CEU Article

Balance and Self-efficacy of Balance in Children with CHARGE Syndrome

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Structured abstract: *Introduction:* Balance is a critical component of daily living, because it affects all movements and the ability to function independently. Children with CHARGE syndrome have sensory and motor impairments that could negatively affect their balance and postural control. The purpose of the study presented in this article was to assess the balance and self-efficacy of balance of these children. *Methods:* Twenty-one children with CHARGE syndrome aged 6–12 and 31 age- and gender-matched sighted control participants without CHARGE syndrome completed the study. Each participant completed the Pediatric Balance Scale (PBS) and a self-efficacy of balance survey, the Activities-Specific Balance Confidence Scale (ABC). *Results:* The PBS results revealed that the participants in the control group performed significantly better than did those with CHARGE syndrome ($p < .05$), with 57% of those with CHARGE syndrome at a medium to high risk of falls but all those in the control group at a low risk. Most children with CHARGE syndrome also had low ABC scores, and these scores were moderately correlated with the PBS scores ($r = 0.56$), but were not significantly associated with gender ($r = 0.065$) or age ($r = -0.169$). *Discussion*: A relationship was found between the balance self-efficacy of the children with CHARGE syndrome and their objectively measured balance. Self-efficacy of balance has been correlated with an increased risk of falls and with decreased participation in physical activities. Increased physical activity with a focus on balance and movement would likely improve these children's balance and self-efficacy of balance. *Implications for practitioners*: Practitioners should understand that children with CHARGE syndrome will likely have poorer balance and lower confidence in their balance. Balance confidence and capabilities have implications for the development of motor milestones, such as walking, and the ability to perform functional activities. Future research should examine interventions to improve both balance and confidence in balance in these children.

CHARGE syndrome is a rare autosomal dominant disorder with multiple cardinal features, such as colobomas resulting in visual impairment, heart defects, vestibular malfunction, retarded growth, atresia choanae, and deafness (Pagon, Graham, Zonana, & Young, 1981), affecting approximately 1 in 10,000 babies (Sanlaville & Verloes, 2007). These physical conditions often result in developmental delays, including cognitive, social, language, and motor delays (Dammeyer, 2012; Smith, Smith, & Blake, 2010).

A common motor delay found in children with CHARGE syndrome is balance problems. Balance is a critical component of daily living, since it affects all movements and the ability to function independently. Balance problems can negatively affect a child's perception of the world, which, in turn, can both delay the onset of independent walking (Dammeyer, 2012) and adversely influence a child's social interactions and learning capabilities. Balance problems are largely the result of sensory impairments and musculoskeletal problems (Williams & Hartshorne, 2005). Children can typically compensate for one sensory impairment, but multiple sensory or other impairments greatly reduce a child's compensatory alternatives (Sobsey & Wolf-Schein, 1996). Sensory system impairments in individuals with CHARGE syndrome vary considerably from one individual to the next, but often include visual, vestibular, and somatosensory impairments.

Typically developing young children use vision to make quick postural compensations to maintain their body position when acquiring new fundamental motor skills, such as walking with and without support (Delorme, Frigon, & Lagace, 1989), and often rely more heavily on vision than other sensory information for postural control (Casselbrant, Mandel, Sparto, Redfern, & Furman, 2007; Foster, Sveistrup, & Woollacott, 1996). This reliance on vision is likely a contributor to significantly poorer performance on balance tasks (Haibach, Lieberman, & Pritchett, 2011) and significant delays in the acquisition of fundamental motor skills (Houwen, Hartman, & Visscher, 2009; Wagner & Haibach, 2012) in children with visual impairments in comparison to their sighted peers. More than 80% of children with CHARGE syndrome have low vision or blindness in one or both eyes (Issekutz, Graham, Prasad, Smith, & Blake, 2005). The functional implications of vision loss are dependent on the location of the coloboma (Smith et al., 2010). Many children with CHARGE syndrome lose vision in the upper visual field, which greatly reduces their central vision (Brown, 2005).

Charpiot, Tringali, Ionescu, Vital-Durand, and Ferber-Viart (2010) found that the vestibular system, which provides information on the position of the head in relation to gravity, progressively matures until age 12 or older and may be as or more important in the development of postural control as vision in typically developing

The authors thank the CHARGE Foundation for its support of this research project. Without the foundation's support, this project would not have been possible.

