

Beautiful Scar: Learning to Live with Tethered Cord Syndrome



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WRITER'S COMMENT: Before taking UWP 104F, my interactions with writing were minimal—mostly confined to the pages of my journal. I never considered that genres such as narrative medicine existed in which I would be able to combine my passion for health and research with storytelling. As an aspiring physician, I appreciate that case studies allow doctors to take rare disease encounters and reflect on aspects of patient care and policy that can be improved—and even changed—by writing about their experiences. In this piece, I chose to write about one of my close friends. I admire her strength in dealing with the physical and mental aspects of having a temporary disability, especially in a society that remains largely unwelcome to people with disabilities. Through my case study, I hope to shed light on different interventions the clinician's role can implement to improve patient outcomes. I also hope to leave the audience thinking of ways to improve the experience of disabled people in society.

INSTRUCTOR'S COMMENT: For this UWP 104F: Writing in the Health Professions lay audience case study, students gather both primary - by interviewing a patient - and secondary source (from medical reference resources and professional journals) research information. In her piece about Tethered Cord Syndrome, we can see Prachi's thoughtful and purposeful research - she gives her patient a voice with carefully selected quotations and paraphrase, while her medical research writing gives us deeper insights into meaningful themes emerging from the patient's experience. Thus, not only do we learn about a lifelong condition of the spine that begins in early childhood, we also learn about how children are often marginalized in medicine, in society, and in families and

cultures. This case study invites meaningful lessons and dialogue for medical providers, parents, educators, and community members - we should all examine how we treat each other, especially about health.

—*Agnes Stark, University Writing Program*

"I would have severe pain in the back of my legs and lower back. Compared to other kids on the playground, it was more difficult for me to climb on the play structure and move around normally", Maya¹ explains as she makes herself more comfortable in her chair, a far-off look in her eyes. The spinal cord is a structure that runs through the center of the spine from the brainstem to the lower back. It serves its role as a part of the central nervous system and carries messages from the brain to the body. Under normal circumstances, the spinal cord moves freely, however, in some rare cases a neurological condition in which the spinal cord is attached to the surrounding tissues of the spine develops and the spinal cord cannot keep up with the lengthening of the spine as it grows ("Tethered Cord Syndrome"). The result of this may be nerve damage and severe pain ("Tethered Cord Syndrome"). This condition is known as tethered cord syndrome (TCS).

TCS manifests itself in a variety of symptoms including back pain, numbness in the legs or feet, walking on toes, chronic constipation, and deformities such as hammertoes. ("Tethered Cord Syndrome"). At five years old, presenting with back pain and numbness in the legs, Maya was diagnosed with tethered cord syndrome. At six years old, surgeons operated on her back. At nineteen years old, although the severe pain has come to pass, Maya still gets annual spine checkups at the hospital, walks with a limp if she gets too tired, and has a scar on her back where the incision was made as a reminder of her surgery all those years ago.

"Getting a diagnosis was the most difficult part of the process,

¹ Maya is a pseudonym used to protect the identity of the interviewee.

because how can a child explain their pain in a way adults can understand it, you know? I didn't have the language to describe what I was going through, I just knew it hurt a lot", Maya explains. Not only was it difficult being a child trying to navigate the intense pain, but it took several doctor visits and persistence from Maya's parents for the correct diagnosis to be made. Usually, TCS is detected and diagnosed quickly in young children with two or three of the aforementioned symptoms occurring at once ("Tethered Cord Syndrome"). In Maya's case, however, the condition was not easily diagnosed. Most doctors performed a physical exam, admitted that they were stumped, and made a reference to another provider. Others made an incorrect diagnosis of scoliosis and sent Maya on her way. This is significant because scoliosis doesn't require surgery whereas TCS requires surgery as treatment.

Making a diagnosis is one of the most difficult but important parts of a primary care provider's job (Singh). They must balance missing a serious illness with potentially making costly referrals (Singh). Concern about patients' health as a result of diagnostic errors has recently risen in the medical community. In their study analyzing 18 databases, Panesar et al found that in primary care, diagnostic and prescribing errors "are the most likely to result in avoidable harm". Singh proposes eight potential interventions to reduce the global burden of diagnostic errors. Three of the most intriguing interventions Singh mentions are: encouraging government policies that support primary care, improving access to diagnostic tests, and providing systematic feedback to clinicians about their diagnosis.

Another situation Maya commonly faced at the doctor's office post-surgery was the doctor debriefing with Maya's parents rather than her about the status and updates of her condition. "It made me feel like I was cast away to the side, and that I wasn't a person, but rather my condition. I was in the same room, and yet, I wasn't being acknowledged although the conversation was about me." According to Strivers, a professor of sociology at UCLA, children's lack of responsiveness to physicians' questions is predictable. It thus

can be improved by implementing three strategies: asking children social questions early in the visit, phrasing questions as yes or no questions, and directing their gaze at children during each question (Strivers). This will help physicians secure more information about the child's health and also socialize the children to be more proactive patients (Strivers). In this way, the effects of including children in their check-ups helps assert a child's autonomy and establish a sense of responsibility for their health early on, encouraging them to continue to care in the future.

