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The development of an educational checklist for individuals with CHARGE syndrome

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CHARGE syndrome is a rare genetic disorder which can impact every sensory system and is often associated with significant medical, communicative, developmental, and behavioral difficulties. Due to the rarity and complexity of CHARGE syndrome, educators often lack the expertise required to effectively understand and accommodate the needs of these students. Therefore, an educational checklist (i.e. “Checklist”) was developed to provide a comprehensive tool that educators and related professionals can utilize to aid in the education of individuals with CHARGE syndrome. The Checklist was developed through collaboration with an international panel of experts; CHARGE Syndrome Research Lab at Central Michigan University (CMU); and a select group consisting of parents, professionals, and state deafblind project employees. The Checklist outlines major CHARGE characteristics, resulting educational needs, team members, consulting professionals, and suggested methods of accommodation. The Checklist may be utilized to develop and inform services for individuals with CHARGE syndrome in the schools.

Keywords: CHARGE syndrome, checklist, IEP, special education, multidisciplinary team

Introduction

CHARGE syndrome is a complex genetic syndrome, which is estimated to occur in approximately 1:10,000 to 1:15,000 births (Trider *et al.* 2017). CHARGE syndrome is multi-faceted, typically affecting every sensory system (i.e. visual, auditory, tactile, gustatory, olfactory, vestibular, and proprioceptive; Davenport and Hefner 2011) to a varying degree. A CHARGE diagnosis is made using a combination of clinical criteria—established by Blake *et al.* (1998) and Verloes (2005)—and genetic testing. Clinical criteria include major criteria, which occur frequently in CHARGE but infrequently in other populations, and minor criteria, which are less common than major criteria, but are still characteristic of the syndrome (See Table 1 for a comparison of the criteria). For additional information regarding CHARGE diagnostic criteria, see Hefner and Fassi (2017).

Educational needs

Given the complexity and severity of CHARGE syndrome, multidisciplinary care is required across medical and educational settings (Trider *et al.* 2017). It is

crucial that educators understand common CHARGE characteristics and resulting educational impact (See Deuce 2017 for an overview). Educational needs of individuals with CHARGE syndrome can generally be grouped into one of the following categories: medical, sensory, communication, developmental, and behavioral. Pivotal educationally relevant characteristics within each category are described below. However, numerous other characteristics exist and are elaborated upon in Appendix A.

Medical

Individuals with CHARGE syndrome experience numerous medical complications and commonly spend the first several years of their lives in and out of the hospital undergoing multiple surgeries and procedures (e.g. cardiac and aerodigestive surgeries; Choo *et al.* 2017). As such, medical—and subsequently, educational—management of individuals with CHARGE can be extremely challenging. While medical management will take priority over educational management (Thelin and Fussner 2005), educators must continuously work to understand the medical complexity of these individuals and the educational needs that result. Additionally, educators must be cognizant of specific medical complications, especially those which require medical management at school. Nursing care may be required to

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Table 1. Diagnostic criteria.

Blake et al. (1998) Criteria	Verloes (2005) Criteria
Major criteria	Major features
Coloboma	Coloboma
Choanal atresia or stenosis	Choanal atresia or stenosis
Characteristic ear anomalies	Semicircular canals
Cranial nerve dysfunction	
Minor criteria	Minor features
Genital hypoplasia	Rhombencephalic anomalies
Developmental delay	Hypothalamo-hypophyseal dysfunction
Cardiovascular malformations	External and/or middle ear malformations
Growth deficiency	Malformation of mediastinal viscera
Orofacial cleft	Cognitive impairment
Tracheoesophageal-fistula	
Distinctive face	
Occasional findings	
Thymic/parathyroid hypoplasia	
Renal anomalies	
Hand anomalies	
General appearance	
Abdominal defects	
Spine anomalies	

provide medical care at school (See Cobert 2019 for an overview of nursing care specific to CHARGE).

Of particular importance are breathing and feeding issues, as these are associated with high risk of mortality. Breathing issues are present from birth in the majority of individuals with CHARGE, primarily due to an array of physical anomalies (e.g. choanal atresia, tracheoesophageal fistula; Rutter *et al.* 2011). Between 14 and 66% of individuals receive a tracheostomy to address breathing difficulties due to airway obstruction (White *et al.* 2005). Additionally, individuals with CHARGE are at risk for aspiration—breathing in a foreign substance, such as food or water—due to related anomalies. Aspiration is estimated to occur in over 60% of individuals with CHARGE (White *et al.* 2005). Breathing difficulties and aspiration both may impact the individual's stamina and ability to fully participate in certain school activities (e.g. physical education) and may require specific medical management (e.g. suctioning a tracheostomy tube; see Rutter *et al.* 2011 for elaboration on airway management).

