Poster Presentation

Prevalence of Balance Issues and Common Accommodations in Individuals with CHARGE Syndrome

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Presenter Information

Taylor Jarnigin is an undergraduate student at Central Michigan University. She is a member of the Honors program, and she is majoring in Psychology. She plans to obtain a Doctorate of Occupational Therapy upon completion of her undergraduate education. As a member of the CHARGE Lab at Central Michigan University, she is interested in studying balance in individuals with CHARGE syndrome and how they accommodate and adapt to their balance-related difficulties.

Tim Hartshorne is a professor of psychology, specialized in school psychology, at Central Michigan University. His doctoral degree is from the University of Texas at Austin. He also has a master's degree in counseling and is a licensed professional counselor. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. Much of his work is influenced and motivated by his son Jacob, who was born in 1989 with CHARGE syndrome. Tim's particular interests include understanding the challenging behavior exhibited by many individuals with deafblindness, CHARGE, and related syndromes, and also how severe disability impacts the family. He is the lead developer of a deafblind intervener training module on behavior for the National Center on Deaf-Blindness. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. His research was recognized in 2009 with the Central Michigan University President's Award for Outstanding Research. He is a frequent presenter on CHARGE and deafblindness.

Presentation Abstract

A common physical characteristic of individuals with CHARGE Syndrome is difficulty maintaining balance (Dammeyer, 2012). Balance difficulties arise from an underdeveloped vestibular, visual and somatosensory systems. Balance difficulties consequently affect developmental milestones such as walking. As an individual with CHARGE Syndrome develops into adolescence, balance difficulties appear to decrease, affecting them less. It is proposed that difficulties in balance decrease throughout development as individuals learn to accommodate and adapt. This study seeks to examine the prevalence of balance difficulties among individuals with CHARGE Syndrome across different developmental stages and explore the ways in which individuals have learned to adapt and accommodate their daily lives to meet the needs of their balance difficulties. NOTE: This study will be conducted during late spring and early summer months

Prevalence of Balance Difficulties and Common Accommodations in Individuals with CHARGE Syndrome

Taylor Jarnigin, Dr. Timothy Hartshorne • Psychology • Central Michigan University

Introduction

A common physical characteristic of individuals with CHARGE Syndrome is difficulty maintaining balance (Dammeyer, 2012). Balance difficulties arise from underdeveloped vestibular, visual and proprioceptive systems, and affect developmental milestones such as walking.

As an individual with CHARGE Syndrome develops into adolescence, balance difficulties appear to decrease, affecting them less. It is proposed that difficulties in balance decrease throughout development as individuals learn to accommodate and adapt.

Accommodating for Sensory Impairment

Fig 1. Individuals with CHARGE Syndrome often develop specific behaviors to accommodate for sensory impairment.

The Three Systems

- Balance difficulties in individuals with CHARGE Syndrome are often misunderstood.
- Balance is affected by three separate and distinct body systems: the vestibular system, the visual system, and the proprioceptive system.
- These three systems work together to regulate balance in an individual (Moller, 2011).

Vestibular System

- Individuals with CHARGE Syndrome typically have malformed, diminished, or absent vestibular organs (Davenport & Hefner, 2010).
- Endolymph in the semicircular canals flows with head movement, and this ignites the vestibulo-ocular reflex.

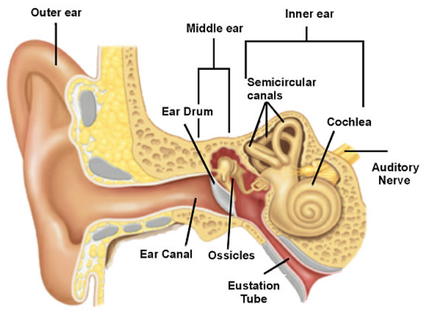

Fig 2. Semicircular canals are often malformed or missing in individuals with CHARGE Syndrome.

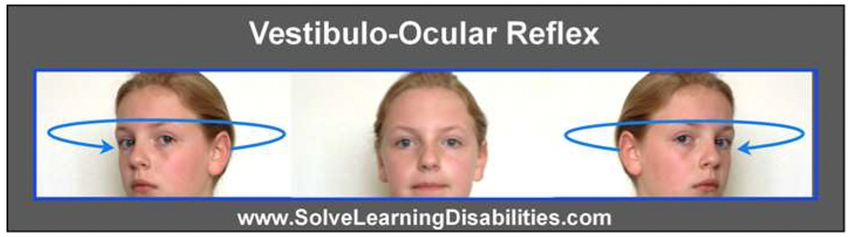

Fig 3. Vestibulo-Ocular Reflex. Many individuals with CHARGE Syndrome do not have this reflex.

- **Vestibulo-Ocular Reflex**: the eyes move in an opposite direction and speed as compared to the head, allowing for a steady image on the retina, making for a clear picture (Highstein, 2004).

Visual System

- University of Nevada school of nursing found that the visual system is what individuals rely on most when trying to maintain their balance (Gaerlan, Alpert, Cross, Louis & Kowalski, 2012).
- **Nystagmus**: Restoring eye movement to counteract head movement.
- Nystagmus is not functional in many individuals with CHARGE Syndrome, causing a blurry and unsteady image with movement.
- Individuals with CHARGE syndrome often have enlarged colobomas and vestibular areflexia.
- There are no vestibular signals; there is no information from the vestibular system being sent to the brain.
- The eyes are unable to move adequately in a way that balances the image steadily on the same place in the retina.

Proprioceptive System

- **Proprioception**: the sensation that comes from movement of stretch receptors in muscles and tendons as well as joint movement (Davenport & Hefner, 2011).
- Blanche, Reinoso, Chang, and Bodison proprioceptive difficulties may contribute to decreased motor planning, decreased postural control, and disruptive behaviors (2012).

Proposed Study

Research Questions:

- What is the prevalence of balance difficulties among individuals with CHARGE Syndrome across different developmental stages?
- What are common behaviors exerted by individuals with CHARGE Syndrome to adapt and accommodate for their balance difficulties?

Methodology

- A survey composed of questions covering the following topics: demographics, developmental assessment, perceived balance, and adaptive behaviors, will be developed and distributed to parents/guardians and caregivers of individuals with CHARGE Syndrome.

The following study seeks to examine the prevalence of balance difficulties among individuals with CHARGE syndrome of different developmental stages and explore the ways in which individuals have learned to adapt and accommodate their daily lives to meet the needs of their balance difficulties.

Contact the Authors

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