The Family Voice

Miscommunicated Care with Ranch on the Side

J. Patrick Haltom

ABSTRACT

This is a narrative reflection of the miscommunicated care provided to the author's family member, Gracie. Gracie is an adolescent who experienced a troubling medical crisis, laden with uncertainty. The author is a clinician-family member whose insight Gracie and her family sought in navigating the erosion of trust that occurred primarily due to "miscommunicated care," meaning care that was provided in such a way that it not only obscured the good intentions of Gracie's medical team, but also neglected the real needs of Gracie and her mother.

With Gracie's permission, I tell her story from my perspective, to reflect on how miscommunicated care can be a disorienting experience for patients and family members, and how it is ultimately patients and family members who bear the associated burdens and harms.

I've never been one of those clinicians who thinks that medical misfortune won't also befall me or my loved ones. Over the years, I've watched several of my family members don the obligatory regalia of the precariously tied hospital gown; they get cancer or have a stroke or develop dementia. Yet, every single time I find myself disoriented, confused, and stunned. A large part of my confusion is emotional. I am devastated when someone I care about abrasively encounters the limitations of their human body. I become even more discouraged when they are forced to confront the shortcomings of modern medicine: how little it can offer in certain circumstances and how it is orchestrated by imperfect people working within even more imperfect systems.

Recently, a loved one in my family, whom I will refer to as Gracie, experienced a troubling medical crisis. At 16 years old, Gracie had only a minimal medical history, including obesity and attention-deficit/hyperactivity disorder (ADHD), but after she experienced a respiratory infection for roughly a month, her mother brought her to the doctor for what they hoped would be a simple steroid shot and quick exam. When Gracie had her blood pressure checked, the monitor screeched in alarm. Her systolic blood pressure was over 220mm Hg, with the diastolic blood pressure trailing slightly behind at 130mm Hg. Everyone in the exam room

---

J. Patrick Haltom, DNP, CRNA, is an Ethics Consultant in the Department of Clinical and Organizational Ethics at Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health in Indianapolis, Indiana, and is a Pediatric Nurse Anesthetist in the Department of Anesthesia at Riley Children's Health at Indiana University Health. *jhaltom1@iuhealth.org*

agreed: that couldn't be right, probably best to check a manual. But that only confirmed what the monitor showed. The clinic recommended Gracie go to the emergency department immediately. There, things only got more worrisome. An echocardiogram showed a large pericardial effusion and heart failure. Gracie's mother explained to the doctors that Gracie had never had high blood pressure before, she gets her blood pressure checked every six months at the primary care office for her ADHD meds, and she's always had relatively normal checkups overall. Sensing that Gracie needed more specialized care, the local emergency room physician recommended urgent transfer to a tertiary care pediatric hospital.

Evaluation there only led to more questions and confusion. Armies of specialists were consulted, each asking Gracie and her mother to recount minute details of her medical history and body. Labs were ordered, and the pale skin on Gracie's arms burst with purple bruises as needles searched for increasingly obscured veins. She underwent a pericardiocentesis to relieve the fluid drowning her heart, only for it to redevelop days after her drain was removed. She subsequently had to endure a pericardial window to relieve a second large effusion. Gracie also started experiencing visual changes, and her exam by ophthalmology was not reassuring. A lumbar puncture was performed, and the opening pressure was exceedingly high. Ophthalmology concluded that she might have permanent vision loss from the high pressures in her skull. Nephrology was concerned about her acute kidney injury and hyperattentive to her sodium levels. As Gracie lay exhausted in bed, developing a pressure sore, and her mother sat bedside vigil, anxious for answers, the nephrologist zeroed in on what he believed to be the clear cause of her borderline sodium levels: a snack-size bag of Doritos, half-finished, that had been on the bedside table for four days. "Those won't help her sodium levels," he reprimanded.

While Gracie's day-to-day became regulated by the clinical rhythm of more labs, more tests, and more scans, her blood pressure and kidneys gradually began to normalize enough for her to discharge. After an extensive and tiresome workup, she returned home, but with no real answer to her mysterious medical events. The best explanation the family has received to date is that Gracie has idiopathic intracranial hypertension, her exceedingly high blood pressure occurred in response to the pressure in her head, and her condition likely involves an underlying history of high blood pressure. Her other medical problems, including her kidney injury and heart failure, are believed to be related to her hypertensive crisis. The cause of her pericardial effusions remains elusive.