Feeding issues are very common in CHARGE, with approximately 90% of individuals experiencing gastrointestinal and/or feeding dysfunctions (e.g. gastroesophageal reflux, excessive salivation, G tube feeding; Blake and Hudson 2017). These feeding difficulties are largely caused by structural anomalies, motor delays, and multiple sensory impairments. While many of these dysfunctions are treated via surgical or pharmacological interventions, there are strategies those facilitating feeding (e.g. educators) can utilize. These include feeding therapy, cutting food into small pieces, and pureeing food. See Blake and Hudson (2017) for a comprehensive review of dysfunctions and treatments.

Sensory

Individuals with CHARGE syndrome experience multiple sensory impairments, the combination of which

profoundly affects the way in which they are able to access information from their environments. While every sense can be affected to a varying degree, the combination of vision and hearing loss and vestibular abnormalities arguably has the most significant educational impact. Approximately 80–90% have coloboma and some degree of vision loss, 80–100% have characteristic ear abnormalities with some degree of hearing loss, and almost all have vestibular abnormalities (Hefner and Fassi 2017).

Colobomas result in visual field loss and light sensitivity, often accompanied by reduced visual acuity and contrast sensitivity, all of which must be assessed early in life and reevaluated periodically (Hyvärinen 2011). In the school, this can be addressed with glasses and several environmental accommodations (e.g. large print, braille; Smith *et al.* 2010). Ear abnormalities occur in the external (e.g. characteristic “CHARGE” external ear), middle (e.g. hypoplastic ossicles), and inner ear (e.g. hypoplastic cochlear nerve), with middle and inner ear abnormalities often causing sensorineural, conductive, or mixed hearing loss (Choo *et al.* 2017). Hearing should also be assessed early in life and reevaluated frequently, as hearing can change. Depending on the type of hearing loss, individuals may utilize hearing aids, bone-anchored hearing aids (BAHAs), cochlear implants, auditory brainstem implantation, or a combination. Educators may further accommodate hearing loss by teaching sign language and utilizing an amplification system (Smith *et al.* 2010). The vestibular system is most strongly associated with balance, but is also thought to unify and process all other senses (Brown 2011). Since the vestibular system is significantly impacted in CHARGE syndrome, individuals with CHARGE often expend large amounts of energy focusing on balancing and stabilizing their gaze. Educators should understand the wide-reaching impact of vestibular abnormalities and the importance of providing

vestibular stimulation via activities such as rocking and allowing individuals to move and sit in ways in which they maximize their vestibular input (e.g. lying up-side-down).

Communication

Receptive and expressive communication are both greatly impacted in CHARGE syndrome due to potential physical anomalies (e.g. cleft lip, choanal atresia), sensory impairments (e.g. hearing and vision loss), and time spent in the hospital undergoing and recovering from surgeries (Thelin and Fussner 2005). During early language development, individuals with CHARGE have been observed to communicate using primarily gestures (Peltokorpi and Huttunen 2008); however, more primary methods of communication (e.g. spoken language sign language, gestures; Thelin and Fussner 2005) are observed throughout the lifespan.

Individuals with CHARGE syndrome display a wide range of communicative abilities. It is *vital* that behavior *always* be interpreted as communication by educators, especially prior to the development of more formal communication methods (Smith *et al.* 2010). Additionally, numerous avenues for communication should be made available, including oral language, sign language, gestures, pictures, touch and object cues, calendar systems, and any other approach that aids the individual's communicative development and expression.

Developmental

The combination of sensory impairments, time spent in the hospital, and physical anomalies (e.g. hypotonia, cleft lip) adversely impacts all developmental milestones (e.g. motor, communication, cognitive; Hefner and Fassi 2017). While individuals with CHARGE commonly exhibit global developmental delays, they can improve in these areas if provided proper interventions (e.g. cochlear implant, hearing aids; Choo *et al.* 2017) and services (e.g. speech and language therapy, occupational therapy, physical therapy; Hefner and Fassi 2017). Educators must address all aspects of developmental delay.

Behavioral

Individuals with CHARGE syndrome can present with extremely challenging behaviors, which can be difficult for parents and educators to understand and address. Hartshorne (2011) compiled behaviors commonly exhibited by individuals with CHARGE into a behavioral phenotype (See Table 2). Problematic behavior in CHARGE is thought to arise from three main sources: pain, anxiety, and sensory issues (Hartshorne *et al.* 2017). While this phenotype does not change the challenging way in which behavior often presents, it can help promote understanding of the reasoning behind the behavior, which is the first step in formulating an

Table 2. Hartshorne's (2011) behavioral phenotype.

