ISSUE BRIEF

Trust and Communication: Cornerstones of Care

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In this issue of the *North Carolina Medical Journal*, authors explore and debate the ways communication can influence how North Carolinians access health care in our state. Articles illustrate the importance of increasing trust in health care providers and systems at a time when care is changing dramatically, and patients have more access to information than they ever have.

Introduction

A lifelong friend of mine faces late-stage lung cancer. I've been helping him parse the medical language and legalese of the test results, payment forms, and applications for financial help that patients must complete when they come to the end of life. I could not have foreseen how much I would learn in the process. Being with an old friend I care about deeply as he struggles to accept his approaching death and has to suddenly learn a complicated, difficult language, has exposed me to many of the situations you will read about in this issue of the *North Carolina Medical Journal*.

John, my friend, probably fits the average patient profile. Like most patients, my friend earned no degrees, hasn't studied medicine or read much at all about the health care system, and gets his news and other information online or from social media. He's stubbornly set in his ways, but a caring friend can persuade him to change. With his decades of smoking cigarettes, John was aware of his odds of getting cancer in much the same way that anyone is; but as so often happens, when the reality hit him, it felt far different than expected.

He had help that most patients don't have at a frightening, uncertain time, including a friend who has decades of experience working in health communication and now teaches it at the college level. I know how to navigate the disjointed, often disconnected system of end-of life care, including oncologists, visiting nurses, hospice, Medicare, and Medicaid. But it was sobering to see how frail he was, and his helplessness in the face of so many decisions was frustrating to us both. He knew nothing of the language of malignancy and alpha fetoprotein; didn't know an HMO from a PPO from an ACO. He trusted me and called me "his doctor" (I'm not that kind of doctor, I kept pointing out) and seemed to feel comfortable asking me the questions he wouldn't ask his own physicians. That trust feels sacred, somehow.

It was a confusing diagnosis, in that the area his cancer had targeted didn't correspond with the tumor markers his physician had found. Needless to say, the uncertainty and unusual diagnosis made John feel less trust for his care team—if they were experts, why were they so confused?

When my friend John first called to tell me about what was happening to him, he sounded lost and confused; it was clear he didn't quite understand what he was going through. His situation at diagnosis was not unusual; many studies of cancer patients' comprehension of their diagnoses show that, especially at first discussion, they are unclear about the extent of their disease, the potential outcome, and even the types of treatment they will receive [1, 2]. The diagnosis shocked John with the impact of an emotional trauma. He couldn't think clearly, could not take it in at all, and at one point attempted suicide. His own diagnosis was unusual even to his oncologists because there were sizable malignant masses in both lungs, but cellular tests showed his cancer originated from another organ. Little of that made sense to John—how could he have cancer in his lungs that wasn't lung cancer?—again, the confusion made him suspicious.

What made matters worse was the difficulty of finding a time to speak with his oncologists and ask questions. Even when he was able to schedule a time, the visits often took place via short online video calls. Studies of the amount of time physicians spend with patients have shown visit length ranges from 4.5 minutes to as much as 30 minutes [3, 4], and that as visit time grows long, physicians tend to spend less time responding to patients' emotional needs [5].

We know that when physician-patient communication is inadequate, care can suffer. When care suffers, and something goes wrong, lawsuits and regulatory actions can follow. As Dr. Benny Joyner—professor of pediatrics, anesthesia, and social medicine at UNC—tells us in his article in this issue, communication training can help prevent the errors and misunderstandings that often occur between physicians or other health care providers and their patients [6]. Training that simulates scenarios that providers are likely to

Electronically published May 1, 2023.

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N C Med J. 2023;84(3):149-152. 0029-2559/2023/84304

face every day can give students the chance to practice CPR on a lifelike mannequin, experience real-world situations in virtual reality, or practice communications scenarios with live humans replicating behaviors of patients in common health care situations. These simulations provide minimal-risk training for providers to learn best practices in communicating with patients.

My own experience working as a communicator and communication trainer for the large nonprofit health plan Kaiser Permanente exposed me to the importance of communication in the practice of health care, and how it can change patient perceptions even after an adverse outcome [7]. Kaiser Permanente has had an ombudsman program since the late 1990s that includes a focus on communication, especially around adverse events, after which the organization emphasizes the importance of apologizing and communicating clearly about what happened and about how care providers will address the situation.

