Your Son Is a Very Sick Boy: What One Says Matters

On a July morning, I was anxiously waiting for a call from my 19-year-old son Adam, who was driving home from vacation. A call did come, but it wasn’t from Adam. Instead, it was someone else informing me: “There had been an accident.” My son suffered fatal injuries, and Adam died that afternoon.

That day began as a typical summer morning and swiftly became anything but. As I reflect, I try feverishly to remember the details. Many remain blurry but there are sentences and words that are permanently etched in my brain.

At that time, I was a counselor at a hospice agency and familiar with death. I had comforted many patients who were dying. From the outside, I might appear to be an “educated consumer” of medical speak. More recently, I have worked as a palliative care counselor at a busy level I trauma center and realize how naive I was to the words that rushed toward me that day. I share this essay to provide the perspective both of a family member on the receiving end of bad news and from my current role as a deliverer of the same.

On the morning of the accident, multiple phone calls arrived. I was told there had been an “accident,” that Adam had a broken leg and that his friends were uninjured. A later call came from a nurse to inform me that Adam had been airlifted to a trauma center and to ask if my son was taking any medication. In that moment, I remember thinking it was odd that she was asking me. Why wasn’t Adam giving her this answer? After posing that question to her, I received a response I will never forget. In a very low, compassionate voice, the nurse replied, “Your son is a very sick boy. He has not spoken to us since he got here.”

Sick. A word I now understand to mean much more than it first appears. In recent years, I have learned the true meaning of sick. I have worked closely alongside the trauma team as they care for patients who are sick, and I see many patients with life-threatening injuries who are sick, just like Adam. Together medical team members conduct formal meetings with patients and families, during which they break bad news, provide updates, dissect medical verbiage, and answer questions. They translate what sick truly means.

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Examining my journey from both sides has enabled me to comprehend and appreciate the complexity of the word sick and the gravity of its meaning. On that day in July, when the nurse used that word to describe my son’s critical condition, I was oblivious to the concept that he could die.

Back then, if I was told someone was sick I would believe they would get well. Conversely, my experience has taught me that when clinicians use the word sick, it usually translates to uncertainty about the outcome and that the family should be worried. They should be worried about the possibility of a complicated hospital course, further invasive procedures, and the roller coaster of emotions that come from fluctuating news, sometimes bad, sometimes good, sometimes in the same hour. Sick could also signify death.

Sick is one of several words that I have learned can be misinterpreted. There are so many others with huge implications that can be easily misunderstood by patients and families. How sick was Adam? He was extremely sick. He was so sick that he couldn’t be saved.

In the whirlwind of calls that day, I was told that Adam’s vitals were stable, another word that confused me. I thought the word stable was a good sign. His vitals were stable, therefore, no need to worry or panic. How is it then that Adam could be stable only to have his heart stop a few hours later? Those were my thoughts long before I became all too acquainted with this scenario. My experience working in a trauma center has taught me that “good things happen very slowly, and bad things happen quickly,” a line I learned from a colleague during a family discussion, and one I have incorporated into my practice. When I heard Adam’s vitals were stable, I remember thinking I could take a breath and that there was light at the end of the tunnel. I assumed that stable implied Adam would be getting better. I was wrong.

Following the news of his crash, I believed that Adam would get better. While I was imagining my son coming home to me, the medical team likely knew he wouldn’t get better. During meetings, families invariably ask whether their loved one will get better. Sometimes it is being asked from a place of despair or the need to hear a glimmer of hopeful news. I have learned never to assume that the family is aware of the continuum the word better lives on. Often families believe and equate better to returning to exactly the way they were before the unexpected occurred. Clinicians owe it to patients and their families to drill down and explain.

Better is a very big word that has more than one meaning after severe trauma. I have developed a practice of asking the physicians to plainly describe to patients and family members what better might look like. I am hypersensitive to the word and realize that better can take a long time, if and when better ever happens. Better will probably look very different from what a family
or patient ever imagined. In my case, I was never given the chance to ask the question: Will Adam get better, or will Adam recover?

Although Adam didn’t get that chance, most patients brought into US trauma centers do recover. Recover, like better, can be unintentionally misleading and doesn’t imply returning to a preinjury state of health. When families ask about recovery potential, it can be the most dreaded question to answer because so much uncertainty remains as to long-term outcomes, especially in the setting of traumatic brain injury. As more data are accrued and outcomes become more clear, it is incumbent on clinicians to convey the news that recovery does not necessarily indicate returning to baseline. Recently, a physician I work closely with said he likes to offer “the most likely scenario” to manage expectations, and the medical team has now incorporated that language into family discussions. Without this additional information, families are left to imagine what recovery may look like and often anticipate or believe the impossible.

Although I live with the indescribable heartache of losing my son, I realize after working in trauma care, I was spared from a different type of heartache, wondering if my son would wake up. I was spared from the overwhelming exhaustion I witness among families that sit vigil, enduring lengthy hospital stays plagued with the ups and downs of daily progress reports and discussions. They experience both hope and the loss of hope and the ongoing wonder of whether their loved one will ever wake up.

Wake up is another term used consistently, but clinicians cannot take for granted that it is understood. Uninjured people go to sleep and then wake up. But waking up following brain injury is an entirely different entity. It has been my experience that many families assume their loved one will wake up when the sedatives are stopped. They often assume there will be an emergence to consciousness. I have observed as families appear both surprised and defeated when they absorb the knowledge that their loved one has not been sedated. Understanding that the severity of the injury being the reason they did not wake up can be a painful albeit valuable piece of information.

The words clinicians say matter, but I would be remiss if I did not mention the importance of the words, which were unfortunately not said. When Adam’s dad and I received the phone call that Adam had died, we were at the Newark Airport. We asked, “What do we do next?” and were told to go home and be with our other son, Jonathan, and that is what we did.

I continuously relive that day and imagine how it might have been different if an option was presented to get on the plane and be given the opportunity to say goodbye and ultimately be the last one to hold Adam before he was taken to a morgue. I have supported and escorted many families who did get this opportunity, which can be so valuable and even sacred. Sadly, in those minutes, I was unable to challenge the directions we were given to go back home.

Clinicians must recognize that families dealing with tragedy have been sucked into a vortex and may need others to think for them. “What do we do next?” is a question our families often ask. Clinicians can help guide them thoughtfully and thoroughly. They simply don’t know what to do.

I urgently want to convey with every part of my being to anyone breaking bad news that words, those spoken and those unspoken, are impactful and can make all the difference. Please remember that you are thinking for a family who didn’t experience the physical injuries but are likely psychologically traumatized.

Adam didn’t get better, even though he was stable, he didn’t have a chance to recover, and he never had a chance to wake up. But the compassion I heard in the voice of the nurse who told me my son was “a very sick boy” is tenderly tattooed forever in my brain. At that moment, I knew she cared about my son before he took his last breath. I could hear it in her voice.