Characteristic
Low normal cognitive functioning
Very goal directed and persistent with a sense of humor
Socially interested but immature
Repetitive behaviors that increase under stress
High levels of sensation seeking
Under conditions of stress and sensory overload, find it difficult to self-regulate and easily lose behavioral control
Difficulty with shifting attention and transitioning to new activities; easily lost in own thoughts

From Hartshorne (2011). Used by permission.

appropriate response. As already stated, behavior should be interpreted as communication; educators should not attempt to change the individual's behavior without giving them another way of communicating the same message.

Educators need not only understand the breadth of medical, sensory, communication, developmental, and behavioral challenges commonly experienced by individuals with CHARGE, but also how to consistently and effectively address these needs in school. This is no small feat, given the complexity and rarity of CHARGE syndrome. Educators may find themselves unsure of where to start in developing services for an individual with CHARGE; parents may find themselves overwhelmed with having to navigate the world of special education and effectively advocate for their child.

Current study

While professionals unanimously recommend early intervention to address the plethora of educationally relevant CHARGE characteristics, there is an identified need for a compilation of the extant literature into a comprehensive, user-friendly tool for educators. A similar compilation of recommendations for medical professionals was developed by Trider *et al.* (2017), who created the *CHARGE Syndrome Checklist for Health Supervision Across the Lifespan*. This Health Checklist was informed by a literature review and expert multi-disciplinary team, and, once drafted, was rated by international experts in the field of CHARGE syndrome (i.e. professionals, parents, and individuals with CHARGE), revised, piloted, and finalized. The methodology for the development of the Health Checklist was remarkably thorough and involved feedback from a diverse multi-disciplinary team, notably highlighting parents of individuals with CHARGE and individuals with CHARGE themselves. The Health Checklist provides an overview of the common medically relevant CHARGE syndrome characteristics and is intended to support physicians in their provision of services.

Similar to the justification for a health checklist, an educational checklist is needed to help educators navigate the challenges of understanding and meeting the educational needs of individuals with CHARGE syndrome. Using a similar methodology to Trider *et al.* (2017), the current study sought to develop a tool to provide an overview of educationally relevant

Table 3. Phases of development.

Phase	Area Rated	Feedback Provided	Rater
One	Categories	Add, remove, change; Necessity and appropriateness of categories	Panel
Two	Characteristics and Concerns	Add, remove, change; Necessity and appropriateness of items within category; Sufficiency of category	Panel
Three	Educational/ Support Needs	Add, remove, change; Necessity and appropriateness of items within category; Sufficiency of category	Panel
Four	Team Members	Add, remove, change; Necessity and appropriateness of items within category; Sufficiency of category	Panel
Five	Consulting Professionals	Add, remove, change; Necessity and appropriateness of items within category; Sufficiency of category	Panel
Six	Examples of Services and Accommodations	Add, remove, change; Necessity and appropriateness of items within category; Sufficiency of category	Panel
Seven	Overall Utility	Add, remove, change; Sufficiency of introduction, checklist, glossary, and selected reference list; Sufficiency of Checklist as a whole	Panel
Eight	Overall Utility	Add, remove, change; Usefulness of Checklist as a whole	Select Group
Nine	Final Draft	Add, remove, change; Acceptance of changes; Sufficiency of Checklist as a whole	Panel

CHARGE syndrome characteristics to aid educators in their provision of services in the schools and to provide parents with a resource to support their advocacy for their child. We sought to develop a comprehensive tool to not only inform educators of the educationally relevant characteristics and concerns commonly exhibited by individuals with CHARGE syndrome, but to also suggest methods of addressing such needs. This is an important undertaking, given the rarity and complexity of CHARGE syndrome and the difficulties many educators face in providing appropriate services for these individuals.

This comprehensive tool (i.e. "Checklist") was developed in collaboration with an international panel of experts in CHARGE syndrome; CHARGE Syndrome Research Lab at CMU; and a select group consisting of parents of individuals with CHARGE syndrome, professionals with experience working with individuals with CHARGE syndrome, and state deafblind project professionals.

Method

Panel of experts

A panel of experts (i.e. "Panel") was convened to assist in the development of the Checklist. Experts on various aspects of CHARGE syndrome (behavior, education, assessment, and treatment) were selected by the authors on the basis of publications, presentations, years of experience with CHARGE syndrome, and unique expertise. The following professionals made up the Panel: David Brown, educational specialist formerly with the California Deafblind Services and Sense in the United Kingdom; Beth Kennedy, director of DeafBlind Central (DB Central), the Michigan deafblind project; Rob Last, special education teacher specializing in sensory disabilities in Australia; Jude Nicholas, clinical neuropsychologist specializing in deafblindness in Norway; Nancy Salem-Hartshorne, expert in assessment of individuals with CHARGE syndrome and parent of a young adult with CHARGE in Michigan; and Kasee

Stratton, psychologist and head of the Mississippi State University Bulldog CHARGE Lab.