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children. The semicircular canals are positioned in the middle ear and provide vestibular information about angular motion. Many children with CHARGE syndrome have either damaged or missing vestibular organs because of abnormal development of the inner ear (Williams & Hartshorne, 2005), which can have a negative impact on balance, delay independent walking, and therefore restrict a child's ability to explore the environment and engage with peers (Smith et al., 2010).

The somatosensory system (sensation of touch, pressure, or temperature) matures much earlier than the vestibular system. Somesthetic sensation in the feet is particularly important for balance, because it provides information in regard to changing body position. If individuals have reduced somesthetic sensation in their feet, they will need a larger perturbation to realize that they need to make an adjustment. Somatosensory impairments in individuals with CHARGE syndrome can range from hypersensitivity to hyposensitivity (limited feedback on joint and muscle position), which can reduce their ability to compensate for a perturbation to their balance.

Musculoskeletal problems associated with CHARGE syndrome, such as low muscle tone, greater joint laxity (loosening of the joint bones), and impairments in skeletal alignment (such as poor posture, kyphosis, and knocked knees), can also compromise balance (Girardi, 2009). Individuals with low muscle tone also have difficulty initiating and maintaining contractions and shifting from one position to another. Their low muscle tone can cause them to use volitional control to maintain their posture even in seated positions, rather than subconscious corrections. Increased joint laxity or hypermobility in most joints results in an unstable skeletal base and decreased postural stability. Children with CHARGE syndrome may contract their muscles to stabilize their joints, as by scrunching their feet or raising their shoulders, which can cause further orthopedic or body alignment problems in the future. The presence of such motor and sensory impairments is a strong predictor of delayed adaptive functioning (Salem-Hartshorne & Jacob, 2005).

In the study presented here, we examined balance in children with CHARGE syndrome, because balance is a critical component of locomotion and affects many activities of daily living (including walking, carrying groceries, dressing, and reaching for objects). It has been suggested that improvements in developmental balance are a result of the improved use of sensory feedback from proprioceptive, visual, and vestibular inputs and that sensory organization abilities are important for increasing balance control throughout childhood (Assaiante & Amblard, 1993; Sundermier, Woollacott, Roncesvalles, & Jensen, 2001), which explains, in part, why children with CHARGE syndrome have significantly delayed independent walking and poorer balance.

Poor balance and low confidence in balance can also cause a fear of falling, which has negative reciprocal impacts on balance because individuals who are afraid of falling tend to reduce their participation in physical activity (Ray, Horvat, Williams, & Blasch, 2007; Vellas, Wayne, Romero, Baumgartner, & Garry, 1997). The fear of falling can be operationalized through a continuum of self-confidence (Powell & Myers, 1995). The Activities-Specific Balance Confidence

(ABC) Scale is based on Bandura's (1977) theory of self-efficacy, an individual's perceived ability to perform a task. It uses situation-specific items related to activities of daily living, because Bandura cautioned against generalizing self-efficacy across tasks that are not highly similar (Powell & Myers, 1995). Individuals rate their confidence with their balance for each item on an ordinate scale, with lower numbers indicating a lack of confidence and higher numbers indicating greater confidence. Individuals who are unable to maintain their balance during simple tasks are likely to reduce their involvement in physical activities, further perpetuating the decline in balance and postural control. Self-efficacy is also strongly related to motor performance (Holbrook & Koenig, 2007). Generally, individuals who perform more poorly on motor skills than their typically developing peers have lower self-efficacy (Harter, 1989).

A study based on parents' responses regarding the physical education experiences of their children with CHARGE syndrome found that the children were given fewer opportunities in their physical education classes than their typically developing peers and the teachers were not receiving enough support to adapt the programs to fit the children's individual needs (Lieberman, Haibach, & Schedlin, 2012; Ribadi, Rider, & Toole, 1987). The lower physical activity levels and physical education experiences of children with CHARGE syndrome are likely a main cause of the children's lack of improvement in balance with advancing age. Children with CHARGE syndrome must overcome many structural and functional impairments and should be given more opportunities to improve their balance, rather than less, which often occurs in school settings. The benefits of improved balance are far reaching because balance is a critical component of most motor skills. Improvement in balance will advance competence in motor skills. Furthermore, competence in motor skills is correlated with fitness levels (Cantell, Crawford, & Doyle-Baker, 2008; Cawley & Spiess, 2008).

