



Poster Presentation

Presence of Sensory Integration Therapies in the CHARGE Syndrome Community

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Presenter Information

Kathryn Parker is in her third year at Central Michigan University studying Neuroscience and Psychology. She is a member of Central Michigan University's Honors Program, and is a Centralis Scholarship recipient. Kathryn has been a member of Dr. Timothy Hartshorne's CHARGE Lab at the University for 2 years.

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

Some of the physical associations of CHARGE syndrome can have an impact on the individual's sensory system. Beginning in the early 70's, sensory integration therapies were developed as a way to help improve sensory related difficulties in children. In the CHARGE community there is a wide range of sensory integration abilities and therapies being used, and with it being such a rare syndrome it is difficult to find concise data on what is being used by individuals with CHARGE to combat their sensory integration needs. With my research I intend to find out (1) which therapies are being used by the CHARGE community, (2) the reasoning behind their use, and (3) if they are viewed as being effective treatments by parents/guardians. To do this I will obtain background knowledge on the current research and use of sensory integration therapies, and the sensory needs associated with CHARGE. After establishing this baseline I will develop a survey for parents/guardians, to understand their experiences with sensory integration therapy and their child. From there I would like to give parents/therapist/schools, access to information about the well regarded sensory integration therapies used by the CHARGE community.

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Introduction

Several conditions associated with CHARGE have a major impact on the sensory system of the individuals. To compensate for the different challenges an individual with CHARGE would need a wide variety of treatments and activities. Some of these activities may include sensory integration therapies (SIT), which would help to improve sensory processing. With the wide range of therapies being used to individuals with CHARGE it can be hard to keep track of the different therapies people are using and whether or not they are perceived as an effective method for sensory/ behavioral improvement.

Sensory Processing Therapy

Sensory Processing: the process of organizing and combining all sensory input, and then using this cohesive information to react and function effectively in the environment.

The Senses:

- Sight
- Hearing
- Taste
- Touch
- Smell.
- Vestibular (balance)
- Proprioceptive (body in space).

Sensory Processing and Implications in CHARGE

CHARGE Syndrome is a disorder that affects approximately 1 in 10,000 individuals and consists of a variety of physical dysfunctions or malformations. CHARGE consists of a coloboma of the eye, heart defects, choanal atresia, slow growth genital abnormalities and ear malformations that can result in partial or total hearing loss.

Current Research

Current research in Sensory Processing Therapy shows common investigations being done with a wide range of individuals who have some level of difficulty of sensory processing for reasons including associated disorders and syndromes. Tests typically involve trying to improve adaptive behavior and motor control.

Difficulties with Experiments:

- Types of therapies needed are varied
- Difficult to get experimental control
- Difficult to test on a large scale

Current Research suggests that the best results occur after an *individual* sensory profile is done, and therapy activities are individually tailored to meet the child's specific needs.



Fig 2. Tactile Tools for Sensory Processing

Sensory Processing in CHARGE

Sensory Integration therapies can provide an excellent resource for those with different physical and sensory needs. It provides:

- Solutions
- adaptations
- opportunities for practice regarding different sensory dysfunctions.

Sensory processing abilities continue to extend their purposes beyond just physical and sensory improvement and can be used as coping mechanisms for anxiety, and social activities..



Fig 1. a Vestibular Sense Activity – Sensory Swing

CHARGE application example:

therapies that involve tactile input (i.e. massage, compression, and weight) by improving awareness and tolerance.

Sensory Processing Sensory Processing Disorder is in the DSM – V and is characterized as a neurological disorder in which the sensory information that the individual perceives results in abnormal responses. With this disorder, even if one has the sensory connection the processing of the information can get mixed up and confusing and result in abnormal behavior.

Sensory Processing Disorder and is association with a range of disorders could mean that CHARGE is another possibility for an associated disorder. Resulting in an increased need for attention for effective therapies.

Proposed Study

Research Questions:

- (1) Which therapies are being used by the individual for sensory processing?
- (2) What sensory difficulty are the therapies being used to address?
- (3) Are they are viewed as effective by their parents or guardians for their purpose?

Collecting this data will not only provide data on the current therapies being used and their perceived helpfulness, but it can be used as a resource for other professionals when deciding on usage of a specific therapy.

Methods

The project will be carried out using a survey. The survey will include some demographic information, and information about sensory processing for the individual with CHARGE.

Survey

The questionnaire will be made using Qualtrics and sent out through the CHARGE Facebook page. The survey is to be taken by the parent or guardian of the individual. The first part of the questionnaire is about the individual's demographics, such as age, gender, impairments, and surgeries. The second part will relate to the individuals experience with an OT and sensory processing therapies.

Contact the Authors

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