Editorial

Talk of Personalization in Health Care

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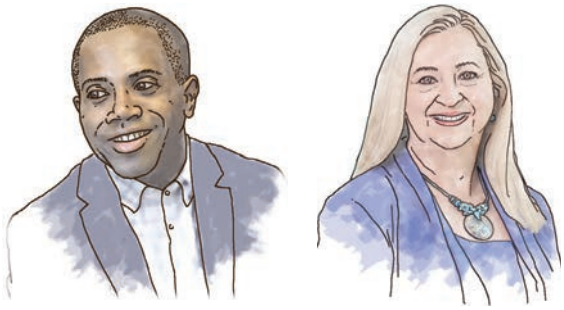

An homage to Jamaica Kincaid, who wrote a series of "Talk of the Town" articles for *The New Yorker* that offered her observations of the culture around her as a newcomer to New York from Antigua.

A physician friend wrote to us after participating in a nurse-physician roundtable during a virtual conference titled, "Healthcare in the Age of Personalization":

I am ashamed to admit that I do not remember the words "personalization," or "person-centeredness" being talked about much while I was in medical school. I do remember the phrase "cultural competence" though.[1] *I attended medical school near the turn of this century, at one of those ivy-walled institutions that was situated in a mostly poor Black neighborhood. Much of the talk about cultural competence that I remember from those days started from the assumption that we were all coming from wealth and privilege, that we all needed skills to be able to communicate with the patients who were coming from different cultures from our own. During all this teaching about cultural competence, I do not remember anyone ever asking me about who I was, where I was from, or about what kind of physician I wanted to be or what my own worries and anxieties were about caring for my patients.*

Later, during my postgraduate training, I was lucky to be exposed to Rita Charon's Narrative Medicine, *which excited me by its proposition that our skills as deep readers of stories could be leveraged to expand our healing potential.*[2] *I had spent much of my childhood reading stories to myself, sometimes aloud, and I had studied language and literature in my undergraduate years. So, I started to learn how to metaphorically "sit on my hands" as I invited my patients' stories. I started to practice the kind of mindful suspension of my own troubles and anxieties to allow me to listen to what was being told to me by my patients or my patients' families.*

It was only through this new way of bearing witness to my patients that I first connected with the notion of being "patient centered." This way of being patient centered was about valuing deep attention as a means toward representation and affiliation. This way of being patient centered was, for me, often about quieting the noisy parts of me that would be liable to get in the way of my ability to deeply regard the patient who was in front of me. This way of being patient centered was also about trusting what the patient was saying, trusting that I could decipher what was left unsaid. And yet, as a young physician I struggled then (as I do now) with the finite nature of my

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time. How do I see the volume of patients on my roster while being an effective witness for my patients' stories? I do not remember anyone ever pulling me aside and saying, "this is how you do it," or even, "don't worry, you will get better with time." So, even before I was exposed to fancy words like "patient centeredness" or "personalization," the tension between the idealism of what was possible and the reality of what was needed was a source of distress for me.

Now, I am a physician who works in an intensive care unit (ICU); I am a physician who leads a critical acute illness recovery engagement clinic. Now I am a system leader and a clinical researcher. Now, I cannot seem to go a week without thinking about the tension between standardization and personalization. On the one hand, we want to ensure that clinicians taking care of patients can provide the highest quality care for each patient. Where there are metrics that have been associated with improved patient outcomes or improved patient experience, we want every patient to receive those metrics. For such metrics, too much variability may be a signal of poor-quality health care. So, health system leaders spend time building workflows and protocols; they spend time building note templates and order templates; they spend time implementing care bundles. The nurse Rebekah who sat next to me virtually at this nurse-physician roundtable put it this way, "there is a protocol for everything. This is good when you are new because it is impossible to know everything you need to know . . . but not every patient fits the protocols."

From this vantage point of leading systems, the challenge of personalization becomes about creating structures to ensure that every clinician has what they need to provide the care with the best outcomes for each patient's illness while also creating structures and processes that allow each clinician to bear witness to patients as they are. Of course, what might seem like a tension between standardization and personalization is more symbiotic, more like yin and yang. Protocols and workflows are dynamic; they change with the most recent emerging evidence. Following protocols and workflows can free up energy for clinicians to be able to see more quickly what a specific patient needs and why. Sometimes, personalization may be highly technical, as it is in modern cancer care, where specific biomarkers are routinely being used to decide on specific treatment approaches.[3] Other times, personalization may be high touch, as it is in rehabilitation and recovery science, where we are often having to transform key principles into strategies and tools specific for each patient on the basis of biopsychosocial factors.

The obstacles to personalization are many: one obstacle might be our desire to make things binary, our want to put things that deserve to work together in opposition with each other[4]; another might be our arrogance, our want to think that conquering disease is the same as conquering illness; another might be our nihilism, our want to focus so much on curing disease that we forget that there is much we can do to heal our patients even when we cannot easily cure them; another might be our blindness to social justice, our willingness to accept the inequities in our system as the status quo.

Too often, when we talk of personalization, we are really talking about ensuring that the privileged few have opportunities to get more access to health care innovation, more access to skillful communication, more access to resources that can improve their health outcomes. Too often, when talking about personalization, we are talking about what patients "want." Of course, those of us who have worked in an ICU will know that what our patients and families "want" is only the beginning of a deeper conversation about what they value. In the face of a complex illness (a particular set of diagnoses and prognoses), our patients' values inform the way we can personalize our treatments.[5] Values are more than mere wants or desires. Our patients' values might include their goals, their fears, and their worries. Understanding patients' values might include understanding their strengths and their weaknesses; it might mean an exploration of what suffering is to them, or of how they want to include their family in the treatment process.

Rebekah, the nurse educator, said something like, "I want to help nurses have enough confidence to speak up in the moment, enough personal satisfaction to come back to work tomorrow." I left the roundtable conversation energized and excited. I cannot help but wonder whether conversations like these between a nurse and a physician about such things like "personalization in health care" is not exactly the kind of revolution we need in health care. I, for one, can't wait to go into work tomorrow.

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We think you have probably worked with physicians or nurse educators whose views are represented by the letter. Sparks of engagement, enthusiasm, and excitement persist despite challenging times. The culture of health care is changing, with more attention to true personalization of care and to a healthy work environment for all members of the health care team. Deep reflection and respectful communication can accelerate the positive change that is the revolution we need in health care. Our hopes are high, and we also can't wait to go into work tomorrow.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

FINANCIAL DISCLOSURES
None reported.

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