Once the diagnosis was made, Maya waited for several months before her surgery took place. Under the bright lights of the surgery room, the surgeons made an incision into Maya's lower back. Metal clamps kept the target area open and accessible. Needles were inserted into her lower body to monitor nerve function even while she was asleep under anesthesia ("Tethered Spinal Cord"). The surgeon carefully lifted the bone over the tethered area of the spinal cord and cut the lesion, releasing it from the spinal cord ("Tethered Spinal Cord"). This is called a laminoplasty ("Tethered Spinal Cord"). Complications as a result of this surgery are rare. After three hours in the operating room and seventy-two hours of strict bed rest, Maya's spinal cord was allowed to freely move and her body could continue to grow with her spinal cord. However, this was not the end of her journey with the condition.

"Many people seem to think, especially with a physically disabling condition, that once you undergo surgery, you are cured and everything will be how it was before, if not better. This is far from the truth," Maya asserts, trying to wiggle her toes (something she is unable to do to this day) to prove her point to me. Besides the small seen remnants of her disabilities, Maya was also dealing with a hidden battle—a mental one.

According to Dr. Ring, a graduate of Dell Medical School of UT Austin, nociception is the pathophysiologic response to actual or potential tissue damage. Pathopsychology is a branch of psychology that studies the mechanisms of mental activity that deviate from the norm (Nikolaeva). As such, it follows that a pathophysiologic

response is a mental response that deviates from the norm (Nikolaeva). Pain, on the other hand, is the “unpleasant thoughts, emotions, and behaviors that can accompany nociception” (Ring). Of course, Maya was in a lot of physical pain following surgery and went to physical therapy to help bring back her normal range of movement, but there was also pain caused by society.

Ring asserts that people experience more pain when they “have more symptoms of depression...[and]...anxiety”. If Maya wore a certain type of shirt to school, her stitches were easily visible for people to see. It wasn’t the curious looks her peers gave her that bothered her, however. It was the parents of those kids and her teachers shutting down her peers’ questions about her condition that was damaging. If we want to minimize the stigma behind being sick, going to the hospital, or having a disability, “we need to talk about it”, Maya says.

Whereas Maya’s advice addresses society, Dr. Ring suggests that there is also something clinicians can do to help the mental health of patients post-surgery and injury. Clinicians can guide people to return to their normal routine as quickly as possible, focusing on meaningful activity as a way to put pain in the background (Ring). Meaningful activities can include reading a book, spending time with friends, crocheting, and taking a walk outside. Addressing the mental and social health aspects of recovery would help patients feel validated and also serve as a preventative measure if symptoms of compromised mental health occur anytime during recovery.

During her recovery, Maya also faced societal ignorance within the community she belonged to. In the South Asian community, there is a popular mentality “log kya sochenge”² that keeps people from doing ‘scandalous’ or ‘shameful’ things. Due to this mentality, with issues of mental health, sickness, and disabilities, the community is quick to want to find an explanation or source of blame. Although Maya’s parents tried to hide the aunties’ intrusive

² Hindi phrase which translates to “what will people think”

questions from her, she could hear whispers that what happened to her was her parent's fault because it was genetic (tethered cord syndrome is not genetic, these were merely speculations people had). In turn, these speculations made Maya place the blame on herself for her condition.

“What I want for people to understand,” Maya says, a solemn expression on her face, “is that I don’t mind questions, in fact, I encourage them. But false assumptions were damaging to my journey to coming to terms with what I had gone through. Also, when symptoms would return, I would lose confidence in my abilities causing me to isolate myself. People expect you to be healed mentally once you are physically healed. They expect it to be a linear growth as well. I would consider these ableist views.”

The US Census 2019 revealed that there are approximately 1.4 million Asian Americans with disabilities in the United States. According to Dhanda, an activist and disability specialist, misinformed ideas of disability persist in South Asian communities due to a “lack of education and understanding of the issue itself”. Dhanda also cites the lack of terminology for disability, impairments, and conditions in South Asian languages (because they don’t exist) as another significant barrier to progress. In this way, changing the South Asian community’s perception of disabilities would simply require an open-minded audience that wants to learn the facts about disabilities, rather than continue to rely on false assumptions.

Maya adopted feelings of shame and loneliness for a long time but was glad to have the support of her family throughout her journey. Now when she looks in the mirror, picking an outfit to wear for the day, she doesn’t try to hide her scar but rather embraces it as a part of her identity and as a part of herself.

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