



Poster Presentation

Anxiety in CHARGE Syndrome

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Presenter Information

Shanti Brown is a doctoral candidate in the School Psychology program at Central Michigan University and a member of the CHARGE Syndrome Research Lab. She has presented at CHARGE conferences in the US, Australia, Norway, and Germany. Her current research is on anxious behavior in CHARGE syndrome and calendar systems as an anxiety intervention for children with multi-sensory impairments.

Presentation Abstract

CHARGE syndrome is a rare genetic disorder that can cause multiple physical, cognitive, behavioral, and sensory impairments. Individuals with CHARGE Syndrome face a wide variety of daily challenges that they, their family, and their community must work to manage. Due to the wide variety in symptoms, these struggles and their solutions are often as unique as the individuals are. Anxiety has been found to be a prevalent and growing concern regarding individuals in this population. Further research is needed to gain a better understanding of the presentation of anxiety in CHARGE Syndrome in order to promote proper diagnosis and effective, tailored treatment. A SurveyMonkey® survey was distributed through social media to parents of individuals (ages 0-18) with CHARGE Syndrome. The results gave an indication of the prevalence of anxiety disorders and the breadth of anxious behaviors exhibited by the population. Results and implications of this research on the behavioral phenotype of CHARGE Syndrome will also be discussed.

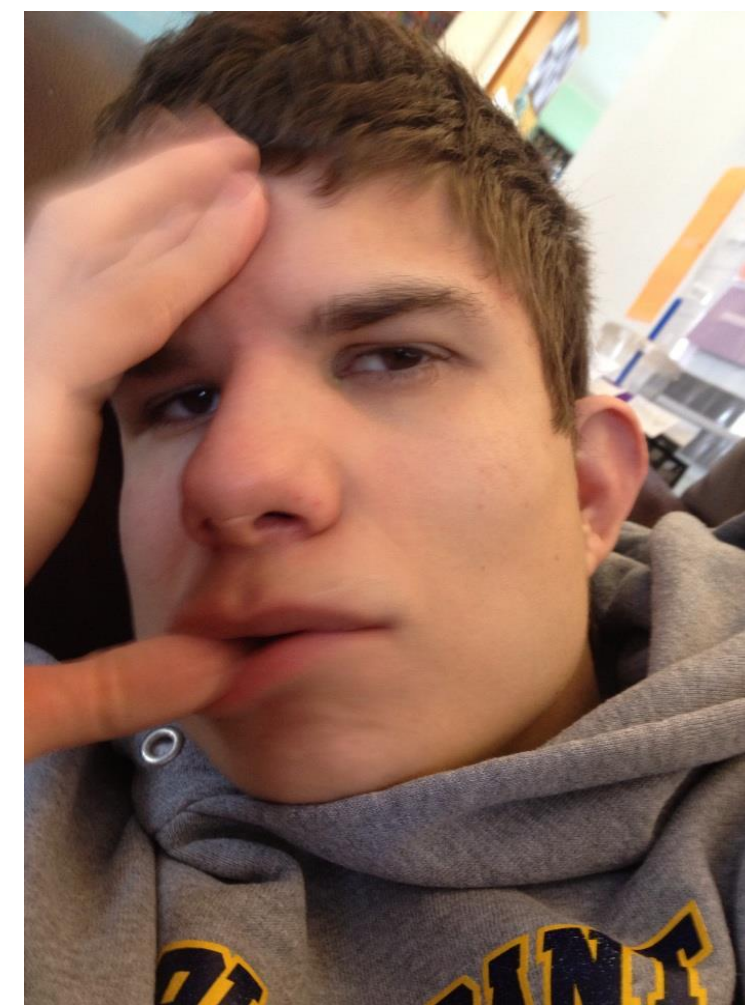


Anxiety in CHARGE Syndrome

Shanti Madhavan-Brown & Timothy Hartshorne, Ph.D • Department of Psychology • Central Michigan University

Introduction

Anxiety has been found to be a growing concern for individuals with CHARGE. This presentation is a synthesis of the current research on anxiety and related behaviors in CHARGE including its behavioral symptoms, prevalence, and effects. Future research projects on anxiety and potential interventions are also described.



Anxious Behavior

Most typical anxious behaviors for children are also seen with individuals with CHARGE

- Pessimism and negative thinking patterns
- Anger, aggression, defiance
- Restlessness, irritability, tantrums, crying
- Constant worry about things that might happen or have happened
- Physical complaints such as stomachaches, headaches, fatigue
- Avoidance behaviors
- Sleeping difficulties
- Withdrawal from activities and family interactions
- Eating disturbances

Obsessive-Compulsive Disorder (OCD)

Definition

- The DSM-V defines OCD as the ‘presence of obsessions, compulsions, or both’
 - Obsessions: persistent thoughts that are repressed
 - Compulsion: repetitive behaviors that they feel compelled to complete and are aimed at reducing anxiety
- “The Obsessions and Compulsions are time consuming...or cause significant stress”

Behaviors Characteristic of OCD

- Some behaviors exhibited by individuals with CHARGE have been categorized as typical of Obsessive Compulsive Disorder:
 - Ordering, lining up objects, making them symmetrical
 - Placing or moving objects to correct place (opening or closing doors)
 - Repetitive question-asking
 - Repetitive, idiosyncratic behaviors: Hand movements, tics
 - Rigid inability to switch activities
 - All-consuming focus on one idea, activity, or item, to the point that it’s not just a hobby/intense interest

OCD or Reasonable Worry?

- Many with CHARGE are diagnosed with OCD, however:
 - “Individuals with CHARGE have TRUE circumstances that lead to UNDERSTANDABLE anxiety!” -Salem-Hartshorne, 2015
- It is important to distinguish because there are differences in intervention (medicine vs a behavior intervention, etc.).

Prevalence

Blake, Salem-Hartshorne, Daoud & Gradstein (2006)

- 30 individuals from CHARGE syndrome family support group (ages 13-30)
- 43% (13 people) indicated an Obsessive-Compulsive Disorder Diagnosis
- 37% (11 people) indicated an Anxiety Disorder
- These were the 2nd and 3rd most common mental health diagnoses

Wachtel, Hartshorne & Dailor (2007)

- 87 families with an individual with CHARGE syndrome
- The largest amount reported an Anxiety disorder as a diagnosis (17 families or 19.5%)

Hartshorne et al. (2016)

- A quality of life study was given to 53 participants (age 13-39) who were either caregivers or individuals with CHARGE
- 49% (26 people) reported Obsessive-Compulsive Disorder
- 45% (24 people) reported Anxiety

Causes and Effects

- Pain
- Sensory Impairments
- Daily Stress or Imminent Events (Doctor Appointment, Family Vacation, etc.)
- Unpredictable Environments
- Quality of Life
- Self-Regulation and Behavior
- Medication
- Sleep
- Social and Emotional Development

Future Directions

We would like to develop an anxiety profile for individuals with CHARGE to determine common exhibited behaviors, causes, effects, and interventions. This information would be compared to other populations with other low-incidence disabilities and be used to inform professionals and parents on effective treatment. Additionally, we would like to conduct an experiment that uses a calendar system in the home of an individual with CHARGE syndrome. By monitoring their behavior before and after, we would like to see if this is a possible method to increase predictability in the environment and, therefore, lower that individual’s anxiety.



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