Select group

A select group was surveyed to provide feedback on the Checklist once an initial draft was approved by the Panel. This group consisted of parents of individuals with CHARGE syndrome, professionals with experience working with individuals with CHARGE syndrome, and state deafblind project employees. Parents were selected from the CHARGE Syndrome Foundation State Parent Liaison Project, which assigns a parent of an individual with CHARGE to be the "point person" for the state. The 17 parent liaisons at the time were surveyed; 10 provided feedback.

Professionals were selected from the best contact list for students with CHARGE syndrome registered with the DB Central on the 2017 census and a list of professionals who work at Perkins School for the Blind, Michigan School for the Deaf, and the Western Pennsylvania School for the Deaf. A snowball sampling procedure was used to collect feedback from professionals with experience with CHARGE syndrome (i.e. the Checklist was sent out to a point-person at each institution and was then forwarded to other professionals; the exact number of professionals reached is unknown). Feedback was received from the following 11 specialists: audiologist, teacher consultant for the visually impaired, job coach, multiple sensory impairment teacher consultant, speech-language pathologist, principal, health/physical education teacher, teacher, interpreter, and intervener.

State deafblind projects are federally funded technical assistance centers in the United States; they provide assistance to families of individuals who are deafblind (i.e. have combined hearing and vision loss) and professionals who serve individuals who are deafblind between the ages of three- and 21-years-old. Because CHARGE syndrome is the leading genetic cause of congenital deafblindness (National Center on

Deaf-Blindness 2018), state deafblind project employees often have experience consulting with educators about the educational considerations specific to CHARGE syndrome. The draft Checklist was sent to the 48 state deafblind projects in the United States. Two state deafblind project educational specialists provided feedback on the checklist. In all, feedback was received from a total of twenty-three individuals, representing parents, professionals, and state deafblind projects from across the United States.

Development of the educational checklist

The Checklist was developed in nine phases; each phase added information to the Checklist (See Table 3). Prior to the first phase, an extensive literature review was conducted in the fall of 2017 on the educational needs of individuals with CHARGE syndrome and professional recommendations for addressing such needs. The literature review informed the initial draft development of the Checklist. Each draft section of the Checklist was reviewed and edited by the CHARGE Syndrome Research Lab at CMU prior to Panel rating. The Checklist was developed during the spring and summer of 2018.

The Checklist was reviewed and rated by the Panel using SurveyMonkey© in phases one through seven and nine of development, and was reviewed by the select group in phase eight. Each Panel member rated whether they agreed that every proposed item was necessary and appropriate and whether every group of items (i.e. categories, items within each category, and checklist overall) was sufficient on a Likert scale of one (strongly disagree) to five (strongly agree). Additionally, the Panel provided feedback on items to add, remove, or change at every phase. The Panel rated the item or group of items until a consensus cut score of four (agree) or higher was reached for every item or group of items. If any item or group of items was rated as less than four by any member, the item was edited or removed until every member of the Panel rated every item or group of items as a four or five. Once agreement criteria were met, development moved to the subsequent phase and continued until a complete draft of the Checklist was achieved in phase seven. The complete draft included the Checklist and an introductory page (overview of CHARGE syndrome and the Checklist), glossary, and selected reference list; the latter three were developed informally, with the Panel providing feedback on aspects to add, remove, or change.

In phase eight, the Panel-approved draft of the Checklist and the rating form were sent via SurveyMonkey© to the select group of parents, professionals, and state deafblind project employees. Respondents were asked their name; their role; whether they would like more information about the checklist when finalized; if anything should be added, removed,

or changed about the Checklist; and how useful the Checklist would be to them on the five-point Likert scale of one (not at all useful) to five (extremely useful). Prior to phase nine, changes were made to the Checklist based on the feedback from the select group. The updated draft was sent to the Panel for final review. The Panel suggested aspects to add, remove, or change, noted if they agreed with the changes made, and rated the sufficiency of the Checklist for use in schools on a Likert scale ranging from one (strongly disagree) to five (strongly agree). A final draft was prepared based on Panel feedback once agreement criteria were met.

