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Serves in Children with CHARGE



What's there to stress about?

The case of CHARGE Syndrome

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Where it all began?

- Children, even high-functioning children, suddenly lose control
- Strike out
- Express remorse
- Understanding such challenging behaviors



Stress and Early Pain Experiences

- Stress Experiences:
 - Increased academic difficulty around grade 3—
cognitive to concrete operational thinking
 - Concentration with sensory deficits
 - Regulatory disorder and maintaining emotional control



Stress and Early Pain Experiences

- Pain Experiences:
 - Multiple medical procedures/surgeries
 - Common CHARGE characteristics, i.e., low muscle tone, jaw discomfort, cranial nerve anomalies, migraines, reflux, gastrointestinal problems, ear infections, etc.
 - Suspect early pain experiences may impact neurodevelopment which may also lead to challenging behavior



CHARGE and High Pain Threshold

- Reported to have a high pain threshold-based on behavior
- Currently, no study has been conducted to identify the pain experiences of individuals with CHARGE
- Suspect they display pain experiences differently than typically developing children



Research on Pain

- Difficult to measure—subjective experience
- “Golden Rule”
 - Identify and treat pain through patient self-report
 - Communication difficulties

Assessment of Pain and Developmental Disabilities

- Studies in the past have largely excluded this population due to:
 - Inability to vocally self-report
 - Pain experiences may differ from the general population (Neurological/ Developmental)
 - Advanced medical conditions could complicate the assessment

Developing Appropriate Pain Assessment Tools

Facial Reactions/Expressions

Body Movement

Eating Patterns

Sleeping Patterns

SIB

My child on a good day

vs.

My child on a bad day



Some interesting findings...

- In 2000, found that children with developmental delays displayed a less intense distress response to everyday pain experiences than non-delayed children
 - More likely to display no reaction and seek help less often
- In 2004, a study analyzing infant expressions during routine immunizations found infants with DD were likely to show pain in facial expression less clearly than typically developing infants



Why do we miss the pain signs?

- Most common reason for lack of treatment is lack of detection
 - Need for appropriate pain assessment tools and caregivers understanding of behavior
- Individuals may not report pain or underreport pain to avoid further hospitalizations or testing—potential signs of Post Traumatic Stress Disorder (PTSD)



PTSD

- Documented in children with a variety of life-threatening medical illnesses
- Children with liver transplants and cancer survivors have significantly greater PTSD symptoms than those compared to routine surgical procedures

PTSD

- Individuals with CHARGE could have some potential sources of PTSD:
 - Life-threatening surgeries beginning very early in life
 - Long-term hospital stays
 - Long recovery periods from medical procedures
- Trauma exposure can lead to loss of self-regulation, aggression toward others and self-destructive behaviors

Hypothesize...

- ...that individuals with CHARGE do not have a high pain threshold; rather they express their pain experiences differently through behavior and other such cues
- Experience more chronic pain than the general population and not report it as often— “learn to deal with it”

Other Stressful Experiences

- Need to look to other stressful experiences for challenging behavior
- Remember those children who lashed out at their best friends...what else is causing such behavior?





Stress and Disability

- Research on parenting stress and family stress, but no research on the individual with the disability's stress outside of research on PTSD



Stress and CHARGE

- Interviews conducted with high-functioning young adults
 - Specific attention was given to behavioral reactions to stressful situations
 - School experiences, social and family relationships, and work experience

School Themes

- Lack of appropriate communication
 - “I get tired easily at school and I find it hard to concentrate. Sometimes my behavior is bad. I don’t know why I do it and I hate it when it happens.”
 - FM system for class only



School Themes

- Lack of understanding from school personnel on student's hearing and vision loss and multi-sensory impairments
 - “I had an FM system to help with my hearing but I found that I didn't have the adequate services for my vision...for whatever reason, I found it hard to communicate what I was being taught.”

School Themes

- Emotional Immaturity
 - “In H.S. I would cry a lot, I would just get so upset.”
- Rapidly tiring from concentration/focusing on environment with sensory deficits
 - “I often came home and I just wanted to lay down on the couch after school... I needed more breaks”
- Bullying

Friendship Themes

- Recognized need for social interaction
 - “I hate being sick and missing out on school. I want to be at school everyday. I want more people like me around.”
 - “Friendships were always hard to make and they still are..I don’t know how to strike one up.”
- Communication difficulties
 - “I get frustrated especially when friends won’t play with me. I don’t know how to tell them what I mean.”
 - “It’s hard to be at the mall and hear and see my friend at the same time. I can’t follow our conversations well, it just makes it hard to communicate.

Friendship Themes

- Concerns about the “social rules” of friendships
 - “Am I bothering you?”
- Need for friends who will remain friends despite unexplainable behavior at times



Family Themes

- Need for positive relationship between the parents and the school
- Need for acceptance of physical characteristics
 - “...then I wouldn’t have been as self-conscious about my looks.”
- Supportive “...they fought a lot for me.”
- Allow for more independence

Other Themes

- Physical Abuse
- Sexual Abuse
- Children with communication and learning disabilities are as much as 2 to 3 times more likely to be victims of child abuse than typically-developing children
- Association with conduct disorder



Dealing with Anxiety

- Obsessive-Compulsive Disorder
 - Anxiety disorder; individual experiences obsessions (involuntary thoughts/impulses), which lead to a repetitive behavior called a compulsion. The compulsion is done to rid the unwanted obsessions or thoughts
- Changing clothes, getting hair, dialing a pattern on the telephone, picking at skin, etc.



How do we help?

- Realize early pain experiences are likely to play a role in a child's challenging behavior
 - Recognition of what my child is like on a good day and what is different on a bad day...could pain be a factor?
- Communication! Need appropriate ways to communicate with others
 - Use of technology
 - Staff trained in various modes of communication



How do we help?

- An understanding of CHARGE syndrome and its many facets
 - DB, multi-sensory impairments, pain experiences
 - Educate staff and caregivers about CHARGE
- Support from OT, PT, and speech therapists in the classroom for adapted classroom furniture, elimination of stressors and to assist with communication



How do we help?

- One-on-one support for access to information, serve as an intervener for communication and safety
- Avoid over-demanding workloads
- Allow for breaks, positive motivation
- Development of a circle of friends



Where do we go from here?

- Unknowns:
 - Understand the function of OCD—pleasure or anxiety?
 - Improve our attention to pain and developing proper ways to assess pain
- My thesis:
 - Investigation of multi-dimensional pain assessments appropriate for children/adults with CHARGE
 - To provide parents/caregivers/educators with the behavior and communication signs that may signify pain within this population