



“Not Your Father’s Heart”: How Healthcare Discrimination for Neurodivergent Patients Taught Me About the Human Experience

Cate Murphy

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Business Administration, Management, and Operations Commons](#), [Health and Medical Administration Commons](#), [Medical Education Commons](#), [Public Health Commons](#), and the [Social and Behavioral Sciences Commons](#)



PERSONAL NARRATIVE

“Not Your Father’s Heart”: How Healthcare Discrimination for Neurodivergent Patients Taught Me About the Human Experience

Cate Murphy

Co-chair, The Beryl Institute Solution Advisory Board and Director, Samaritan Technologies

ABSTRACT

It is easy to assume all patients who come into a hospital for acute crisis care have a clear understanding of how their experience will be facilitated. When a patient is neurodivergent, they cannot always agree to needed intervention. This is exacerbated by the “poor timing” of questions portrayed to impact the critical care received, sometimes irreparably. This is my story of watching my young, active partner suffer two massive heart attacks and refuse intervention because he was ashamed to admit he had not seen a doctor in over thirty years. Due to his neurodivergence, he could not process questions under pressure, held the belief he had no health insurance, and could not afford care. This is also the story of how one talented cardiothoracic surgeon listened to my partner through the ears of a patient and nothing more. My experience with the intersection of patient experience and healthcare volunteerism led me to advocating for a truly terrified human being and I realized this was not the storybook heart attack portrayed in movies or what we typically hear from our parents or grandparents. This was living, in real-time, the thought I would lose my partner because he could not cope. We are on the other side now, but I wonder what other neurodivergent patients do when they do not have someone like me. I hope my story helps providers and PX professional think through the lens of those who cannot follow the traditional expectations of emergent care.

Keywords: Healthcare equality, Quality of care, Quality of life, Emotional readiness for care, Care disparity, Patient experience, Human experience, Healthcare gaps, Connecting resources, Healthcare advocate, Heart attack, Inclusion, Neurodiversity

1. Experience framework

When I met my now partner in 2018, I was instantly drawn to the nitro-head, outdoorsy, extreme sports attitude he had for life. I knew I needed that balance for my hidden joy to thrill-seek, but my embarrassment at not fitting the body type of an outdoorsy woman. He was an IT professional of the dorky persuasion and I was a consummate professional of the “let’s get things done” persuasion. We were (and still are) a great fit. We had a whirlwind romance and decided to blend our lives and kids after six-months of dating, and we’ve been rather inseparable ever since. My “fella”, as I call him, is not a traditional “adult”.

His brain does not see much need for structure or containment. This translates into him not setting up or keeping track of adult life requirements; documentation, insurance, records, or id cards, you get the idea. He also refuses to run a household in any sense of traditional standards. My partner is neurodivergent – something even he did not know until about eighteen months into our relationship. Shortly after we blended family life, I learned he had not been to a doctor in over thirty years and had never carried health insurance for himself. He comes from a family full of brothers who are successful doctors. If he needed anything medical, he would show up at a brother’s medical office and have a nurse patch him

Received 24 August 2023; accepted 22 November 2024.
Available online 30 April 2024

E-mail address: cmurphy@samaritan.com (C. Murphy).

<https://doi.org/10.35680/2372-0247.1863>
2372-0247/© The Author(s), 2024. Published in association with The Beryl Institute.

up. Easily done. I took out health insurance on him 2 years later, thank goodness.

2. Famous last words

Fast-forward to August 2022, and for some time, the Fella seemed off. If you ask me, he had not been himself since December 2021. All suggestions he go to a doctor for a checkup “just to see” were met with being reminded he was invincible. It was mid-August when he finally relented to go to Urgent Care because he was struggling to breathe. He was diagnosed with pneumonia and given strong antibiotics. But by day five of taking meds, his symptoms got worse and his legs and abdomen expanded with heavy fluid retention. He muscled through until Labor Day weekend. We cancelled our family trip because the Fella had a pounding headache. I had never known him to have a headache before, and with what I consider to be divine intervention, along with my previous medical training many lifetimes ago, I convinced the man to chew an aspirin. “I think you are having a heart attack. Chew this.” Attempt forty to get the aspirin chewed was successful and within five minutes, his headache subsided. My requests to go to the emergency room went unheard; “You’re overreacting. I did not have a heart attack. I’m fine!” So fine in fact, he decided to drive halfway across the country with a friend to pick up farm equipment and bring it back to our house to be tinkered on. “I’m fine,” was the record on repeat until the end of September, some thirty days after his first heart attack, but we wouldn’t learn that until later.

