

OFF THE CHART



Imagine you're sitting alone in an exam room, struggling to catch what your doctor is saying.

Because you are hearing impaired, you ask the doctor to repeat himself, but he seems irritated. Eventually, you stop asking. You agree to a medical test without understanding what it's about. And you leave, unsure of your diagnosis.

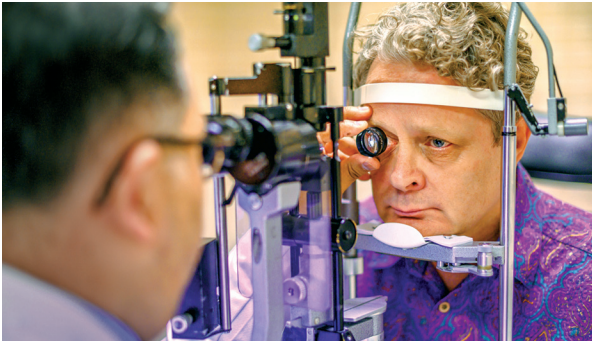
All of this happened to Alexis Johnson, one of several patients who shares her health care journey in 2019's "Narrating Patienthood: Engaging Diverse Voices on Health, Communication, and the Patient Experience," edited by Professor of Communication Studies Peter M. Kellett.

Through compelling first-hand accounts and interviews with researchers, patients share a variety of stories – often exposing how stereotypes and discrimination have impacted their care.

"Numbers can really count in medical research, but I don't talk to thousands of people," Dr. Kellett says. "For me it's about getting into a few people's lives in a really deep way. This helps us learn how humans talk about, live with, and care for others with diseases and illnesses. The approach gives us a valuable understanding of patient experience that huge medical studies can't offer."

While Kellett has published extensively on narrative approaches to conflict communication, his interest in health communication only began when he was a

STORY LISTENING The narrative method illuminates how patients experience communication gaps – empowering them, their loved ones, and health care providers to build connections and advocate for change. Kellett's work grew out of his own experience with a rare diagnosis. Here, he and his wife attend a checkup with his ophthalmologist Dr. Rajiv Shah.



patient himself. In 2011, he was diagnosed with macular telangiectasia, which leads to loss of vision.

“At that moment,” Kellett recalls, “I wished I had a coach who could explain what was happening, what to do, and how my life story would be impacted by this condition. We’re narrative creatures. We want the full story, and we rarely have that.”

Kellett wrote a book on his own experience, published in 2017. But he wanted to explore how patients different from him – in race, class, gender, age, sexual identity, or disability – encountered health care communication and the impact that had

A FACE TO THE NUMBERS “Narrative medicine utilizes patient narratives to improve understanding and empathy,” says Kellett. “It promotes more personally sensitive and culturally responsive care, and thus better health outcomes.”

in shaping their health care experiences. That led to “Narrating Patienthood.”

A personal story in one chapter, for instance, encourages readers to examine why African Americans use hospice care at a much lower rate. Another account follows a young mother of limited means, misdiagnosed by more than five physicians until she finally finds a practitioner who discovers she has Stage 4 breast cancer. “Can you please direct me to a doctor that has a heart?” she asks at one point in her journey.

The publication is part of the “Lexington Studies in Health Communication” series. While the series mostly targets academic audiences, Kellett says this entry will also resonate with patients, family members, care providers, health system administrators, and medical schools teaching narrative approaches to medicine.

“Stories have a way of lifting the lid off the interpersonal world,” Kellett says. “You recognize: That’s another human being like me. He or she is different from me also, but there’s something in their story that I can relate to, and that creates a powerful connection.”

By Dawn Martin • Learn more at go.uncg.edu/kellett

HER STORY

Maya Angelou once said, “There is no greater agony than bearing an untold story within you.”

Conversely, Kellett and his co-editor Dr. Jennifer M. Hawkins hope the telling of personal stories in their newly released book can promote healing and transformation.

“Women’s Narratives of Health Disruption and Illness” shares women’s firsthand accounts of significant health experiences across the lifespan – from childhood to motherhood, from caring for aging parents to letting go at the end of life.

“Readers will learn how women – as they care and advocate for themselves and their loved ones during illness – communicatively create strength and balance in their life stories,” says Kellett.

Across his work, Kellett has found that sharing narratives profoundly influences storytellers themselves.

“When we communicate about health,” he says, “we can more effectively integrate these experiences into our broader ongoing life stories, leading to long-term positive impacts.”

