



Overcoming Adversity: A Tale of Resilience and Rehabilitation in Transverse Myelitis

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Introduction:

Transverse myelitis, a rare neurological disorder characterized by inflammation of the spinal cord, presents significant challenges to both patients and healthcare professionals. Among the myriad of cases, Keyur's journey stands out as a testament to the resilience of the human spirit and the profound impact of comprehensive rehabilitation. At just 15 years old, Keyur's life took an unexpected turn when he was diagnosed with transverse myelitis affecting his cervical spine, resulting in full quadriplegia and ventilator dependency within a mere 24 hours.

The swift and severe onset of Keyur's condition presented a daunting prognosis, compounded by the absence of sensation from the neck down and significant impairments in mobility. His dreams of becoming a pilot for the U.S. Air Force seemed dashed as he faced the daunting prospect of adjusting to a life drastically altered by his condition. Moreover, Keyur's familial circumstances added another layer of complexity; with the recent loss of his father to cancer and no nearby relatives to provide support, Keyur's journey toward recovery was fraught with emotional and logistical challenges.

Amidst these daunting circumstances, Keyur's unwavering determination and the comprehensive care provided by a multidisciplinary team of healthcare professionals, including physical therapists, became instrumental in charting a path toward rehabilitation and eventual reintegration into his community. Physical therapy played a central role in Keyur's rehabilitation journey, focusing on goals ranging from enhancing mobility and strength to providing caregiver education essential for his safe discharge home.

Keyur's progress throughout his rehabilitation journey serves as a beacon of hope, illustrating the transformative power of perseverance and interdisciplinary care in the face of seemingly insurmountable odds. From initial interventions aimed at maintaining range of motion and skin integrity to the gradual reemergence of neurologic recovery, each milestone achieved underscored the importance of constant reevaluation and adaptation of treatment strategies.

Moreover, Keyur's story highlights the indispensable role of patient advocacy and empowerment in navigating the complex landscape of disability. Through ongoing communication with his care team and active engagement in his rehabilitation process, Keyur and his mother emerged as powerful advocates, not only for themselves but also within their school and broader community.

As we reflect on Keyur's remarkable journey, it serves as a poignant reminder of the profound impact healthcare professionals can have in empowering individuals to defy expectations and reclaim agency over their lives. Keyur's determination, coupled with the unwavering support of his care team, embodies the essence of resilience in the face of adversity, inspiring countless others to embrace the transformative potential of rehabilitation and the boundless possibilities of the human spirit.

Case Description

Keyur is a 15-year-old boy who developed transverse myelitis of his cervical spine (C-2 to C-5) with full quadriplegia and ventilator dependency within the first 24 hours. Over the course of the first month of hospitalization, Keyur made very little recovery and could only demonstrate trace to poor movement in the right wrist and right ankle. He was transferred to an inpatient respiratory rehabilitation unit with the goal of providing family education for a safe discharge home. Prior to his illness, he lived alone with his mother in a two-story condominium. His father recently died from cancer and there was no other family nearby to provide support. Keyur was an honor student and wanted to become a pilot for the U.S. Air Force. His past medical history was significant for depression.

Examination

Keyur initially presented with 0/5 strength throughout except minimal right ankle dorsiflexion and minimal right wrist extension. Sensation was absent from the neck down, and he was dependent for all mobility. He was unable to tolerate sitting out of bed in a chair owing to anxiety and discomfort, and

was unable to hold up his head. His tone was flaccid from the neck down and ROM was within normal limits throughout. He was dependent on a ventilator for all breathing, and he was unable to produce a cough.

Evaluation

Keyur presented with the following problems: decreased strength, decreased mobility, decreased airway clearance, and respiratory insufficiency. In addition, he had immense needs for caregiver education. His initial goals for physical therapy included tolerating out of bed in a wheelchair for 8 hours to prepare for return to school, power mobility on level surfaces with supervision, and caregiver education regarding all aspects of dependent care.

Physical Therapy Diagnosis

Impaired strength and decreased functional mobility due to transverse myelitis.

Physical Therapy Prognosis

Good potential to achieve the above goals with caregiver assistance. Ambulation not likely due to medical prognostic factors of quick speed and severity of onset, slow rate of neurologic recovery, and complicating factors such as ventilator dependency. Keyur did have good potential to use a power wheelchair with a head array or sip-and-puff mechanism in the community.