3. Admitting defeat

When the Fella came home, I became some banshee version of myself and insisted in no uncertain terms that an emergency room visit take place, “or else”. I’m not sure what the “or else” was going to be, but I meant business. A 4-hour ER visit turned into the news after tons of bloodwork, EKG, and CT scan that the man had experienced two heart attacks and was in active heart failure. It also revealed he was a raging diabetic with unchecked cholesterol off the charts. He had to be transported to the main hospital some thirty minutes away in order to be immediately admitted inpatient for a heart catheter and possible emergency open heart surgery. He had zero time to process. And, even worse I knew his brain well enough to know he wouldn’t process any of this any time soon. He immediately went into denial and refused any further intervention. Medical staff were shocked and appalled anyone receiving this news would refuse

treatment. I saw the scans, the bloodwork, the radiology report. I knew he was on literal borrowed time and yet, my brain kept saying, he’s so young, in his forties, we eat healthy, I ban sugar, he is so active, this is impossible. The euphoria of my thoughts snapped back to reality when I heard, “Sir, what type of insurance do you have?” and then came the rage. Watching in slow motion as a myriad of emotions flashed across his face in record time that only I would recognize due to his tough-guy exterior made me spring into action. “Do we need to know that right now? You just told him he is practically dying. I will speak to you outside about this.” As I exited the ER room, I saw the Fella rip out his IV while ranting explicative words and practically walking out. I didn’t get the chance to explain to him that he had insurance. I don’t have it with me. Could we focus on the next steps. I will get it when I can pause and run home to get it,” I explained to the admin staff outside of his room. In the space of the 3 hours it took to convince the man to transport to the main hospital, that his life was in danger, and he needed to do this for every reason under the sun, we would be asked no less than 13 times, “What insurance do you have?”. We would also hear coming from the halls a few choice phrases alluding to the Fella’s stupidity in not caring for himself in the past nor the present. My heart sank at the shame I knew the Fella felt from hearing his condition would have been manageable with early intervention, and hearing it in conversation against him.

4. The outcome

We made it to the hospital. An anticipated 2-day stay turned into 2-weeks. By day five on unit, and after intensely reading the hospital’s policy on patient’s rights, I had the nursing staff block any administrative staff from his room. I also gave strict instructions not to discuss insurance or any type of costs associated with post-discharge care. We were working around the clock to stabilize a very reluctant patient. A patient whose brain worked differently and required a non-logical approach to his care. No one understood my several requests to speak plainly, not in medical terms, to slow down, to schedule extra time during rounds so he could ask questions, to validate his emotions, and to understand he wouldn’t understand for a while. He’s not “slow” or “handicapped”. He just processes differently than your typical patient, and he won’t be rational until he is out of care and can think. All of this earned me the label of “difficult”, and to my dismay, I learned a patient advocate had been called to see if the Fella “felt safe” at home. Later

that evening upon arriving back to his room after a heart catheter, a cardiothoracic surgeon came into the room. "We are sending you home! You'll get three months to recover on some pretty great meds and then, I want you back in my operating room where I'm going to save your heart." Both the Fella and I were shocked. But there is more. "I read your chart and I had to meet your crazy wife" (Not yet – I'm just his partner). "I'm just kidding, but you've earned quite the reputation for setting people straight and protecting this man. I think that is great! Your chart says you need lots of time to talk through care plans so, my residents are going to manage my rounds for a while and I am going to stay here until you are ready for me to leave."

