Behavioral management during inpatient rehabilitation for an adult down syndrome: A Case Report

Breanne Tuohy, SPT

Background and purpose: Down Syndrome (DS) is the most common chromosomal disorder in the United States. The prevalence of DS is increasing in the United States, subsequently increasing the number of individuals who will require medical care.[8] While the number of individuals with DS is growing, those with DS also require greater medical services due to premature aging, medical comorbidities including cardiac, respiratory and renal disease[2], intellectual disabilities, behavioral, and emotional needs. Due to these complexities, hospitalization rates for adults with DS are significantly higher than the general population with significantly longer durations.[14] As the life expectancy of DS continues to improve, all healthcare providers should be prepared to provide these individuals high quality medical and rehabilitation services. Current literature lacks evidence related to rehabilitative care along with behavioral management strategies for adults with DS. This case describes the physical therapy interventions provided in an inpatient rehabilitation setting for a 57 year old adult female with DS, exemplifying the success of motivation strategies adapted to her plan of care.

Case description: A 57 year old female with DS was admitted to an inpatient rehabilitation unit after a fall that resulted in a left radial shaft fracture and the discovery of multilevel degenerative spondylosis. Her past medical history included chronic lumbar compression fractures and chiari malformation. The physical therapy examination included the assessment of strength and independence with mobility. The Functional Independence Measure (FIM) was used to examine functional mobility skills. Multiple aspects of the examination were unable to be tested due to patient safety concerns and limited participation. FIM scores measured as dependent for transfers and gait, requiring two clinicians to assist her. She required maximal assistance for wheelchair management with verbal cues. Her strength in the manual muscle test for both her lower extremities were graded as a 3+/5 grossly. The prognosis of this patient was determined to be poor due to lack of motivation, willingness to participate, and lack of success with previous physical therapy. Retrospectively, physical therapy interventions were divided into 2 phases: before and after the implementation of behavioral management strategies. Behavioral management strategies included a sticker chart reward system and incorporating patient specific meaningful activities into exercises. During phase 1 the patient displayed a severe lack of interest in participation. However, after the implementation of a sticker chart reward system, the patient demonstrated improvements during phase 2 in participation, motivation, and skill progression.

Outcomes: After a 4 week course of inpatient rehabilitation the patient was discharged home with family. Clinically significant improvements were made on the FIM scoring, as she was able to preform transfers with supervision, required moderate assistance for walking. She was not only more receptive to care, but

also had increased willingness to participate in therapy and enjoyed attending therapy sessions.

Discussion: This case report demonstrated the importance of including behavioral intervention strategies to maximize rehabilitation for people with DS. The absence of appropriate understanding and assistance for people with DS along with an increasing life expectancy can result in greater emotional and financial burdens. However, with better understanding and application of behavioral principles across age and demographics, we could see decreased hospitalization length of stay, increased participation, and decreased burden on healthcare providers and caregivers.

Sources:

1. Cuthbert SC, Goodheart GJ. On the reliability and validity of manual muscle testing: a literature review. *Chiropractic & Osteopathy*. 2007;15:4.

2. Glasson EJ, Sullivan SG, Hussain R, et al. The changing survival profile of people with Down's syndrome: implications for genetic counselling, Clin Genet , 2002, vol. 62 (pg. 390-3)

3. Kempen GI, Yardley L, van Haastregt JC, Zijlstra GA, Beyer N, et. al. The Short FES-I: a shortened version of the falls efficacy scale-international to assess fear of falling. Age Ageing. 2008 Jan; 37:45-50. Epub 2007 Nov 20.

4. Kendall, F. P., et. al. *Muscles, testing and function: With Posture and pain*. (1993) 6th edition.

5. Krentz H, Miltenberger R, Valbuena D. Using token reinforcement to increase walking for adults with intellectual disabilities. Journal of Applied Behavior Analysis. 2016;49:745-750.

6. Martin K, Natarus M, Martin J, & Henderson S. (2017). Minimal Detectable Change for TUG and TUDS Tests for Children With Down Syndrome. *Pediatric Physical Therapy : The Official Publication Of The Section On Pediatrics Of The American Physical Therapy Association*, *29*, 77-82.

7. Nakamura E, Tanaka S. Biological ages of adult men and women with Down's syndrome and its changes with aging, Mech Ageing Dev , 1998, vol. 105 (pg. 89-103)

8. Neff S, Goldschmidt R. Centers for Disease Control and Prevention 2006 human immunodeficiency virus testing recommendations and state testing laws. JAMA. 2011 May 4;305(17):1767-8.

9. Naghdi, Soofia, Noureddin Nakhostin Ansari, Parvin Raji, et.al. Cross-cultural validation of the Persian version of the Functional Independence Measure for patients with stroke, Disability and Rehabilitation, (2016). 38:3, 289-298.

10. Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. Arch Phys Med Rehabil. 1996 Dec; 77:1226-32.

11. Schoufour JD, Echteld MA, Bastiaanse LP, Evenhuis HM. The use of a frailty index to predict adverse health outcomes (falls, fractures, hospitalization, medication use, comorbid conditions) in people with intellectual disabilities. Research in Developmental Disabilities. 2015.

12. Roth GM, Sun B, Greensite FS, et al. Premature aging in persons with Down syndrome: MR findings, Am J Neuroradiol , 1996, vol. 17 (pg. 1283-9)

13. Raji NS, Rao KS. Trisomy 21 and accelerated aging: DNA-repair parameters in peripheral lymphocytes of Down's syndrome patients, Mech Ageing Dev , 1998, vol. 100 (pg. 85-101)

14. Tenenbaum A, Chavkin M, Wexler ID, Korem M, Merrick J. Morbidity and hospitalizations of adults with Down syndrome. Research in Developmental Disabilities. 2012.