

Threading Hope: Transformative Rehabilitation Strategies for KESHAV and Duchenne Muscular Dystrophy

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Introduction:

Duchenne muscular dystrophy (DMD) is a progressive genetic disorder characterized by muscle weakness and degeneration, often presenting challenges that evolve. KESHAV, a 10-year-old Caucasian boy, was diagnosed with DMD at the age of 4, marking the beginning of a multifaceted rehabilitation journey encompassing various interventions to address his evolving needs and optimize his quality of life.

From the initial stages of diagnosis, KESHAV's family embarked on a proactive approach to managing his condition, seeking periodic physical therapy sessions for family education and monitoring of muscle strength, function, and joint contractures. Early interventions included stretching exercises and the use of night splints to mitigate the progression of contractures, highlighting the importance of early intervention in the management of DMD (Emery, 2015).

Despite the challenges posed by DMD, KESHAV's family pursued pharmacological interventions such as prednisone under the guidance of his neurologist, resulting in modest improvements in strength but also presenting with notable side effects. This underscores the delicate balance between therapeutic benefits and potential adverse effects in the pharmacological management of DMD (Bushby et al., 2010).

As KESHAV progressed through childhood, the emergence of contractures and increased falls necessitated a comprehensive reassessment of his rehabilitation needs. Physical therapy sessions focused on addressing contractures through stretching exercises and discussions regarding the possibility of contracture releases in consultation with an orthopedic surgeon (Scott et al., 2018).

The transition to wheelchair use marked a significant milestone in KESHAV's journey, reflecting the progressive nature of DMD and the evolving needs for mobility assistance. Collaborative efforts between physical therapists, orthotists, and educators facilitated the transition to power mobility devices and addressed accessibility concerns in both home and school environments (Kientz et al., 2013).

As KESHAV entered adolescence, the focus of rehabilitation shifted to maintaining hand function and addressing emerging challenges such as scoliosis and difficulties in accessing technology. Adaptive equipment, including mobile arm supports and joystick-controlled wheelchairs, were integrated into his rehabilitation plan to enhance independence and participation in daily activities (Gonzalez et al., 2017).

Furthermore, KESHAV's evolving needs underscored the importance of a holistic approach to rehabilitation, encompassing not only physical interventions but also cognitive and psychosocial support to optimize his overall well-being and participation in society (Pane et al., 2018).

As KESHAV transitioned into young adulthood, ongoing assessments and interventions aimed to address emerging challenges in driving his wheelchair and accessing technology, reflecting the dynamic nature of DMD and the need for lifelong rehabilitation support (McDonald et al., 2018).

Through collaborative efforts between KESHAV, his family, and a multidisciplinary team of healthcare professionals, his rehabilitation journey serves as a testament to resilience and

adaptation in the face of progressive neuromuscular conditions, highlighting the transformative impact of comprehensive rehabilitation in optimizing the quality of life for individuals with DMD.

Case Description:

KESHAV, 10-Year-Old Caucasian with DMD KESHAV is a 10-year-old Caucasian boy with a diagnosis of DMD. He was diagnosed at 4 years of age when it was noted that he was slow getting up off the floor after story time at preschool and appeared unable to keep up with his schoolmates. He has been followed periodically by physical therapy since that time for family education in ROM and active stretching exercises and for monitoring the status of his muscle strength, function, and joint contractures. At 4 years of age, the family had been instructed in stretching of the heel cords to be performed daily and KESHAV had been fitted with night splints to maintain a neutral position at his ankles during sleep. (He was encouraged to wear his “moon boots” throughout the night, but if it was only 2 to 3 hours at neutral before he took them off, this shorter period was considered beneficial.) KESHAV was started on prednisone by his neurologist and became somewhat stronger and was able to run better. These functional gains, however, came with a price. KESHAV initially gained some weight, but since his parents knew to watch for this, his weight gain was not as great as it could have been. In addition, KESHAV was somewhat more active and inattentive in school. Despite the side effects, his parents chose to keep him on the medication because they felt the benefits outweighed the side effects. At 5 to 6 years of age, the stretching of hip flexors and iliotibial bands had been added to the daily stretching regimen because he had developed mild flexion and abduction contractures. At this time, KESHAV comes to physical therapy with the chief complaint of an increased number of falls (approximately four per day), increased difficulty rising from a chair and ascending and descending stairs, and no longer being able to get off the floor without the use of “furniture” along with his Gower’s maneuver. Strength in the upper extremities (UE) is graded in the “good” range (4 out of 5), with the lower extremities (LE) grading “fair” (3 out of 5) to “poor” (2 out of 5) in the proximal muscle groups. Measurements of joint contractures revealed hip flexors that measured –10 degrees bilaterally, iliotibial bands at 0 degrees bilaterally, knees at neutral, and –10 degrees at the right ankle and –8 degrees on the left. In the UE, ROM was within normal limits bilaterally and functionally still independent. Stretching exercises were reviewed and emphasized with the family. Contracture releases were also discussed with the family as an option and a future referral to the orthopedic surgeon was discussed. KESHAV and his family were instructed to return to physical therapy in conjunction with being fitted by the orthotist with the long leg braces should they opt for surgery. The need for a wheelchair, only to be used for long-distance transport and on uneven terrain, was addressed, and since it had been discussed at previous visits, they were ready to order this and chose a power wheelchair. They had a “buggy” that they used for long distances, but it was clear that this did not provide the independence that KESHAV wanted, especially outdoors with his friends. Contact was made with the treating physical therapist in the school district for his or her suggestions or comments regarding power mobility, and issues related to home and school accessibility were discussed with the family and therapist, in terms of both transport and access. KESHAV became a full-time wheelchair user at 12, and despite the lateral support on his chair, he developed scoliosis, which required fusion when it reached 40 degrees. Following the fusion, KESHAV had trouble feeding himself and was ordered a mobile arm support and also began to use the tilt feature on his most recent power chair not only for pressure relief but also to clear the door while entering his adapted van since he grew 3 inches following the surgery. As KESHAV got older, the focus of therapy shifted to maintaining hand function, and resting hand splints and ROM for the long finger flexors and elbow flexors were taught. At 22, KESHAV was having increasing difficulty driving his chair. He was unable to drive in reverse and could no longer reposition his arm when

he went over bumps. In addition, through further discussion, it became apparent that he had been having trouble accessing his computer and had not discussed this at previous clinic visits. KESHAV was ordered a mini-joystick to drive his wheelchair and a mouse emulator so he could access the computer with his wheelchair control. In addition, he was referred for evaluation for an on-screen keyboard word prediction software and a dictation program.

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