The purpose of our study was to examine balance using the Pediatric Balance Scale (PBS) and self-efficacy of balance using a modified ABC scale in children with CHARGE syndrome. Although poor balance can have a dramatic impact on functionality, independence, and future career prospects, no research has assessed balance or self-efficacy of balance in children with CHARGE syndrome. We expected that children with CHARGE syndrome would have even further delays in developing balance because of the multiple conditions that can compromise balance and delay the development of walking and locomotor patterns.

Methods

Participants

The participants were 22 children (9 girls and 13 boys) with CHARGE syndrome aged 6–12 years (mean 8.50 years, *SD* 2.09 years) who attended the CHARGE Syndrome Foundation Conference in Chicago (see Table 1). Of the 22, 14 had fallen in the previous year, and 14 of the parents indicated that their children had a fear of falling. Nine children always used a mobility aid (to compensate for vision loss), 2 usually used a mobility aid, 7 sometimes used a mobility aid, and 3 never used a mobility aid. The mean age

Table 1
Description of the diagnoses of the CHARGE participants.

Participant	Age (years)	Gender	Reported diagnosis
1	11	Female	Large choridal colobomas microphalmia, right eye blind, left eye 20/200; bilateral severe to profound hearing loss; severe cleft lip and palette, TEF; heart—PDA resolved; heart murmur; significant developmental delays; missing semicircular canals
2	11	Female	Not reported
3	6	Female	Retinal colobomas bilateral; bilateral hearing aids; partial atresia
4	7	Female	Not reported
5	11	Male	Mild right ear hearing loss, severe left ear hearing loss; vision: farsightedness, left eye worse
6	8	Male	Colobomas in both eyes; g tube track from birth to age 2.5, deaf in left ear, missing semicircular canals; left kidney removed; PDA closed at 6 months, nonverbal: communicates with body; severe developmental delays
7	7	Female	Not reported
8	12	Male	Colobomas of retina, choanal atresia, VSD (repaired), kidney with reflux, profound deafness, nonverbal, limited communication, no semicircular canals (just buds)
9	10	Male	Not reported
10	12	Female	Colobomas, cleft lip palate, hearing loss, developmental delay feeding issues, behavioral difficulties, OCD
11	10	Male	Has all CHARGE defects; lost his balance because of vision and ear issues
12			Dropped out
13	6	Female	Retinal colobomas, sees best from left side of left eye; has a head tilt to the right and nystagmus, low muscle tone, very weak upper body strength; hips dislocated; nonverbal
14	9	Male	Colobomas (both eyes); very good functional vision; severe to profound hearing loss (aids); G tube; facial palsy; kidney malformation; balance issues
15	8	Male	Colobomas bilateral, leaking mitral valve PPA surgery at 3 months, choanal repair; has stenosis and not full atresia; swallow dysfunction; significant hearing loss on one side, no semicircular canals
16	6	Male	Large optic nerve coloboma, small right optic nerve coloboma, no vision in left eye; tricuspid and palm atresia–hypoplastic right heart,; cleft lip and palate; mixed, conductive sensorineural hearing loss; undescended testicles and microphalus; severe reflux, GI to be fed
17	8	Female	Colobomas in both eyes, left eye blind; heart malformation—PDA liugated; choanal atresia repaired numerous times; retarded growth, delayed gross and fine motor and cognitive skills; left ear profound loss and right ear moderate to severe loss
18	6	Male	Bilateral colobomas; mild ASD; growth retardation; micropenis and undescended testes; moderate bilateral hearing loss; unilateral facial palsy; one eye with microphthalmia

(cont.)

Table 1
(cont.)

Participant	Age (years)	Gender	Reported diagnosis
19	7	Male	Coloboma and microphthalmia in left eye; bilateral sensory neural deafness; TE fistula repair; g button funds; retarded growth; bilateral facial palsy; tube fed overnight, eats a little by mouth; very busy, constant motion; easily frustrated; poor impulse control; uses sign language to communicate and walk independently
20	7	Male	Heart PPA; inner ear malformed—affects balance and hearing loss; breathing—requires tracheostomy tube for breathing
21	8	Female	Bilateral choanal atresia—surgically corrected; bilateral colobomas—wears eyeglasses most of the time; moderate hearing loss—should wear a hearing aid, but rarely does; small size; has some GI issues
22	11	Male	Heart—ASD-USD repair; retardation of growth at first; has one kidney; has some hearing loss in the left ear

