't have had a stroke. They wouldn't have had a heart attack.

And then I would leave the hospital, and I would go to my office, and I would see somebody that looked like them 10 or 15 years earlier, and I would see that their blood pressure was 200/120 or their A1C was 10 or 11. And I would say, "Are you taking your medicine?" and they would maybe say yes. But I'd say, "Well, did you take it this week or did you run out?"—and we'll talk about how you can uncover the real medication-taking behavior.

But if they told me that they weren't taking their medicine, I would chastise them. I would say, "What do you mean you're not taking your medicine?" and they would feel admonished. They would feel that I was yelling at them, which I was, and what they were learning is that the next time I asked, they would give me the answer that I insisted they give me. So, I was part of the problem. Because of their social desirability, patients want to say yes when the doctor that they've known for a long time, or even a new doctor, asks them if they're taking their medicine.

So, it may take me with a new patient, if I suspect non-adherence, it may take me two or three visits to develop a relationship and enough trust for that patient to really share what they're doing. And in the long-run, it saves a tremendous amount of time.

Unger: But isn’t it the responsibility of the patient to take their meds? How do you navigate that?

Dr. Brown: That's a really good question, and early in my career, I felt the same way. That, I went through all these, minimum 11, years of training, I learned what I should prescribe for you, I prescribe it for you, and haven't I discharged my duty? And isn't it then up to you?

And when I talk to people in training, physicians in training, and young physicians, they often feel the same way, because they have worked hard and they're doing their job, and isn't it then the patient's responsibility to do their part? And that was a real eye-opening experience for me, when I began to ask the patients why they weren't taking their medicine. I was very surprised at the answers they gave me, once I was open to listening to why they weren't taking their medicine.

Unger: You mentioned that, sometimes, it may take two or three appointments to get that trust built up. But how do you incorporate this into your workflow?

Dr. Brown: Well, the first thing that I needed to do was change the culture of the physicians in my practice, the nurses and the medical assistants. Because if one person on the team understands why a patient has a reasonable reason for not taking their medicine and respects that reason and then can tailor the message, but not everybody on the team understands it, then the patient will get mixed signals.

For instance, if the medical assistant, who rooms the patient, uncovers that the patient's not taking their medicine and then puts in the chief complaint, "Blood pressure, 180/120, patient not taking their medicine," if that's followed by the doctor walking in and saying what I used to say, "What do you mean you're not taking your medicine?" what that patient has learned is not to tell the medical assistant what they're doing. And again, that cycle gets repeated.

So, I found that the first step is to educate us, educate the physicians, educate the whole team so that we're all on the same page. Until we develop a completely blame-free environment, we're never going

to provide a safe space for the patient to tell us that they're not taking their medicine.

Unger: How do you ask patients about their medication adherence?

Dr. Brown: So now, we assume the patient is not taking their medicine, if their blood pressure, A1C, whatever we're monitoring, is not under control. We will ask in a nonjudgmental way. So, we might ask questions like, "It's difficult to take all these medicines. Do you have a hard time occasionally?" Or we might say, "Not everybody takes their medicine every single day. How about you?" Or, "We have lots of patients that stop taking their medicine when they don't feel that they need it anymore, or don't feel any different when they take their medicine or they don't take their medicine. How about you?"

So, it's very important to permit the patient to tell us what they're actually doing, and then once they say, "Well, you're right, I haven't been taking my medicine for about a month, or longer," then it's very important to respond positively and thank them for telling you what they're really doing, because without that knowledge, we physicians could actually make a mistake. We would assume that they were taking their medicine. It was not under control, and we would reach for the second or third or fourth-tier drug, which would be incorrect, because they weren't taking all of their first-line drug—and their first-line drug, of course, is probably the best drug and the least expensive drug.

Unger: When it comes to questions about adherence, how can medical assistants and nurses help you in bringing about this change?

Dr. Brown: In our office, we print out a list of the patient's medications on a very simple piece of paper, with a cover sheet that says, "Circle the medicines you need refills for. Cross out the medicines you're not taking. Put a question mark next to the ones you don't think you need anymore." And that alerts the medical assistant and the physician or the nurse to look at that question, because if they don't think they need it anymore, that is a sign that, perhaps, they're not taking it. And especially with hypertension … it is called the silent killer because they don't feel any different whether they take their medicine or not. So, that is done in the reception area, while the patient's waiting to be roomed, so that doesn't add any time to the visit.

