Intersections

Tolerable Pain

Arielle Schecter
School of Medicine and Dentistry, University of Rochester, Rochester, New York

In accordance with respect for medical privacy, certain identifiers about the people in this story have been altered. The physician and the patient have both provided written approval for this piece to be published.

Our patient says, “My eating disorder is always there. It is with me every day. It is with me all the time. I think about it constantly.”

Her face is hard to read: at once serious and warm. She is taking this seriously. She takes herself seriously. She wants to give back to the people who cared for her when she was sick. She wants to be truthful about her own story, for others to learn from.

I am on a video call with her because I am a medical student working on research with Dr. Brown, a retired adolescent medicine physician, who is interviewing his now-adult patients about their experiences being treated for eating disorders in their childhood and teenage years. We want to know what coping strategies they use and what their lives are like now.

“What has helped and what has hindered your recovery?” Dr. Brown asks.

Our patient is a professional athlete, a decorated Olympic medalist. Her body has carried her to victory again and again. Parades have been given in her honor. Her photo has been in sports magazines. She does not like being called “strong” because it makes her feel big.

Dr. Brown treated this patient when she was a young phenom on a high school basketball team, at the time unknowingly destined for greatness in the realm of physicality.

But first came the anorexia.

Dr. Brown coached her through her malnourishment and disordered behaviors for many years. She recalls her mother driving her an hour each way several times a week for weigh-ins at his office. This was 15 years ago, before the Olympic medals.

She now talks to her therapist about how much she resents her body for being the wrong shape and size. She tries to thank her body in the mirror. She feels guilty for eating too much at Christmas. She knows this is not a healthy thought pattern. She is open to learning mindfulness exercises with Dr. Brown over Zoom.

“What’s a reasonable expectation of recovery from an eating disorder?” I ask Dr. Brown after we hang up with our patient. I had been having trouble hiding my sadness for her during the call. It was not pity, exactly, but something closer to empathy for someone in pain.

“Obviously she’s had success in life,” I elaborate. “But she’s still struggling so much.”

Dr. Brown answers with a pragmatic enthusiasm: “In terms of prognosis, you can have a successful life. You can get married, have children, a career. Live your life.”

He smiles and launches into the story of another one of his former patients who seemed to be very happy and stable in her adulthood. This other patient had recently admitted to him that although she spends most of her day undisturbed by the ghost of her eating disorder, at times it does pop into her mind in the form of self-berating thoughts around food choices. She shared that when this happens, she acknowledges the thoughts, and she then makes room for them to pass.

“So maybe you’ll be bothered by five seconds of the angel fighting with the devil in your head when the dessert cart is wheeled around to you,” Dr. Brown continues. “Is that recovery? Is that 100%? It’s hard to say.”

He leaves me to consider his words. So much of what I’ve encountered in medical school—and in my social work career before—has circled this idea of reasonable expectations or tolerable pain.

For our patient with anorexia, recovery might mean physiological health but persistent mental anguish. For another patient with the same condition, the mental anguish might be intolerable; recovery is where it subsides.

I have come to see “recovery” as a nebulous space between the status quo and a total alleviation of the illness. Most of that space represents a kind of improvement, but like Dr. Brown suggests it is hard to say if that is enough.

Medicine, technology, therapy, and all the other available resources for healing can solve only a certain depth of problems. We as clinicians are constantly calibrating odds: Odds that a test will confirm a diagnosis, odds that a treatment will cure an ailment, odds that a patient will survive their disease course (or our intervention), and so on.

This is the same principle that leads us to treat a patient who suffers from chronic lower back pain with nonsteroidal anti-inflammatory drugs and “as much activity as tolerated.” There is no better 21st century intervention for musculoskeletal discomfort.
The odds that the patient will improve are highest with that particular treatment plan.

But what does it mean to tolerate pain? What threshold of pain does the physician expect the patient to tolerate, and how much should a patient endure before they can say they can tolerate no more? Where is recovery to be found?

Before medical school, I coordinated a syringe access program for people who inject drugs. A lot of our participants would tell us that doctors do not believe them when they are in pain, regardless of their chief complaint. They are told they are addicted to drugs, to painkillers. They are told they are "drug-seeking." They are told to manage their pain on their own. They are told that sobriety is the only route to recovery. The doctors are gatekeepers of relief, in their view.

Perhaps the doctors have a different version of healing and recovery than they do. Perhaps these versions are reconcilable.

At the syringe access program, I worked with a teenager who annoyed me to no end. Every time he came in, he wanted something from me: a snack, water, to use my phone, for me to watch his dog while he went to the bathroom. I thought he was disorganized and childish. I thought he should get his act together and stop asking me for things that he could do for himself.

He came in week after week, until he did not. I later found out he had died.

I have to admit, I assumed it was from an overdose—not an uncommon tragedy among our participant base. It turned out he had brain cancer, an insidious malignant growth that ultimately caused his death. He had been using heroin for the pain caused by his disease. Seeing in him only an irresponsible junkie, his doctors did not adequately treat his pain, so he found another way to “tolerate” his reality.

I felt like I failed him just as his doctors had. I had not heard his pain, only his requests for me to do things for him—things that I thought he could do on his own. I had an expectation for his life that was not reasonable. He told me clearly about his needs, and instead of meeting them or helping him meet them elsewhere, I just willed him to become more self-sufficient.

I think about that kid all the time, especially when patients request “extra things” like ice water or another blanket just as I am leaving their room. I often feel a flash of resentment, but then I wonder if the “extra things” are actually the most human things I can offer to someone in their time of suffering, the things they are asking for and need most.

“Never see in the patient anything but a fellow creature in pain,” enjoins the oath of Maimonides, a version of the Hippocratic oath that new doctors take, known best for the promise to “do no harm.”

And so to see the patient, we must see their pain. We must try to reconcile our expectations with theirs and arrive at a shared vision of what constitutes a reasonable recovery for them. We must understand their requests as communiques from a place of suffering.

“It’s nothing I can’t deal with, really,” our patient with anorexia tells us. “I just take it day-by-day.”

I hope that she is right. I hope that her pain is tolerable, and if it is not, that she has people around her who will help her get to a place of recovery, whatever that looks like for her.