What? What did I just hear? No fighting? No interrupting? No anything? I think for the first time in five days, I sat down outside of the Fella's room and took a long moment for myself in tears. He was safe, and it struck me as odd that, up until that time, in the one place I thought every person should feel safe, I didn't trust that he was. We made it through another week, discharge, and three months of waiting for surgery. At every post-inpatient visit, pre-op appointment, blood-work, pharmacy refill, and billing department call, someone had a comment from the Fella's file that mentioned a professional version of "crazy wife" or "she (not he) did "X" ". I was there for every single one, and I wear those badges with honor.

In January 2023, three weeks after his 50th birthday, the Fella successfully underwent nine hours of open-heart surgery. The doctor who stayed that fateful night on the unit was true to his word. He backed up the call time on surgery day two full hours so the Fella could cope with his emotions and his brain telling him to run. He called extra operating room staff and pre-op staff to rotate in fifteen-minute increments so the Fella could be entertained and reassured while he was systematically prepped for surgery. Each new nurse was the next step in the process; nurse one put on his socks, nurse two took off his shirt, nurse three took his vitals, nurse four shaved one arm, nurse five shaved the other arm, on and on until the Fella was ready. The surgeon requested an extra anesthesiologist "just in case", and he showed up one full hour before his normal scrub time to just sit with the man and make sure he was ready. Upon waking from his surgery, the Fella asked, "Am I alive?" I replied, "Yep, you are babe." To which he said, "At least he didn't ask me about my insurance", and promptly fell right back to sleep. From the moment I left the cardiac ICU that evening to the moment of the Fella's last telehealth visit a few weeks ago, this has been a path of not only

advocating for someone who truly had no idea what was involved with caring for his health, but training providers that different brains are not stupid. They are smart on the other side of traditional thinking that is stellar, perfect, and far more intelligent than any of us neurotypical thinkers could ever be.

5. Lessons I have learned

Lesson 1 – For providers: Please take note of how your patient's receive information. Not everyone is a critical thinker at the best of times let alone during acute crisis. I promise you that neurodivergent patients observe your quirks about yourself more than you do. They will know if you are inauthentic. It takes just a moment in a sea of hours in a day to be human with one another.

Lesson 2 – For caregivers like me: Do the hard things even if it means you are labeled. Don't be afraid to set boundaries for the emotional and mental safety of **your** patient. The professional version of me would be highly embarrassed at the way I put my foot down, but when the real and present needs of my partner were ignored, it was enough. Read the patient's rights and follow the escalation procedure for patients. Know when it was time to stand down and trust.

Lesson 3 – For administrative staff: With all due respect, read the room. There is nothing administrative happening in the moment of saving someone's life that can't be handled at a more appropriate time. Immerse yourself in any training your health system or hospital has to offer for neurodivergent sensitivity. There is always that one time when someone looks like they "should" be able to handle their own care, but they can't.

Lesson 4 – For patient experience professionals: Please investigate reports through the lens of, "a rational person would not act this way. I wonder what is happening", rather than assume the patient and their caregiver are incompetent. Patient safety is crucial to patient care, but preemptively assuming patient care is being jeopardized is not your best foot forward.

Lessons 5 – For resource staff at discharge: Wait until the patient is ready to receive resource information. Make resource lists as fully filled out as possible, in small sound bites with lots of white space and use graphics. No matter how smart the patient is, their entire life and wellbeing have been destroyed. Help them build back up by being a partner in that process.

6. Conclusion

I wish I could admit that my snap-to-it approach to the Fella's care was from a place of intentional thought. It wasn't at first. I panicked. No one was listening to the man and I feared their judgement of him. I'm grateful I have resources in my profession that kicked in, took over my own brain, and yielded

a positive outcome. Our experience has gone down in the books of our talented surgeon and I now use my story professionally as reinforcement of how needed patient experience participation is via organizations such as The Beryl Institute. The human experience looks different for everyone. We need to be okay that this truth is unwaveringly fact.