Results

The Checklist was developed through collaboration with a panel of six international experts on CHARGE syndrome; CHARGE Syndrome Research Lab at CMU; and a select group consisting of 23 parents, professionals, and state deafblind project employees. For phases one through seven, agreement criteria were met by the Panel after revisions. In phase eight, every parent, professional, and state deafblind project employee respondent rated that the Checklist would be useful to them (See Figure 1), with responses ranging from somewhat useful (20%), to very useful (25%), to extremely useful (55%). The mean rating of the usefulness of the Checklist was 4.32 ($SD = 0.82$). Additionally, approximately 80% of respondents in the select group requested a final copy of the Checklist. In phase nine, every Panel member agreed with the changes made after phase eight and strongly agreed that the Checklist was sufficient for use in schools ($M = 5$; $SD = 0$).

After reviewing the feedback with the Panel, edits were made and the final draft of the Checklist was prepared. The final product is a Checklist that thoroughly describes the educational needs commonly experienced by individuals with CHARGE syndrome and methods of meeting those needs (See Appendix A). The Checklist is a 14-page document, which includes four sections: an introduction, the checklist, a glossary, and a selected reference list.

Discussion

We sought to develop a comprehensive tool which could be used to guide educators on the educational needs of individuals with CHARGE syndrome and provide a collection of resources to address such needs. Prior to the development of this Checklist, there was no tool which could be utilized by educators to help in the provision of services for these individuals.

Given the positive feedback received from the Panel, select group, and informally from parents and professionals at international CHARGE conferences, this Checklist has the potential to be highly useful in schools. This Checklist may help ameliorate some of

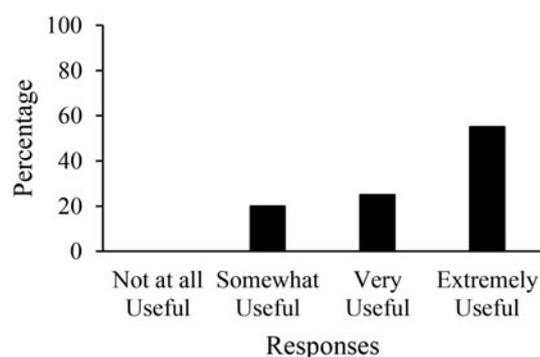


Figure 1. Select group response to usefulness of checklist.

the stress felt by parents when having to explain the complexities of CHARGE syndrome to educators, and may help educators better understand and address the educational needs experienced by individuals with CHARGE syndrome. This Checklist can be distributed to schools where individuals with CHARGE syndrome attend and can be used by multidisciplinary teams when developing and implementing Individualized Education Plans (IEP).

Limitations

While the Checklist was extensively and meticulously rated by the Panel at every step of development, there was a relatively low return rate from professionals in the select group. The Checklist was sent to upwards of 100 professionals, with 11 professionals responding, and 48 state deafblind projects, with two employees responding. Feedback from this group was requested during the summer, which most likely influenced the return rate since many school professionals do not work in the schools during the summer, and, in addition, the state deafblind projects were preparing for a federal grant application. Ideally, there would have been greater returned feedback. Additionally, not every professional mentioned in the Checklist (e.g. physical therapist, occupational therapist) is represented in the feedback on the Educational Checklist. However, the Checklist can be thought of as an ever-changing resource, so feedback can continue to be collected moving forward.

Future directions

The purpose of this project was the development of the Checklist, which has been achieved; however, the Checklist has yet to be validated. A validation procedure could further strengthen the utility and evidence base of the Checklist. Such a validation procedure could involve distributing the Checklist to the school teams of several individuals with CHARGE syndrome who have IEPs, implementing use of the Checklist with the team, and recording various outcome measures (e.g. changes in IEP pre- and post-implementation, parent satisfaction, child progression towards IEP goals). As the Checklist is utilized and feedback is received, we can

seek to expand the Checklist to reflect educational priorities specific to age (i.e. early intervention, school age, and transition).

The Checklist was distributed to those individuals who requested a final copy. Moving forward, this Checklist can be utilized as a tool for individuals with CHARGE syndrome in the schools. Additionally, the methodology used to create this Checklist can be used as a template to develop similar tools to increase knowledge about other complex, rare disabilities.

Conclusions

This Checklist may be utilized by educators to increase their understanding of CHARGE syndrome and better provide accommodations and services for individuals with CHARGE syndrome. This Checklist should be used by a multidisciplinary team and is intended as a *starting point* for designing services for individuals with CHARGE. While the Checklist is comprehensive, it is not exhaustive; educators should be encouraged to use the Checklist to work collaboratively to determine the needs of the individual with CHARGE syndrome.

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Declaration of Interest

The authors declare that they have no conflict of interest.

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