Being Sick Isn’t Easy

Recently, a serious health problem put me in the hospital. No worries: I am fine now, but the experience taught me some painful lessons about what our patients go through. It’s not intentional, of course, but I fear the effort to be more efficient and more transparent can add to the wide gaps in access to care.

Let’s focus on the electronic health record (I was using MyChart; I suspect you know this tool or something similar). These electronic systems allow patients to request or schedule an appointment, view laboratory and imaging reports, communicate with providers and, oh yes, pay bills! For patients who are even modestly computer savvy, it is easy to use and very convenient. But if you are a Luddite like me, just putting in a password to access the chart can seem onerous. Why can’t I just pick up a phone and talk to someone?

And if I am too sick to do this myself, who do I rely on? My elderly husband? He is even less comfortable with navigating this, and frankly has healthcare issues of his own! I suspect many senior folks like me would struggle and might not be able to get to necessary post-discharge follow-up instructions.

The next concern with electronic records is whether the patient even has a computer or device with which to access them. If you don’t at least have a smartphone, you are left high and dry unless a friend or family member can help you out. Whether the lack of a device is by choice or from a lack of resources, it still creates potential gaps in care.

Of course, the other gorilla in the room is language. If you are not a native English speaker, you may be out of luck. At UCSF, we message by phone in both English and Spanish, but the addition of Spanish is not offered in MyChart. And of course, at UCSF, we care for many populations who speak other languages. How do we ensure they receive and understand our instructions? Studies tell us that these folks generally rely on their English-speaking relatives, especially their children, to navigate for them. But I imagine that for some, it is downright degrading to need your children for this. It would be for me.

I think the digital world has been transformative and I do embrace it. Personally, I usually manage pretty well. (Honestly, I am not as lame as I profess.) But vulnerability for any reason cited above allows potential cracks to develop in our healthcare delivery system.

I don’t pretend to have all the answers. But for those of us experiencing difficulty with access, having a real person to talk to could make all the difference.

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