I'll Be Able to Walk When You'll Be Able to Fly: The Impact of Spinal Cord Injury

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WRITER'S COMMENT: Before I took UWP104F: Writing in the Health Professions, I do not think I truly realized how strong my passion for narrative medicine was. Writing had always been close to my heart, but as I traveled further down my path to medicine and enrolled in this class, I grew more and more aware of this concept of storytelling in science. As an aspiring physician, the idea that medical professionals can uplift patients' lives with their ability to write honestly about the obstacles of their patients' conditions—and even inspire change in healthcare policy—was revolutionary. I decided to write about a man I have had the privilege of knowing all my life, whose strength and discipline knows no bounds, even with an injury that modern medicine still cannot repair. I hope my piece sheds light on the intersection between government policy and human lives, and how every patient is affected by the decisions we make as a society.

INSTRUCTOR'S COMMENT: Shreya offers us a poignant and insightful case study on a family's ordeal with a father's devastating spinal cord injury. Purposefully crafted for a healthcare lay audience, Shreya's readers learn about the horrific accident, about spinal cord injuries, and about a family's life. With clear and precise detail, the case study weaves Dev's story with that of significant contextual medical information, and we learn the stark reality that this family faces every day, while at the same time feeling the love that keeps them together. We also learn about the fragile hope of spinal cord patients and their families when they face the political landscape's power over science research. Without judgement—and with so much honesty—Shreya conveys to us all what's at stake in the debate about the use of embryonic stem cells.

—Agnes Stark, University Writing Program

When Dev Khanna's[1] five-year old daughter sat on his lap and asked him a question she had asked countless times before, he could not help but feel yet another wave of exhaustion wash over him.

"Papa, why can't you get up and walk?"

"I can't walk for the same reason you can't fly, *gudiya*.[2] It's impossible."

Seventeen years ago, at only forty years of age, Dev lost an ability he had taken for granted his whole life. He and his family were involved in an accident on the freeway returning home from a road trip to Shenandoah National Park. A mere few moments was all it took for everything to change—a deer jumped in front of their minivan, and his wife lost control of the vehicle. It turned over a few times, killing his aunt in the process and smashing his neck forward, causing a contusion to his spinal cord.

What came next was the start of a harrowing medical journey. Horrified bystanders to the accident called 911; helicopters rushed Dev to the nearest hospital while paramedics stabilized his neck and back to prevent further injury. Once there, doctors dosed him with methylprednisolone, a steroid, in a desperate attempt to bring down the swelling in his spine, a key step taken to prevent the death of nerve cells ("Spinal Cord Injury: Hope"). Then, they operated. Two vertebrae in Dev's neck had partially shattered, so they took a piece of bone from Dev's hip and used that along with a titanium plate and titanium cage to repair the damage. They attached trails of tubing to his body that remained there for a month: a ventilator covering his face, and a gastrostomy tube and jejunostomy tube for feeding, respectively attached to his stomach and small intestine. In the beginning, he was unable to move any part of his body from the neck down. Time passed. Three different hospitals and three months later, Dev would emerge alive but forever changed.

The spinal cord is composed of nerves running down the length of the spine. It is a vital part of the body's central nervous system, serving as a conduit for electrical signals to travel to and from the brain to the rest of the body ("Spinal Cord Injury"). On both sides of the spinal cord exit nerves that connect to the peripheral nervous system, allowing movement

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[1] Patient name and medically irrelevant details have been changed to maintain confidentiality.

[2] Hindi epithet meaning "doll".

of the extremities (Rubin). An impact to the vertebrae—the bony disks of the back—causes corresponding damage to the soft spinal cord beneath ("Spinal Cord Injury: Hope"). Nerve cells die or become too badly damaged to conduct signals, resulting in either incomplete paralysis, in which some movement and sensation below the site of the injury is preserved, or complete paralysis, in which no movement or sensation is preserved ("Spinal Cord Injury: Hope"). No two SCI patients are exactly alike in terms of the extent of their paralysis, which depends on what vertebral area of the spinal cord was affected and individual differences beyond that. Generally, the higher the site of the injury, the more widespread the paralysis. Starting from the neck down, the four sections of the spinal cord are: seven cervical (C) vertebrae, twelve thoracic (T) vertebrae, five lumbar (L) vertebrae, and five sacral (S) vertebrae (Rubin).

Dev's injury spans the C4-C5 vertebral area. He has incomplete quadriplegia, which affects him neck down in all four limbs. Just after his accident, the right side of his diaphragm was paralyzed. Over time it recovered enough so that he is able to breathe on his own, but his ability to cough is diminished, leading him to struggle to clear his throat. His bowel and bladder functions were also impacted, requiring catheterization every four to six hours. He retains some sensation in his legs, though no movement, and he has limited movement in his arms, so he can only use a power wheelchair for mobility. He cannot type, write, or firmly grasp objects, but with the little movement he retains in his left hand, he is able to feed himself, which is something he remains grateful for.