Note: ASD = atrial septic disorder; ASD-VSD = atrial septic disorder–ventrical septic disorder; g button = gastrostomy button; G tube = gastrostomy tube; GI = gastrointestinal; OCD = obsessive compulsive disorder; PDA = patent ductus arteriosus; PPA = propionic acidemia; TE = tracheoesophageal; TEF = trancheoesophageal fistula; VSD = ventrical septic disorder.

at which the participants began walking was 41.65 months (*SD* = 17. 35 months). The sighted participants in the control group were 31 children (mean age 9.3 years, *SD* = 1.8 years). The average age at which they began to walk was 13.66 months (*SD* = 2.83 months). One control participant indicated a fear of falling. The participants and their parents signed informed consent forms approved by the institutional review board committee. The participants were informed before the tests began that they could withdraw from participation at any time during the testing. One participant with CHARGE syndrome withdrew from the test.

Measurements

The participants completed the PBS, a modified version of the Berg Balance Scale for school-age children with mild to moderate motor impairments (Franjoine, Gunther, & Taylor, 2003). On the basis of an ICC (intraclass correlation) model 3,1, the PBS has been found to have high test-retest reliability (*r* = 0.998) and interrater reliability (*r* = 0.997). The PBS was chosen because it is easy to administer, does not require expensive equipment, and requires less than 20 minutes to complete. For the PBS, the participants completed 14 balance tasks and were rated on a scale of 0 to 4, with a maximum score of 4. The tasks included sitting to standing, standing to sitting, transfers from chair to chair, standing unsupported, sitting unsupported, standing with their eyes closed, standing with their feet together, assuming a tandem stance (one foot in front of the other), assuming a one-footed stance, turning 360 degrees, turning to look behind, retrieving an object from the floor, placing the alternate foot on a stool, and reaching forward with an outstretched arm.

The participants received oral; visual; and, when necessary, sign language instructions. If they needed further clarification, they were allowed practice trials and given further prompts. If they required multiple attempts at a task (a maximum of 3), which might have occurred if they did not understand the directions for the task or if their attention shifted during the completion of the task, only the best attempt was scored. For some of the tasks, being able to maintain a position for a specified period was part of the directions (as with standing unsupported, sitting with the back unsupported, standing unsupported with the eyes closed, standing unsupported with the feet together, standing unsupported with one foot in front of the other, and standing on one leg), while for two other tasks, completing the task in a timely fashion resulted in higher scores (for example, turning 360 degrees—in 4 seconds or less—and placing the alternate foot on step stool while standing unsupported—in 20 seconds or less). For these tasks, points were deducted if that duration was not met. That the participants could choose which leg or arm to use to complete a task could have influenced their performance on that task if they used poor judgment.

To assess self-efficacy of balance, we administered a 17-question survey that was modified from the ABC (Powell & Myers, 1995) to the participants. Specifically, the scale was modified from 0 to 100% to 0 to 10% to make the rating more appropriate for the children. The participants were instructed to rate their confidence with their balance for each item on a scale of 0 to 10, with 0 being no confidence and 10 being complete confidence. Because of their ages and cognitive functioning, the participants completed the survey with their parents' assistance. The ABC was found to be highly reliable over a two-week period ($r = .92$, $p < .001$) (Powell & Myers, 1995). The survey was administered by the principal investigator (the lead author) prior to the balance assessment. Twenty-one participants with CHARGE syndrome and 31 sighted participants in the control group completed all the activities and answered all the questions. The entire protocol took 30 or fewer minutes for the children with CHARGE syndrome and typically fewer than 15 minutes for the children in the control group. The expert observers were two university professors in the areas of motor development and adapted physical education (one was fluent in sign language) and a research assistant with a master's degree in adapted physical education and many years of teaching experience with children with disabilities (who was also proficient in sign language). If there was a question about a score, the observers collaborated until they reached a consensus.

Descriptive statistics (including the means and standard deviations) and comparative statistics (an analysis of variance—ANOVA) were computed for the PBS and the modified ABC scores. Pearson's correlation was used to assess the ABC scores, including the relationship among the PBS, age, and gender. The ANOVA was used to compare the groups on the total scores of the PBS and the ABC. The statistical tests were set at a level of .05.