Once the medical assistant brings the patient back to the exam room, we have all of our patients bring in all of their medicine each visit, including the medicines that they're not taking or the medicines they don't think they need anymore, and that's called a brown bag review. The MA will go through each of the medicines, and that's another opportunity to say, "Are you taking each of these once a day or twice a day?"

That can be time consuming early on, when you're uncovering non-adherence, but once you build the relationship with the patient and adherence is improved across your panel of patients, it's less time-consuming. The important thing is to make sure the patient feels comfortable sharing their true

medication-taking behavior and that they will not be chastised for not taking their medicine.

Unger: Once you identify that a patient isn't taking their meds, what's next?

Dr. Brown: At that point, you can begin to understand or tailor your message, and find out why they're not taking their medicine. And if I have 10 patients who are non-adherent, I have 10 different reasons why the patient's not taking their medicine.

On the AMA STEPS Forward™ website, there's a module on medication adherence that includes a video of real patients. Most of them are my patients, who were kind enough to come into my office and share why they weren't taking their medicine, and you'll see that it took me, perhaps, years before I developed a trusting enough relationship with the patient that, one, they told me what they were really doing, and then maybe another year to encourage them in a variety of ways to begin to take their medicine.

That is a brief video of real patients telling their stories that many people have used as a lunch and learn, so that you can watch it. It's open-access. You can watch it over lunch. It takes about 10 minutes, and most people who view it recognize many of their patients there.

Some of the reasons that patients give are, one, the cost—they couldn't afford it. And that's embarrassing. So, a patient would say, "I was embarrassed to tell you that I couldn't afford my medicine." Another person might say that they heard that there were side effects that they didn't want. One gentleman says, "I heard you could lose your hair," and, in fact, there are medicines that we give for hypertension that can cause reversible hair loss.

So, every single patient has a completely different reason. One surprise was the amount of mistrust many of my patients had in the medicines. If you understand their perspective, they may be listening to daytime television, and a medication advertisement might come on that lists the benefits, but then always lists a very long list of potential side effects, sometimes including death. It's very scary for a patient to take a medicine when the potential side effects are highlighted more than the potential benefit.

Patients are also concerned that they may become dependent on a drug, and, in many communities, they may have lost a loved one, a brother, a child, an aunt, uncle, to a drug problem, and they are confused. Isn't all drug dependence bad? So, it's very hard for them to understand why they have to take this medicine lifelong.

Some patients are on a limited budget, and they might recognize that somebody in the family needs something more than they do, and they're actually being altruistic. If they're on a limited budget and their grandson needs a backpack for school, they are sacrificing for their family. Isn't that a wonderful, altruistic thing to do? And that may be part of their culture. So, making sure that we understand why a

patient is choosing not to take their medicine, or doesn't have their medicine, is absolutely imperative in order to tailor the message.

Unger: So how do you help get them back on track towards adherence?

Dr. Brown: Making sure the patient understands why the medicine is important is paramount, and patient education can be delivered in a variety of ways. Understanding that, perhaps, a patient finds it difficult to take medicines twice a day, or three or four times a day, is very important as well, because we can look at the regimen, maybe change the medicine so that they can take all of their medicine once. And there's tremendous opportunity to simplify the regimen.

Sometimes, for patients who are a little confused or overwhelmed by the number of medicines, we encourage them to use pill boxes or go to the pharmacist and ask them to help them load their medicines. If a patient has trouble paying for their medicine, we will help the patient find a way to use a website or pharmacy plans to allow them to obtain the medicine that's within their budget.

We can also look at generics. Eighty percent of medicines in the United States that are prescribed now are generic, and we physicians should be attentive to what their out-of-pocket cost is, and if we can switch to generic, we should. Also, prescribing, which we'll talk about in another podcast, simplifying the regimen so that they only refill it once every 90 days, rather than going to the pharmacy three times a month, which may mean time off from work for them, their family, or even the cost of a bus ride to the pharmacy.

So cost, access, making sure we understand the importance of the medicine, often using forgiving drugs, is helpful. If a patient has trouble remembering to take their medicine or doesn't want to take it every day, there are medicines that can be given once a week, and even some less frequently than that, and we call those forgiving drugs.

