

Benefits of Family-Centered Intervention in Children with CHARGE Syndrome

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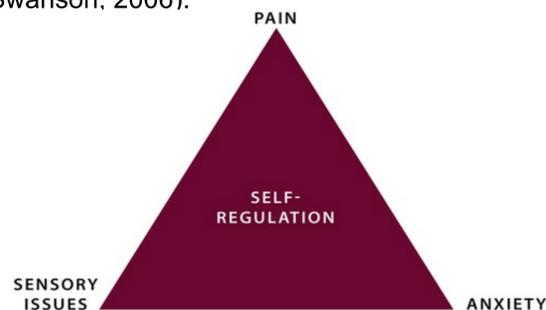
Abstract

Early childhood is a critical, yet potentially and stressful time for a parent of a child with CHARGE syndrome. However, an interdisciplinary team of professionals (physical therapist, occupational therapist, speech-language pathologist, early interventionist, teacher of the deaf, etc.) can make a positive impact on the child's overall development. CHARGE syndrome presents challenges across a range of sensory domains. Individuals with CHARGE may experience: vision/hearing loss, balance disturbances, decreased or absent sense of smell and tasted, tactile defensiveness, and diminished interoception (understand and feel what's going on inside of your body).

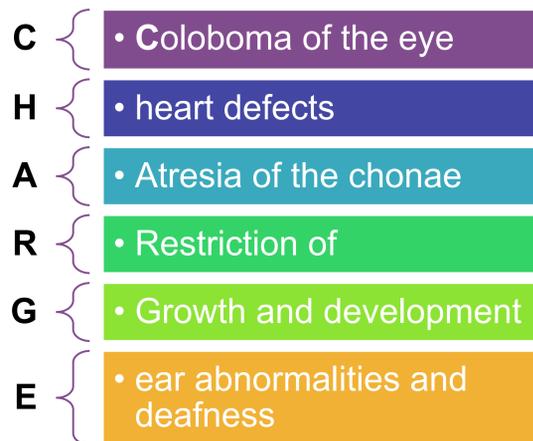
Family-centered and relationship-based care will benefit families of children with CHARGE syndrome. To effectively support young children and their families through family-centered care, consistent collaboration of effective interprofessional teams who share information and solve problems, will be necessary. Interprofessional collaboration is critical in ensuring successful outcomes for children diagnosed with CHARGE syndrome.

Common Characteristics

- Multi-sensory impairments - including possible difficulties with vision, hearing, interoception, touch, temperature, pain, pressure, smell, breathing and swallowing, eating and drinking, digestion, and temperature control (Hartshorne and Cypher, 2004).
- Students with CHARGE syndrome may exhibit high levels of anxiety or nervousness, repetitive questions about the same topic, inflexible behavior, upsets over changes or disruptions in schedules/routines, repetitive non-functional behaviors (OCD-like), aggression or self-injurious behavior as a result of redirection from repetitive non-functional behaviors, withdrawal, autistic-like behaviors, sleep problems (Hartshorne and Cypher, 2004).
- Communication is an essential part of an effective clinical response, i.e. the inability to communicate effectively with those around them, leading to inappropriate behavior (Thelin and Swanson, 2006).



Behavior Triangle: Major sources of problem behavior in CHARGE syndrome (Hartshorne et al., 2017)



Early Intervention is Key

- CHARGE syndrome can have high morbidity, but the morbidity can be minimized by early diagnosis and treatment
- Children benefit from early evaluation, regular follow-up, and a comprehensive intervention program (Blake and Brown, 1993).
- Early intervention by speech-language pathologists, audiologists, and educators of the deaf can enhance the acquisition of symbolic language that is crucial to communication development, social interaction, and learning (Thelin and Swanson, 2006).
- Early and persistent intervention for speech, language, swallowing, and hearing disorders can greatly enhance the quality of life for children with CHARGE syndrome-even for those who have frequent illness and those who are severely involved (Thelin and Swanson, 2006).

Interprofessional Collaboration

- Professionals should collaborate and use intervention strategies that encourage the child's exploration and interaction with the environment while moving the child to more advanced skills and greater independence (Griffin, Davis, and Williams, 2004).
- Teams should name a coordinator of services for each child, who communicates with the family and professionals who have a more in-depth knowledge of the condition (Blake and Brown, 1993).
- Time spent trying to reduce stress levels and trying to give the children acceptable strategies for doing this for themselves, is the best thing we can we do for these individuals, as professionals (Brown, 2005).

Strategies for EI Providers

Flexible Work Environments:

- Having a space that reflects the likes of the student (hanging up pictures from their favorite television show to make their work or relaxation zone more inviting)
- Having some environments or spaces created with intriguing materials that pique the interest of the student can make learning fun.
- Rotate materials to keep the child interested and motivated.
- Using creative, imaginative ideas can change an ordinary space into anywhere from the world (making their workspace come alive)

Strategies for Structuring Activities:

- Working in an organized manner, negotiation, sharing, motivation, people preferences, modeling, maximize participation (have the child do as much as they can in order to feel successful)

Sensory Techniques

- Awareness of hands/touch
- Signals: verbal/auditory/visual gestures to gain attention
- Prompt levels hand-under-hand: use adults' hand as a guide under the child's for a less invasive technique
- Sensory breaks: allow pause time both during and after activities

Timing

- Clear beginning-middle-end
- Structure and routine
- Pause time for response

Curriculum

- Child-centered curriculum
- Expanding environments: starting in smaller environments, eventually working towards bigger physical spaces

References

