Trust Me, I'm a Patient! Mutual Respect in the Treatment of Medical Mistrust

By John Lewis, MD, MS; Kristen M. Bascombe, MD; and Kimberly Herard, MD

Case One

Mr. J is a 75-year-old male with past medical history of hypertension, coronary artery disease (CAD), first-degree atrioventricular block (AVB), and pulmonary embolism (PE) who was admitted two weeks ago for new onset third-degree AVB, however left against medical advice (AMA) after declining cardiac pacemaker placement. He presents to the emergency department (ED) one week from discharge after an episode of chest pain and dizziness similar to his last hospital visit. He is now asymptomatic.

Me: If you don't mind me asking sir, why did you decline getting a pacemaker?

Mr. J: I don't want anything foreign put in my body.

Me: Tell me what you understand regarding the reason the doctors wanted to place a pacemaker.

Mr. J: It's something about my heart not functioning right

Me: Yes. You have a third-degree heart block which causes your heart to beat too slowly. It sounds like you've had multiple conversations with the previous doctors about your condition, but do you understand there is a risk you could die suddenly without a pacemaker?

Mr. J: I understand, but I believe that God will heal me, and I will die when he says it's my time. I told them I'm willing to take a pill if there is one for this.

I informed Mr. J that unfortunately there is no medication to fix this. I asked for his permission before explaining the condition further. I drew a simple heart divided into four quadrants, explaining how the top part of the heart signals to the lower part so the heart squeezes and pumps enough blood to keep him alive. I also drew an EKG strip of a normal functioning heart versus his heart. Lastly, I asked if he had been shown what a pacemaker looks like. I googled a picture and explained how the device sits beneath the skin and has leads that connect to the heart, signaling the heart to beat at a normal rhythm.

Mr. J: No one explained this to me the way you did. If I would've understood this before, maybe I would've agreed to the procedure.

Me: It's not too late. You returned to the ED today for symptoms that are due to the same problem. I can admit you to the hospital and have the cardiologist see you.

Mr. J: Oh no. I can't stay in the hospital today because I have an appointment tomorrow for getting housing. I don't trust anyone else with my money. I can come back later this week. I can tell you are a good person and that you care. Will you be here when I come back?

Case Two

Mr. X is a 35-year-old man with a past medical history of hypertension (untreated) who is awaiting admission to the ICU for hypertensive emergency with new heart failure and acute kidney injury. His care is transferred during shift change as pending ICU bed placement if he decides not to sign out against medical advice (AMA). There is an AMA form sitting at his bedside. He is the first patient I see before picking up new patients.

Me: I heard that you were thinking about leaving.

Mr. X: I know that I need to take care of my blood pressure. I'm just anxious, and I know that is making my pressure and heart rate go up even more.

Me: You're right and your being anxious is legitimate, but it is not the cause of your blood pressure being this elevated or the damage being caused to your heart and kidneys.

Mr. X: Tell me what I really need to do, doc. I'm already eating right — no meat. I'm on my phone right now researching natural treatments. I know that I need to start taking blood pressure medications, but what else?

Me: Good job on the diet. Keep it up. In addition to that, you should stay overnight so that we can lower your pressure more rapidly in a controlled fashion and prevent further damage.

Mr. X: How bad is it, seriously? It's not permanent, right? I'm scared because my mother died with fluid in her lungs, and she had high blood pressure and diabetes.

Me: That's why we need to admit you. We want to prevent this from being life threatening and stop or even reverse the damage if we can. That is what your mother would want too. As parents, we want our children to not suffer the same losses that we did, especially if they are preventable. This is preventable. In fact, before I came in tonight, I almost forgot to take my blood pressure medication. I ran in the house to take it. Yes, I have to take medicine for blood pressure too. That's advice from one brother to another.

Mr. X: You take meds too? Alright, I'm going to stay. Do you know how long? Thanks doc (extends arm for a fist bump).

Me: Long enough to put you on the path of health (I give him a "pound," aka fist, bump back). Can I tear this up? (Referring to the AMA form at his bedside.)

Mr. X: Uhh. Yeah, I'm going to stay.

While all experiences are not universal, the human experience is. Broken trust, whether at an interpersonal or institutional level, takes significant time and effort to reconcile. When confronting medical mistrust, the phrase "trust me, I'm a doctor" holds little weight for many and does little to dispel the opposing belief, "I don't trust you BECAUSE you're a doctor", which stems from historical and present-day discrimination in health care.

Social psychologist, Laura Bogart, PhD, defines medical mistrust in part as "an absence of trust that health care providers and organizations genuinely care for patients' interests and are honest." In some cases, your humanness means more than your expertise and credentials. In cliché terms, patients don't care how much you know until they know how much you care.

The first goal is to meet the patient where they are. Ask questions to understand your patient's decision-making process. Seek permission before soliciting or providing information. If you share anything in common (race, gender, culture) meet them there; you will have less distance to traverse and fewer bridges to cross. Respect the uniqueness of each patient's story and beliefs. Provide empathy along with information. Be transparent, sharing your concerns, uncertainties, and the limitations of medical research.

Secondly, in humility, acknowledge that the shared goals between provider and patient is caring for the patient's overall well-being but has been complicated by legitimate fear and historical abuses. These ideas are not without merit and often stem from well-documented misuse and abuse of minorities in science. Physicians must also address how factors such as social and structural determinants of health impact their patient's health and decisions, which requires an investment of time and patience. Mistrust develops over time; we cannot expect it to be dissolved using anything less.

Mistrust in medicine is not an isolated concept. Mistrust exists wherever a power gradient exists. Daily experiences reinforce that certain populations are affected by institutions of power differently. This "everyday racism" that flows into health care can widen the divide between patients and physicians. A true partnership is needed for patients to feel safe from mistreatment. Respect these differences and the conclusions that are drawn from them.

The treatment protocol for medical mistrust must include:

- Time
- Transparency
- Empathy
- Patience
- Humility
- Respect

These six items do not guarantee a 100% first-pass rate, but they do significantly improve success in building a relationship of trust.

Always remember, both of you are provider and patient — the difference is when and for whom. Patients are the most powerful agent and advocates for their health. Share and respect that power. ◗

ABOUT THE AUTHORS

Dr. Lewis is an assistant professor of emergency medicine at Emory University. He serves as the cochair of the American College of Emergency Physicians (ACEP) Social EM Section Education Workgroup. He created and cohosts the podcast, Emergency Medicine Remix (EM Remix).

Dr. Bascombe is a third-year emergency medicine resident at Emory University. She serves as cochair of the SAEM Social EM and Population Health Interest Group. She has an interest in community paramedicine as a means of addressing health disparities and will be completing her EMS fellowship at UCSF.

Dr. Herard is second-year emergency medicine resident at Emory University. She serves as the Emergency Medicine Residents' Association (EMRA) International Committee chair-elect and Emory University Social Committee cochair. Kimberly helps write expert declarations for Physicians for Human Rights.