When physicians hurry through a visit, or are inadequately trained in communication skills, patients can feel unheard and uncared-for. Kate B. Reynolds Charitable Trust President Laura Gerald's interview in this issue addresses how, even as a physician herself, she has felt unheard by those who were caring for her when she became a patient [8]. If that can happen to a professional intimately familiar with the system, how much worse is the situation for an elderly patient with a high-school education? Gerald also explores how institutions can show patients and communities—especially marginalized ones—that they are trustworthy.

Pharmacists are among the most highly trusted sources of health care information. Ouita Gatton, professor of the practice and assistant director of the PGY1 Community-based Pharmacy Residence Program at UNC, writes in this issue about the importance of pharmacists as providers, since we tend to see them more often than we see our physicians or physician assistants [9]. Pharmacists have become sources of information for patients, as well as providers of care; many pharmacies offer childhood vaccinations as well as vaccines for adults, a consideration that became more important during the COVID-19 pandemic, when vaccines became available to fight that highly contagious disease.

In the case of my friend John, the pharmacist he frequented became an advocate for his care when he could not afford the cost of the new drug prescribed by his oncologist. She found funding through Medicare and Medicaid and helped further reduce his financial burden by suggesting a less-expensive way to treat one symptom of his multiple sclerosis. She advised prescribing, separately, the two key ingredients of a highly expensive brand-name drug he takes to control the pseudobulbar affect that often accompanies MS and causes uncontrolled laughing and crying.

Physician assistants can affect the ability and willingness of patients to actively participate in their own care, as Lisa P. Shock, chief population health officer of the Managed Medicaid Plan of NC at UnitedHealthcare, details in her piece in this issue [10]. PAs are often part of a patient's medical "home," and with their communication skills training, patients often find them to be the best care providers to address doubts and concerns about their treatment. Openness, honesty, and a willingness to admit errors and correct them are key to the effectiveness of physician assistants' role in a health care team, and are qualities all providers can use to create, build, and sustain trust.

Certain patient communities may be less likely to trust the health care system in general—and their own providers in particular—if they feel those providers do not understand their culture, language, or race. In this issue, Dr. David G. Jacobs in the Department of Surgery at Atrium Health – Carolinas Medical Center, addresses the concept of concordance, the similarity of patients' race and/or ethnicity to that of their physicians [11]. In January 2023, the Association of American Medical Colleges (AAMC) published a report showing that, among other things, just 5.7% of American physicians are Black, and 6.9% are Hispanic [12]. Contrast those figures with US Census data: as of July 2021, 13.6% of respondents categorized themselves as Black and 18.9% as Hispanic; 2.9% reported themselves as mixed-race [13]. When multiple studies indicate that racial and ethnic concordance increase patient trust—and that shared cultural beliefs, languages, values, and experiences improve patient trust in, and communication with, their physicians—efforts to increase the numbers of Black and Hispanic physicians could clearly improve patient care.

Rose Hoban is a nurse and health care journalist who founded the nonprofit news site North Carolina Health News. In an interview in this issue, she explains her perspective on the problem of health communication from a unique position, having been on both sides of communicating medical matters to the general public. As a journalist, she knows the importance of clear communication about important health issues and sees firsthand the reluctance of credible sources to comment on the record to reporters—even those who, like her, have experience behind the medical curtain. Especially after the COVID-19 pandemic, when authoritative nonpartisan figures like Dr. Anthony Fauci were pilloried online, she sees many medical experts in a "defensive crouch," reluctant to speak on the record [14]. She credits Gene Matthews at the UNC Gillings School of Global Public Health with the idea that "if you don't tell people something, they'll go out and make up their own facts." I can attest to this, having been both a broadcast journalist and a health communication professional in my early career. Not communicating with media representatives can backfire spectacularly and sully the reputation of health care entities that would otherwise have a chance to steer the conversation. Reporters are often the quickest route to disseminating important health news to a broad audience, and training providers how to speak effectively and clearly to journalists can go a long way toward increasing trust in medical professionals and health information.