Results

PBS

The sighted control participants performed significantly better on the PBS, $F(1,48) = 53.64$, $p < .001$, with all of

Table 2
Pediatric Balance Scale scores and times for each activity.

	PBS score		Time (in seconds)	
	CHARGE participants	Control participants	CHARGE participants	Control participants
Task	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)	*M* (*SD*)
Sitting to standing	2.9 (1.18)	4 (0)	NA	NA
Standing to sitting	3.33 (1.24)	4 (0)	NA	NA
Transferring	3.05 (1.36)	4 (0)	NA	NA
Standing unsupported	2.33 (1.39)	4 (0)	18.16 (10.82)	30 (0)
Sitting with the back unsupported for 30 seconds	3.67 (0.73)	4 (0)	28.81 (3.56)	30 (0)
Standing unsupported with the eyes closed	2.86 (1.56)	4 (0)	8 (6.66)	10 (0)
Standing unsupported with the feet together	2 (1.9)	4 (0)	17.38 (12.68)	30 (0)
Standing unsupported with one foot in front of the other	0.4 (0.94)	4 (0)	4.66 (7.41)	30 (0)
Standing on one leg	0.85 (0.88)	3.9 (0.31)	2.38 (6.61)	9.5 (1.33)
Turning 360 degrees	2.9 (1.61)	4 (0)	7.56 (10.46)	2.17 (0.33)
Turning to look behind left and right shoulders while standing still	3.29 (1.27)	4 (0)	NA	NA
Picking up an object from the floor from a standing position	3.35 (1.46)	4 (0)	NA	NA
Placing the alternate foot on a stepstool while standing unsupported	2.53 (1.81)	4 (0)	9.09 (5.57)	5.16 (1.46)
Reaching forward with an outstretched arm while standing	2.95 (1.43)	4 (0)	NA	NA
Total *M* (*SD*)	2.6 (1.34)	3.99 (0.02)	12.01 (7.97)	18.35 (0.39)

NA = not applicable.

them scoring 55 or 56 points out of a total of 56 points (M = 55.93, SD = 0.26), placing them all in the low fall-risk category. For the participants with CHARGE syndrome, the results of the PBS revealed that 12 of the 21 (57%) were at risk of falling; 9 scored in the low fall-risk (41 to 56 points), 8 scored in medium fall-risk (21 to 40 points), and 4 scored in high fall-risk (less than 20 points) (M = 35.67; SD = 14.69) categories. There was a small correlation (r = 0.08, p .05) between age and the PBS.

Table 2 presents the means and standard deviations for each of the 14 activities for both groups on a scale of 0 to 4 with a maximum of 4. When applicable, the means and standard deviations for the time to complete the task were also included. Lower scores indicated poorer performance. It is important to note that better performance was indicated by a longer duration (up to a maximum of 30 seconds) for standing unsupported, sitting with the back unsupported, standing unsupported with the eyes closed, standing unsupported with the feet together, standing unsupported with one foot in front of the other, and standing on one leg. For the turning 360 degrees and the alternating feet activities, better performance was indicated by less time, since the task was to determine how long it took the participant to turn 360 degrees.

The participants with CHARGE syndrome performed the best on sitting with the back unsupported for 30 seconds (M = 3.67, SD = 0.73) and performed well on standing to sitting, transferring, turning, and picking up an object, with scores higher than 3.0 for each task. This group performed the poorest for the tandem stance (M = 0.40; SD = 0.94) and the one-footed stance (M = 0.85; SD = 0.88). For the one-footed stance, the participants were instructed to stand on their preferred foot. The participants with CHARGE syndrome performed with scores lower than 3 points on the PBS for sitting to standing, standing unsupported, standing unsupported with the eyes closed, standing unsupported with the feet together, turning 360 degrees, placing the alternate foot on a step stool while standing unsupported, and reaching forward with an outstretched arm while standing. The only task for which some of the sighted control participants did not earn a score of 4.0 was the one-legged stance for not holding the one legged stance for the entire duration of 10 seconds.

Self-efficacy of balance

The responses to the ABC scale revealed that the participants with CHARGE syndrome had significantly lower scores, F (1,47) = 51.12, $p < .001$) than the age-matched sighted control participants. The participants rated their confidence in their balance from 0 to 10, with 10 being complete confidence and 0 being no confidence. Of the participants with CHARGE syndrome, 29 rated their confidence as zero, indicating that a low confidence in balance was a significant problem for them. The ABC scores were found to be moderately correlated (r = 0.56, p = .008) with the PBS scores of these participants but were not significantly correlated with either gender (r = 0.065, p = .778) or age (r = −0.169, p = .465).