Physical Therapy Interventions and Reexamination

Interventions were initially aimed at maintaining ROM and skin integrity through positioning, pressure relief, and family education. Out-of-bed tolerance was increased with the use of a tilt-in-space wheelchair with elevating leg rests, an abdominal binder, and compression stockings to provide vascular support. Strengthening of available muscle groups was performed using traditional therapeutic exercises as well as biofeedback and neuromuscular electric stimulation (NMES). As the weeks went on, Keyur began to experience neurologic recovery, and it was crucial to reexamine and reevaluate and adjust goals and interventions as necessary. A time line is provided below to illustrate the highlights of his medical and physical therapy course in rehabilitation:

September: Onset of illness, full quadriplegia, and vent dependency in first 24 hours

October: Interventions as above; began standing program using a tilt table, sitting edge of mat with maximal assistance; development of grip on right upper extremity, development of increased tone (modified Ashworth scale 2 to 3) throughout all extremities

November: Began stand-pivot transfers; developed gross flexion/extension of right leg, minimal right elbow flexion (brachialis) and bilateral elbow extension

December: Began ambulation training in partial weight-bearing walker (knee immobilizer and molded ankle-foot orthosis on left lower extremity); developed right biceps strength; started weaning from the ventilator; received power wheelchair for mobility

January: Began walking with platform rolling walker, rolling supine to prone independently; moved left leg for first time (knee flexion/extension, great toe extension); tracheostomy capped during the day and bilevel positive airway pressure (BiPAP) at night

February: Decannulated with no external support and was transferred from the respiratory rehab service to the neuro rehab service to achieve new goals of increasing independence with transfers and ambulation

March: Started performing bed mobility, sit to stand, and transfer board transfers with supervision only; ambulating with walker and no bracing and supervision only; starting to propel manual wheelchair with minimal assistance; received Botox injections to bilateral adductors and left hamstrings

April: Ambulating with forearm crutches; stood with quad cane for 30 seconds; moved left ankle for first time; discharged from inpatient setting to outpatient therapies

Currently: Primary power wheelchair user in community; uses walker at home and for short distances; Keyur is now working toward long-term goal of independent ambulation in the community.

Owing to Keyur's unexpected but definite neurologic recovery, it was crucial to constantly re examine and reassess his goals and interventions. It was also important to communicate his changes with the family and the team and to advocate for more time in intensive rehab. Finally, it became very important to Keyur, his mom, and the team to return Keyur to home and school before the end of the school year to get assimilated back into the community and to re-form peer relationships before the summer, when he would have a bigger chance of isolation.

A constant theme during his physical therapy course included the constant reexamination of strength in upper and lower extremities and the neck and trunk. This also required careful assessment and a good working knowledge of Keyur's fluctuating spasticity and subsequent communication with the medical team who adjusted his antispasticity medication. Interventions were progressed to work on Keyur's current strengths and to challenge his weaknesses. Gait training and orthotic and assistive device assessment was also everchanging and constant, and a variety of bracing options were tried to correct his left knee. Keyur was able to flex and extend his left hip and knee, but he felt unstable in late stance. An articulating ankle-foot orthosis (AFO) did not achieve the stability he needed, so he trialed a stance-control knee-ankle-foot orthosis on loan from a local vendor. He had difficulty making the mechanism work properly for him, so he continued on with the current program and continued to use only an articulating AFO on his left ankle. Another constant theme in his physical therapy course was the consideration of the disablement model. While addressing Keyur's impairments and functional

limitations was critical in the achievement of his goals, considering the impact of disability and handicap in his life was also very important to him. Physical therapy played a definite role in assisting Keyur and his mother to become advocates for themselves, both to his school and to the community. Currently, 18 months after his initial diagnosis, Keyur remains a primary power wheelchair user in the community and uses a walker at home and for short distances. He is now working toward his long-term goal of independent ambulation in the community and is beginning to take independent steps with a quad cane. Socially, he is active in extracurricular activities and is on the honor role at his school. He currently works for an airplane museum, where he is able to enjoy his love of aviation. He continues to work hard and is looking forward to attending college for technical engineering. This case is an example of the vast diversity PTs encounter in patient populations. Although all factors indicated a poor outcome, Keyur's immense determination and constant hard work helped him to achieve goals no one dreamed possible. PTs have an awesome responsibility to balance being realistic about expected outcomes while also challenging their patients to achieve their fullest potential. Working together as a team with patients and families, amazing and life-changing things can be accomplished.

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