On the Other Side of the Table

Venkata Pradeep Babu Koyyala

Address for correspondence: Venkata Pradeep babu Koyyala, Tezpur Cancer Center, Near Bihauri Mini Stadium, Bihaguri, Tezpur, Assam, 784153, India (e-mail: pradeepbabu.koyyala@gmail.com).

Department of Medical Oncology, Tezpur Cancer Center, Assam Cancer Care Foundation, Tezpur, Assam, India

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After nearly an 8-hour journey, the smile on his newborn face and the first touch were memorable and precious—for any father seeing his first born. The routine of my wife Pavani has changed forever, perhaps for good. And priorities changed in life—both personal and professional. Despite being an anesthetist, she has to bear the pain due to incomplete epidural anesthesia. But, she still managed to smile. The last 9 months changed her levels of endurance permanently to much higher levels.

I was engulfed in my oncology fellowship. I just had barely enough time to spend, only a few weekends and evenings with young Viswa.

Everything in life seemed absolutely beautiful and exciting. Until one day, Pavani told Viswa does not give eye contact with her and did not have a social smile. I told it’s quite normal at that age and asked her not to worry. Her worry persisted as much as my denial that anything was abnormal.

As a physician, I was trained to question the diagnosis till I was satisfied with my own findings and able to explain the condition. At last, the father in me overtook the physician in me overtook the father in me to rule out any possible abnormality. Following the first appointment with New Delhi’s prime child psychiatrist and a full day’s battery of tests, he was labeled as having autistic spectrum disorder.

We never knew that these appointments and assessments are going to be a part of our life for years to come. We joined him in a day care, only to see that he never preferred to play with other children. He chose to be around his teacher. He never passed a ball to another child nor did he comprehend what the other child was trying to communicate with him. However, I always wondered how only his mother understands his tantrums and his needs, whether it’s his favorite music channel or a fruit. She started supporting mothers of other autistic children who were unable to understand the condition completely and no counseling could be better than a communication between two mothers. One of such event was a phone session with a sister of my colleague whose marriage was disrupted and attempted suicide along with her autistic child, luckily saved in time. The problem of autistic spectrum disorder in India is bigger than it is assumed and less understood than what is needed. I involuntarily became a passive observer of the daily totally new counseling and therapy sessions in action. And I embraced them into my practice. And I am sure that a mother of an autistic child sweeps any new place for safety better than secret services, though looks like exaggeration, one has to witness the act before disagreement!

While working at Vizag, I tried to understand and visualize what each of my patients and their families undergo, hearing a diagnosis of cancer. Slowly, most of my patient and family conversations moved beyond cancer and cure.

Despite working in a hectic cancer outpatient, from two border states and the districts beyond, for, I never hesitate to spend few extra minutes with every patient and family, trying to make them understand the situation and possible outcomes, so that they can feel better and plan accordingly.

Ailments, regardless of whether they are mental or physical, disturb the emotional atmosphere of the family, and a few supportive words during such distressing times matter a lot in restoring some sense of balance and sanity.

While Viswa is growing, the problem seems to increase more than him, and I am now equally worried as his mother. Unable to see any improvements over a year at a local therapy center, and, satisfied with the discouraging remarks of a popular adult neurologist, we traveled to Christian Medical College (CMC), Vellore to seek the opinion of their child psychiatry division. Fearing how the rather 900 km overnight journey might impact negatively on Viswa, we planned to cover it by road, in the family car.

My decision suddenly provided an answer to a nagging question as to why even poor patients spend a lot of money on motor cabs while cheaper public transport is available. Several
cancer patients have poor general condition, some have complications, and some have post therapeutic complications limiting the chance of “normal modes of transport.” I dialed up all my contacts who were ever in CMC and finally uncovered a colleague in the department of child psychiatry.

Most psychiatric diagnoses appear to be made by excluding all possible organic causes. It is easier to ride a wild horse than getting a magnetic resonance imaging for a special child. The psychiatrists were kind enough to explain, reassure, and make us understand that the therapy and training were necessary for parents—to be patient with the child to an imperceptible but slow and steady improvement. We were asked to visit pediatric neurologist to exclude anything “organic.” We were astonished by the number of children and their parents waiting at that outpatient department.

Even for the pair of us who were doctors, the endless waiting outside consultation chambers, laboratories, and review rooms was physically tiring and mentally exhausting. Relief was in the kind words and courteous language of the very many doctors and the ever-smiling nurses.

Insistence on repeating a test at a particular laboratory is often futile. We were warned that reports from laboratory other than their hospital could be erroneous! We were often told that reports from elsewhere for metabolic screens were unreliable! Had it been a seminar or a classroom, the statistician in an oncologist would have been in complete disagreement over such super confident lecture.

As I was on the other side of the table, I did not dare to negate his tirade, fearing to see more fatigue in the little eyes of my son. The rigmarole of yet another round of billing, laboratories, and a urine sample from an autistic child could be very daunting! Despite our pleas that Viswa was not toilet trained and obtaining a urine sample would be rather difficult, the resident seems to care two hoots!

But that instance brought a permanent change in my practice. Whenever I now prescribe a test, I make it a point to ask the patient and attendant, whether they could afford the test and the treatment. Although I cursed the resident on that day, I was happy that this change helped a good number of people I am dealing with in my practice. I also understood the responsibility of giving feedback. I wrote a lengthy letter describing the ordeals being faced by patients seeking the best medical care in one of the premier institute in India.

Interacting with various people in the never ending queue lines at various junctures in the process of consultation, we observed that more than one-third to half of the families we interacted were from North Eastern India and from the neighboring country Bangladesh.

Despite good contacts, no economic constraints, and a colleague’s place to stay within the hospital campus, we were exhausted and sometimes aggrieved. We really felt bad for the families hailing from over two thousand kilometers, just on the belief and trust of better care, struggling with language, completely different food habits, understanding hospital procedures and endless tests done on their loved ones, and precious one’s.

My thoughts wander around to the cancer patients who require frightfully long periods of stay in more excruciating conditions, very far away, albeit abandoning their primary source of income. When I received a call from Tata Trusts about the option of serving in the Northeast, I made an instant decision, but was hesitant to discuss with my wife, to leave home and travel far. She, however, agreed readily, referring to the countless who travelled to the South, eager for relief like our own son.

Many of my friends and well-wishers questioned my decision and rationality of moving to Assam. Coincidentally, Tezpur is home to a big psychiatry facility. We were indeed astonished to find that more stigma is attached to a mental hospital than a cancer hospital in the society. My wife joined in the same institute as consultant where my son is currently receiving therapy. There is a remarkable improvement in Viswa in the 1 year we moved here, close to nature, our home away from home. Not everything is slow and gloomy while dealing with an autistic child. Each child with this condition has a special interest and ability beyond what is considered normal. It is the responsibility of parents to guide them through. Our Viswa runs like a horse, climbs like a trained commando, and solves the jigsaw puzzles in less than half a minute once he understands it. We never considered his condition as a disability, instead because of him we have paused our mechanical run in the life and started exploring other angles that are meaningful. He is our lucky charm and so is his laugh like pleasant and peaceful waves on the beach in a low tide.

I thank the Almighty for giving us the opportunity to sit “on the other side of the table.” It has completely changed my perception of how a good physician should be like. It is not the suffixes after the name, the medals, publications, and degrees that help patients and families suffering from any cause, but, the honest conversations embellished with honest empathy and concern, words, phrases, and suggestions that instill hope and trust.

Conflict of Interest
None declared.