Gracie's mother told me she hoped that her daughter's first follow-up appointment, scheduled shortly after her discharge, would provide some clarifying answers to the dizzying inpatient experience they had endured. Perhaps outside the chaos of the inpatient unit, ping-ponging to-and-fro the intensive are unit (ICU), and a baker's dozen of doctors, one of her outpatient physicians might be able to explain what had happened over the last couple weeks, why Gracie still breathed funnily, how much damage had actually been done to her organs, and whether she might get back to normal.

But the first follow-up appointment only seemed to widen the communication divide. After the cardiology attending entered the room, he began asking Gracie some basic questions about how she was doing. He then shifted the conversation to her diet. He asked her what healthy foods she likes to eat, seeming to focus on Gracie's weight. She listed off some fruits and vegetables and added that she also really likes salad.

"Do you put dressing on your salad?" he responded, priming the conversation to explain how a salad isn't really *that* healthy of a choice. Gracie explained that, yes, she does like salad dressing, and then she and her mom found themselves in the disorienting position of having to defend Gracie's healthy food choices. They explained that they understand Gracie is overweight, but that her diet isn't as bad as the clinical team might believe. Gracie and her mother left the appointment confused, frustrated, and angry. Why was the heart doctor talking to them mostly about Gracie's nutrition and weight after such a terrifying medical crisis? And why were they defending Gracie enjoying a salad? After weeks of uncertainty and fear buffered by patience and perseverance, they felt the mutual trust between them and their doctor eroding beneath their feet.

"Do you put dressing on your salad?" has become quite nearly a dark joke in my family now. Our quips about Thousand Island punctuate the headline thought: If only this major medical crisis could be explained so easily! Imagine if avoiding Ranch was the remedy for hypertensive crises. Oh, you have liver failure? Don't have that balsamic vinaigrette, and you'll be back to normal in no time! Want to get out of the ICU for care of your sepsis? Best to skimp on the honey mustard. And just wait until patients learn about the all-healing power of avoiding those nutritiously bankrupt croutons!

Dark humor aside, Gracie's mom and I have spent long hours dissecting this interaction. I believe that somewhere within the triangulated chasm of what this clinician thought, felt, and eventually said, lies his intention, which—if I am being charitable—I think was ultimately caring. Yet, to our family, it felt like drastically "miscommunicated care," meaning that, despite a caring intention, it was provided in such a way not only obscured that very intention, but also neglected the real needs of Gracie and her mother, beyond that of a simple instance of communication failure. Perhaps this then prompts the question of whether it's fair for one comment made by a clinician to fracture the therapeutic relationship from the family's perspective. Perhaps a similar question could be asked of whether it's fair for one half-eaten bag of Doritos to be treated as the defining feature of sodium levels in the setting of a medical crisis. In complex situations, especially within the therapeutic relationships between pediatric patients, families, and clinical teams, blame can be easy to assign, mostly because it is multidimensional. My goal in reflecting on Gracie's case is not to assign blame. Rather, I want to point out how miscommunicated care, especially when laced with bias, can serve as a foil for clinicians' ethical and medical obligations to their patients. To put it differently, if the clinical encounter is a crisp wedge salad, then miscommunicated care is the gravy boat of Ranch dressing.

While the physician may have regarded his intent as the appropriate medical recommendation, it was perceived as a betrayal of the obligation to act caringly toward Gracie and her mother, extending the dimension of harm.

For Gracie's mom, the physician's intention was baffling. In our conversations, I tried to offer a different perspective: Perhaps his goal was to have Gracie and her mom focus on the somewhat insidious foods that we may think are part of a healthy diet. And his question isn't as ludicrous as it may seem to salad dressing aficionados like my family. In my undergraduate nursing program, I even remember specifically being taught to ask patients about salad dressing and explain how unhealthy it is! What I was not taught nearly enough, though, was how my preconceived bias can infect the questions I ask patients, and how the choice and phrasing of these questions—even before any real clinical "education" has taken place—can erode the therapeutic relationship and obscure what I *actually* want to communicate. I was recently venting about Gracie's situation and the elements of miscommunicated care to one of my friends who is a therapist and an inpatient social worker, and perhaps he distilled our moral dilemma best, wondering: "What good is modern medicine if we can't communicate any of it?"