If a patient is very distrustful of the system, that may take a longer conversation to understand why they're distrustful. We do live in an era where patients do remember what happened with the Tuskegee Experiment, and it is important for physicians and all health care providers to be familiar with that study, to understand the perspective of the patient.

Many patients often have mental illness as a reason for their non-adherence, so before trying to encourage a patient to take medicines for other conditions, we need to get the depression under control, and then once the depression is under control, the patient may be open to and able to discuss the importance of other medicines, like their diabetes medicine or their hypertension medicine.

Unger: How do you set patients up for success?

Dr. Brown: We want to be patient-centered. The patient has to take their medicine every day. We may only see them once every two or three months.

So, if the patient says they don't want to take their statin drug every single day, we'll say, "Well, how often do you think you could take it?" And if the patient says, "Well, maybe I'll take it three times a week," I'm not going to say, "That's not enough." I'm going to say, "Great, start with three times a week." And when I have done that, usually patients recognize that nothing untoward happened when they took it three times a week, and slowly I'll get them to take it on a daily basis.

So, it's very important to build that trust and reward them and tell them that what they've done is very helpful, and, "Wow, your blood pressure was 210 last month, and now it's 190, and maybe next month it'll be 180." So, helping the patient understand what the journey is, that we may take six months to get the blood pressure under control. It may take six months to get their sugar under control. But often we don't tell patients what the journey looks like and where the end point is. Many of our patients don't know what the goal blood pressure is or what the goal A1C is.

We physicians also don't tell our patients often enough that, when we start a lifelong medicine, that they will have to take it for the rest of their life. In fact, the majority of physicians, when we start a lifelong medicine, do not tell patients—and I was one of them. When I started somebody on a blood pressure medicine, I did not routinely tell patients that they would take this for the rest of their life.

When we surveyed doctors about why they didn't say that, it was very interesting, because doctors are human too, and emotional. So, many doctors said that they didn't want to deliver bad news, they were afraid that it would prolong the visit and they were optimistic that, maybe, if the patient followed weight loss and other lifestyle changes, they would be able to get off their medicine.

However, it's very confusing for a patient, when they receive a medicine that says "take one every day for the next 90 days," why wouldn't a patient stop it at the end of 90 days? So, we have a lot of education we need to do amongst ourselves that I hope I've highlighted, and until I changed my attitude and my understanding of adherence, I was not able to affect change amongst my patients.

Once I did understand and accept that patients had very good reasons, and was more successful at identifying them and then improving their adherence, it brought much more joy to my practice, so that rather than seeing a patient who was non-adherent and thinking, "Oh, dear, this patient's blood pressure is never going to be under control," instead I thought, "This is a challenge. I know better now what might be driving that behavior," and I am much more successful at helping the patient begin to understand the importance of the adherence and get back on track. And that, when you see blood pressures at goal—knowing that you prevented a stroke, knowing that you prevented an amputation down the road, blindness, kidney failure—it brings tremendous joy to my practice.

Where I found that a tremendous amount of time was saved, was, once you uncover non-adherence, rather than spending the time getting pre-authorization for that second-, third- or fourth-line drug, I took that time and spent it with the patient to develop the trusting relationship, uncover the non-adherence, and my team and the frustration in my office went down because the number of pre-authorizations we needed to obtain significantly diminished.

Unger: We've talked a lot about identifying the reasons why patients aren't adherent and the solution seems to be building this trust and this deeper relationship, which is certainly something we want to strive for, but isn't there an easier solution? Don't they just need a reminder?

Dr. Brown: When you look at this problem of adherence, most people think that it is all about the patient forgetting. So, many solutions out there—internet based, app based, pill bottles—are connected to some sort of a reminder. But when you really look at the problem, forgetfulness is only about 30% of the reasons patients don't take their medicines.

So, reminders are helpful for a significant number of patients, but the majority of patients are choosing not to take their medicine for the reasons we've talked about. A Cochrane review recently looked at studies, and over 150 studies, no one answer was successful to improve adherence. So, the Cochrane review showed that text-based and internet-based solutions have not consistently been shown to increase adherence. So, developing a relationship with a trusted clinician seems to be key.

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