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Implementation science for the bedside

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Early in the morning, my intern told the patient that his kidneys had quit working, that he was in danger from electrolyte derangements, and that dialysis could save his life. In the 24 hours since his admission to the hospital, several doctors had told him similar things. He listened politely, but his answer was the same: he didn’t want dialysis. “If it’s my time,” he said, “it’s my time.”

For decades, the man had lived a stone’s throw from the hospital. Originally from South America, he’d developed diabetes but never started treatment. High blood glucose levels are said to injure our organs like tiny pieces of glass, making microscopic cuts in blood vessel walls. Now the man was 55, and despite his large, muscular frame, a closer look revealed clear signs of the damage. Knobby bones protruded from the backs of his hands, unearthed by the wasting of muscles. The joints were firm and almost wooden. His internal organs had sustained similar injuries.

When our team rounded later that morning, the intern reported, “Overnight, hyperkalemia to 6.6, EKG normal, will rewrite for Kayexalate. He continues to refuse dialysis.” The normal electrocardiography results meant that immediate death from hyperkalemia was unlikely. Still, we were at an impasse. Even if we could temporarily lower the patient’s potassium level, if we sent him home with a follow-up appointment and he didn’t show up, he might die; yet an indefinite period of inpatient monitoring without dialysis was no solution either. Our only plan was to talk to him again.

We entered his room. I restarted the discussion, but I fared no better. After my soliloquy on the dangers of high potassium, he refused dialysis again. He also ended the conversation, asking me to respect his desire to rest. I resisted momentarily but chose exit over escalation. As we continued rounds, the standard stream of patient refusals stung a bit more than usual. An elderly man with coronary disease refused a transfusion despite having symptomatic anemia, a woman recovering from alcoholic hepatitis refused physical therapy, a young man with severe cellulitis left against medical advice. Every refused recommendation was supported by science, yet patients were unconvinced.

In the afternoon, I scanned current information on hyperkalemia. Its clinical management hadn’t changed in the 10-plus years since my residency. What to do medically was clear, but the next steps were not. Googling “patient refusal,” I found articles about patients’ right to refuse treatment and exhortations to respect patient autonomy. Somehow, none of these hit the mark: we didn’t lack respect for the patient wishes, he clearly didn’t want to die, and yet we were lost, wandering in the thorny terrain between a medical condition and its meaning for the patient’s goals, mental models, and life.

My research uses perspectives from implementation science — an emerging field that draws on such disciplines as psychology, sociology, economics, and marketing to close the widely recognized gap between evidence-based clinical interventions and their use in routine care. Although these perspectives are increasingly discussed in public health, they seem underused but relevant in one-on-one interactions with patients. Coincidentally, earlier that morning, Richard Thaler had won the Nobel Prize in economics for the insight that people are “predictably irrational”: our neurobehavioral decision-making processes are imperfectly aligned with what we think we want. Extending a scientific lens beyond hyperkalemia into the behavioral dynamics that determine use of clinical interventions opened a path forward.

In the team’s afternoon discussion, I skipped the planned talk on antibiotics and presented a quick survey of ideas about implementing evidence-based interventions. We discussed newer concepts such as the Consolidated Framework for Implementation Research, which offers a framework for mapping diverse approaches to understanding the implementation process. We also discussed the older Health Belief Model, which sees behaviors as the result of a person’s perceived susceptibility to a given illness, the perceived severity of that condition, the perceived benefit of a potential therapy, and cues to action. We touched on the concept of “social proof,” which suggests that when faced with uncertainty,
people seek guidance from decisions made by people like them and the consequences of those decisions. Just as five-star reviews on Amazon may convince you that the probable outcome of a purchase is happiness, the decision to use a medical therapy can be influenced by observing others with similar backgrounds and conditions.

That evening, the intern visited the patient. She sat in a chair next to the bed, her urgent tasks completed. The patient told her that his children were in his home country, and he hadn’t seen them for 20 years. His wife also lived there and they were estranged, but he hoped they would reconcile someday. When he’d arrived in the United States, he’d worked in construction, until a beam fell and crushed his leg. He lived in a boarding house with other men from his country. About the dialysis, he said, “My mother, she had diabetes, too. The doctor told her she needed dialysis. She started it, and 2 months later she died.” Eight years ago, doctors had told his sister she should begin dialysis; she’d refused — and was still alive.

By the next morning’s rounds, the intern’s analysis had evolved. “It’s not that he doesn’t think he has renal failure or that it could kill him,” she explained. “He just doesn’t really believe that dialysis will help him. Our problem is with his perception of potential benefit.” Furthermore, the patient was under the impression that once on dialysis, he’d never be able to travel, which would end his dream of returning to his home country and reconciling with his wife. This analysis was as much a diagnosis as hyperkalemia was.

We decided to look into and confirm the availability of dialysis in his home country, to link him to those services, and thus to reframe dialysis for the patient as a means for achieving his goals. Since social proof seemed an appropriate part of the prescription, we would contact the dialysis center seeking a patient, preferably one with a background like our patient’s, to talk to him.

Wait, I imagine physicians asking, isn’t this a job for a social worker? Shouldn’t the doctor simply give patients the facts and let them decide? It’s not our fault patients make irrational decisions. Indeed, the renal fellow had suggested that we “Call psych, to check out his capacity.” Yet some of the richest moments in practice come from exploring the complicated landscape between clinical science and a patient’s perceptions, needs, values, and goals. Capacity and autonomy, though important, seem inadequate guidance for this journey, because they fail to account for the complexities of an illness’s meaning to the patient and for predictable irrationality. On the other hand, using our own native emotional intelligence seems to ignore that the behavioral drivers of the use of evidence-based interventions such as dialysis has increasingly been rigorously and scientifically mapped. If health depends as much on decisions about the use of treatments as on treatments themselves, applying insights from implementation and behavioral sciences is perhaps no less a doctor’s job than prescribing the right dose of Kayexalate.

In this case, dissecting “refusal” also changed our relationship with the patient and made us better doctors and advocates. Instead of an “uncooperative” patient with “hyperkalemia from acute renal failure,” he was someone with “hyperkalemia and acute renal failure who understands that he has a severe condition yet doubts the therapy, because his life experiences are at odds with expert advice.” In addition, while we were focused on treating the hyperkalemia, he was focused on reuniting with his family. We were looking for each other in the dark. Shining a scientific light on the problem revealed that being frustrated by his refusal was as absurd as being frustrated by hyperkalemia itself.

The next day, the intern reported that the patient had been discharged with an appointment to have a tunneled catheter placed and to see her soon as a new primary care outpatient. We’d helped him take a step forward, but the journey would be long and uncertain. I hoped he would reach his goal of reuniting with his family. We had started by trying to change the patient’s perspective but found that the real solution was in changing our own. By doing so, we’d come closer to the Oslerian ideal of treating not just the medical condition but the person with the condition. Today, doing so is no longer just the art of medicine, it is the science as well.

Identifying characteristics of the patient have been changed to protect his privacy.

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