When I asked Gracie about why she thinks this doctor was so fixated on salad dressing, she told me straight: it's because of her weight. And she's not alone. Bias against patients because of their weight is disappointingly prevalent in medicine, and it is a significant barrier to patients getting thorough, high-quality care. Medical problems are often misattributed or dismissed due to a patient's weight, especially in cases like Gracie's, when the resources and answers medicine has to offer are insufficient to fully explain or treat a patient's condition. Like many patients, Gracie is not ignorant about her weight or how it may contribute to her symptoms, even if it may not have been *the* cause for her initial medical crisis. Her clinicians aren't prophets, revealing to her and her mother something they didn't already know; my guess is that no doctor has thought more about a stereotypical teenage girl's weight than that girl herself. The ultimate *hamartia*—fatal flaw—of Gracie's clinical team was that the failings of miscommunicated care frustrated an opportunity for the physician to connect with the knowledge and discipline that Gracie and her mom had already cultivated to promote her healing and well-being.

I recently spent about a week with Gracie and her mother for a family reunion and was able to witness these attributes firsthand. Gracie was still pretty deconditioned from her inpatient stay and heart issues. Every night she would slowly make her way down the stairs, sometimes stopping to rest at the halfway point, to take her stack of pills that crowded the kitchen near her blood pressure monitor. Her mother would take Gracie's blood pressure and attentively record it in a log. At dinner, I watched Gracie shift dietary choices to healthier items than the rest of us were wolfing down, choosing grilled fish and salads, splitting a milk shake when the family went out for ice cream, and opting for water over soda or sweet tea. I can't underscore enough how these conscious decisions are nearly heroic and certainly countercultural in the Deep South, where we deep fry everything, and anything green is colloquially termed "rabbit food."

Instead of capitalizing on the strengths, knowledge, and intentional choices Gracie was already demonstrating, miscommunicated care in this case fractured the therapeutic relationship and eroded medical trust. Gracie's local primary care doctor has even offered a second opinion to a new health system, which would likely sever the therapeutic relationship completely. While I am sure that Gracie's medical team will feel bad about her leaving, it is ultimately Gracie and her mother who will bear the burdens and harms associated with clinician bias and miscommunicated care. How will Gracie think about her body, weight, and dietary choices in light of her encounter with the medical team? What coherent explanation of Gracie's condition can help her family make decisions about her future when most of it continues to feel like a mystery? When Gracie leaves for college, how will her mother be able to sleep at night without worrying whether Gracie's heart or blood pressure might be dangerously affected again? These are the unanswered questions and lurking anxieties that Gracie and her mother shouldn't be expected to navigate on their own. They deserve clinical expertise and support to answer them.

My family, especially Gracie and her mother, have learned that in the face of a health crisis, medical mystery, and imperfect system, the good that modern medicine has to offer *is* the caring intention. The frustration for Gracie, her mother, and the rest of my family is not merely that we don't have a clear explanation for her situation; our family has often discussed preferring an incomplete answer over having a wrong one or one that is misattributed to her weight. Instead, it's an even greater frustration that the clinical team's caring intention has felt inconsequential and obscured by miscommunicated care when, to my family, that was what we needed most to help us navigate the uncertainties of Gracie's situation. Because of this unmet need, my family has sought my clinical impressions to help them investigate the clinical team's intention and make sense of what is happening to them. I believe that as clinicians, we have obligations that extend beyond our good intentions. Gracie's case illustrates this, underscoring that clinicians have a duty to ensure that their communication is aligned with their caring intention. Failure to do so is a harm in and of itself. Patients like Gracie will suffer from miscommunicated care, and the good medicine has to offer will never be realized. Instead, all the hard-won expertise and heartfelt intentions on the part of the clinical team will be obfuscated by something that appears entirely trivial and out of touch, like: Do you put dressing on your salad?

DISCLOSURES

Names and other details have been changed to protect patient privacy. Permission was obtained from both Gracie and her mother to publish her story in this format.

ACKNOWLEDGMENTS

I would like to thank Gracie, her mother, and the rest of her family for their perseverance during a scary and uncertain time; Eli Wynn, for being one of the most insightful and thoughtful individuals I have the privilege of knowing; Colin Halverson for his continued patience, brilliance, and feedback on a prior version of this narrative.

Thanks to the editor and reviewers who provided thoughtful feedback on a prior version of this narrative.

I am related to Gracie and her family. This narrative is from the perspective of the family, and does not intend to be fully representative of the interactions with all clinicians or the perspective of the clinical team. I have no other financial or conflict of interest to disclose.