Spinal cord injury (SCI) is a relatively rare medical condition in the United States. A quarter of a million Americans are currently living with SCI, and about 12,000 new cases arise every year ("Spinal Cord Injury: Hope"). Yet the human toll it takes on the lives of those affected is immeasurable. Though Dev has made peace with how his life is now, he admits that sometimes it is hard for other people to understand his condition. "They see people in wheelchair[s], but they don't know too much about it . . . [T]here's a very great misconception that if we work hard enough we would be able to walk," he says, as his fingers twitch on the joystick of his wheelchair, a reminder of the lingering spasticity in his body that remains despite his medications.

Dev's daughter, only four years old at the time of the accident, found it especially difficult to understand why her father was not able to carry her on his shoulders anymore. He tried to explain it to her as gently as possible: the same way she was not able to fly like the butterflies she chased in the backyard, the same way he was unable to stand and walk like her. The frustration only settled in when he found himself explaining the same thing to his adult acquaintances, who wondered why he couldn't work. After all, Dev still needed to provide for his young family at the time: his wife, his daughter, and his eight-year-old son.

This remains to be one of Dev's most pressing problems. Financial troubles have plagued him ever since the accident. He used to be an engineer and had been pursuing an advanced degree at the time. Now, Dev regards it as nothing short of a miracle that his ten years of work prior to the accident allows him to receive Social Security disability income. However, the total is only a fraction of what he used to make seventeen years ago, and it is a fixed income, meaning only about half of it adjusts for the rising inflation each year.

Dev's wife cannot work since, as his primary caregiver, she must stay home all day. When asked about her, his voice quiets. "My wife is a petite woman," Dev says, staring off into the distance. "She was never built for the heavy work of lifting or turning an adult male . . . but we cannot afford to hire a caregiver."

Dev and his family are in a very difficult situation. In Dev's case, there is no long-term disability care plan offered by Medicare for in-home care. They had limited benefits for a few years following the accident, which included having a home health aide come by for two hours in the morning to help Dev get ready. When those benefits ran out, the burden fell on Dev to pay for it out-of-pocket. Unfortunately, he cannot afford more than those two hours of help, even as Dev's wife has developed arthritis and struggles more to take care of him every day.

His only other option is to go to a nursing home as a permanent resident, but this is the last thing his family wants for him due to a bleak past experience. Dev's condition makes him susceptible to catching urinary tract infections (UTIs); a few years ago after a routine hospital procedure, he contracted a severe UTI that required treatment by intravenous antibiotics. He was sent to a nursing home covered by Medicare to stay for a little over a week, during which he was routinely ignored by staff, who refused to perform parts of his bowel management program, and where he was surrounded by other ill patients, which posed a danger to his weakened immune system. He reflects on his experience with chilling honesty: "The day my wife is unable to take care of me, I can go to a nursing home and they'll take me, [but] I know [with] the kind of care they'll be able to provide, I'll likely fall sick very quickly. . . then die."

As for a cure? The medical community seems miles away from a substantive answer on how to completely restore mobility, sensation, and function to SCI patients. Part of the answer may lie in research into stem cells, undifferentiated cells in the body that can develop into any cell—including nerve cells. In particular, fetal stem cells, which are harvested from discarded embryos from fertility treatments, have the greatest potential to differentiate into any type of cell, whereas adult stem cells are more limited in the types of cells they can produce ("What Are Stem Cells?").

However, the politics surrounding abortion stand as a significant roadblock to promising stem cell research. Conservative administrations in the past, such as that of George W. Bush in 2001, have repeatedly denounced the use of human fetal tissue stem cells from elective abortions and leftover embryos from in vitro fertilizations in stem cell research, claiming the government cannot support the "destruction of human life" (Park). This is despite the fact that these tissues would be thrown away regardless (Park). At present, the Trump administration is placing restrictions on the use of fetal tissue despite provisions that ensure informed consent from would-be donors (Andrews). The Administration's Health and Human Services (HHS) department says on its website that it will strive to find alternative ways to advance stem cell research without using fetal tissue, but top researchers in the field have their doubts ("Statement").

Dr. Lawrence S.B. Goldstein of UC San Diego School of Medicine notes that there is a common misconception that our knowledge of stem cells is extensive enough to find viable alternatives to the stem cells found in fetal tissue. In an interview with Julia Haskins from *AAMCNews*, he explains that there is no easy replacement for fetal tissue. Adult stem cells have limited potential to develop into different types of cells, so when researchers use them in experiments, they must check these experimental cells using fetal tissue as a reference to make sure the correct cell type has formed. Because stem cells in fetal tissue have the unique ability to differentiate into almost any type of cell, they serve as a necessary validation step for comparison (Haskins). Further adding to the confusion and hampering stem cell research are new federal restrictions on research involving fetal tissue (Haskins). These policies now call for redundant ethics reviews that slow down progress and discourage new researchers from starting projects looking into cures for SCI (Haskins).

SCI is a devastating diagnosis with lifelong impacts. The search for a cure remains politicized, and it is the patients and their families who must pay the price. While Dev remains hopeful for a cure, he ruefully reflects on how ever since the potential of fetal stem cells was discovered, a cure has been promised every five years, only to be repeated as another five years passes. There is a long road ahead for him as well as for many other SCI patients. He can only hope that the road comes to an end before it is too late.

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