Two articles in this issue focus on the importance of working with faith leaders and institutions to increase trust. Spirituality has been shown to help patients cope with diagnoses of serious illness, and belonging to a faith or a given religious group gives its members a strong sense of community and belonging [15]. Those faith institutions can give their members and the larger communities of which they are a part more than just emotional comfort; they can influence their members to adopt healthy behaviors. Researchers at Northwestern University and the US Department of Veterans Affairs even suggest that partnerships between academic medical centers and faith communities can help increase vaccine delivery, including during the COVID-19 pandemic [16].

As the Reverend Paul Anderson shares, spiritual leaders can reassure their followers, help guide them through frightening situations, even inform them of actions they can take to cope with a serious public health situation like the COVID-19 pandemic [17]. This leadership helps reach audiences that might never see or hear other public health messages, or who are skeptical of secular authorities. In this issue, former Duke Divinity Dean L. Gregory Jones points out that the earliest examples of faith leaders and medical authorities who worked together were the early Christians, caring for the sick and establishing the first health care facilities [18].

My friend John first learned his diagnosis months ago. During that time, he's felt as well as a late-stage cancer patient can feel, but gradually his condition has worsened: after at first experiencing an inexplicable lack of pain, the discomfort his care team had expected arrived and started to keep him awake. As he's become more disabled, the cane he had been relying on occasionally turned into a walker, then to a wheelchair, and now the pain keeps him in his small house, awaiting visits from his hospice nurse. As 24% of all Americans could attest [19], disability can be life-altering, and it is often accompanied by chronic pain.

After years of multiple sclerosis, my friend knew how the world saw disabled people, and tried to make light of it, calling himself the "handy cripple." He never said this to me, but watching him walk with such difficulty—determined not to be diminished by it—seems to get at what Virginia Knowlton Marcus writes in this issue: "…every human has the right to experience life how they see fit, in whatever setting they choose. Trust depends on respecting and valuing each person's choices, including the fundamental choice to live, work, and play in the setting of one's choosing" [20].

At least he now has a highly rated nonprofit hospice organization visiting him regularly. He 's got Meals on Wheels. He's enrolled in Florida's Medicaid program. He had no idea he was eligible for those things or how to access them, and often is still baffled at the process of paying for the care he needs that isn't covered by Medicare, Medicaid, or the Department of Veterans Affairs. The opacity of these systems makes him suspicious of them. He's a living example of what David Anderson writes about, that "invisibility buys bureaucratic simplicity, but it spends social trust" [21].

It's difficult to talk or write about what John is going through. At the same time, I am aware that his story might help us better understand the importance of trust and communication in health care. Understanding what he is going through could help us think more personally about how health care can be better for the patient when communication is considered as equal in importance to knowing anatomy or diagnosis codes. We do not serve patients well when the person upon whom all this care centers doesn't understand what he's being told, or even his own diagnosis. Add to that the COVID-19 pandemic, with mis- and disinformation spreading widely online, and none of us should be surprised by the systemic lack of trust exacerbated by stress and poor communication, as Lorrie Basnight's article points out [22].

In the end, health communication is a public health strategy, as we have seen these last three years. Tracy Zimmerman, vice president for policy and communications at Neimand Collaborative and former deputy director for policy and communications at the North Carolina Department of Health and Human Services, writes about how trust in the latter organization increased by 35% during the pandemic, and even more among Black and Hispanic North Carolinians, at 47% and 39%, respectively [23]. The work of NCDHHS Secretaries Mandy Cohen and Kody Kinsley likely contributed to the state's rate of vaccination, with 74% of us completing the initial series of vaccines and 99% of those aged 65 and over getting the shots [23].

Finally, whether or not any of us would like it to be so, politics and health are inextricably mixed in America and that connection can make it difficult to communicate clearly and accurately about health policy. As Christopher H. Cooper, PhD, professor of political science and public affairs at Western Carolina University, points out in his essay, health policy communication involves more than "speaking truth to power" and having facts at your disposal; it requires the cultivation of a network of people who make policy and who can influence changes [24]. NCMJ

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Acknowledgments

Disclosure of interests. The author reports no conflicts of interest.

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