Table 3 presents the descriptive and comparative results for both groups for each ABC survey question. A follow-up test and a Bonferroni correction were applied to account for the increased chance of a Type I error occurring with these data. The Bonferroni correction was applied by dividing the level of significance (alpha) by the number of independent hypotheses. The correction was conducted through Minitab. Fourteen of the 17 comparisons were found to be significant even after the more stringent Bonferroni adjustment was applied. The exceptions were walking around in the house, reaching at eye level, and taking a bath or shower. The results for the individual questions revealed that the participants were more comfortable in familiar settings in that they rated themselves the highest on walking around the house (M = 8.95, SD = 1.91). The other questions on which the participants rated themselves highly were reaching at eye level (M = 9.14, SD 2.17) and picking up a pencil from the floor (M = 8.35, SD = 2.41). This score matched their performance in that the participants with CHARGE syndrome performed well on picking up an object while standing (M = 3.35, SD = 1.46) in the PBS. These participants performed particularly low on riding on an escalator without holding on (M = 3.42, SD = 3.24) and walking on icy sidewalks (M = 3.21, SD = 2.82).

Table 3
Self-efficacy of balance scores.

	CHARGE participants		Control participants			
Item	*M*	*SD*	*M*	*SD*	*F* (49)	*p*
Walk around the house	8.95	1.91	9.79	1.11	6.57	.014*
Walk up and down stairs	6.48	2.96	9.90	0.41	34.43	.000**
Pick up pencil from the floor	8.35	2.41	9.93	0.26	11.90	.001**
Reach at eye level	9.14	2.17	9.97	0.19	3.97	.053
Reach on tiptoes	5.14	3.53	9.55	0.83	39.81	.000**
Stand on chair to reach	5.35	3.47	9.10	1.54	28.87	.000**
Sweep the floor	5.94	4.08	9.69	0.97	23.29	.000
Walk outside to a nearby car	7.52	2.82	10.00	0.00	22.88	.000**
Get in or out of a car	7.55	2.72	9.93	0.37	18.32	.000**
Walk across a parking lot	7.00	2.95	9.86	0.44	25.33	.000**
Walk up and down a ramp	6.71	2.80	9.83	0.38	31.65	.000**
Walk in a crowd, bumped	5.67	3.28	9.38	0.94	27.42	.000**
Ride on an escalator holding the rail	6.40	3.19	9.69	0.89	28.09	.000**
Ride on an escalator not holding the rail	3.42	3.24	9.24	1.46	63.70	.000**
Walk on icy sidewalks	3.21	2.82	8.28	2.52	37.55	.000**
Dress	7.05	3.41	9.79	0.56	19.24	.000**
Take a bath or shower	7.75	3.08	9.45	1.40	5.67	.022*
Mean scores	6.57	2.99	9.61	0.84	51.12	.000**

* = $p \leq .05$; ** = $\leq .003$.

Discussion

The study found that many participants with CHARGE syndrome were at a moderate to high risk of falling and had low confidence in their balance on the basis of their ABC scores. These findings are particularly important because minimal research has been conducted on children with CHARGE syndrome. Furthermore, there is high variability among children with CHARGE syndrome, making it more challenging to make generalizations. More than 20 children with CHARGE syndrome is a large number in view of the low incidence of this population. Considering that these participants traveled nationally and internationally to attend the conference on CHARGE syndrome, it may be assumed that their parents were vested in their education and physical well-being in many areas.

The participants with CHARGE syndrome appear to have performed better on static balance tasks (tasks in which they balanced without changing their body position) than on dynamic balance tasks. Lower scores were found for many of the ABC survey responses as well in comparison to the static tasks with the exception of walking around the house. This finding has practical implications because most activities of daily living, such as walking, dressing, sweeping the floor, carrying bags, reaching for something in a cabinet, and taking a shower, require dynamic balance. Children with CHARGE syndrome should focus on improving their dynamic balance through physical activities that promote movement, increased strength, and flexibility.

The study revealed that there was a relationship between how the participants with CHARGE syndrome evaluated their self-efficacy of balance and their objectively measured balance abilities. It is important to note that on the basis of the ABC scores, they had significantly lower confidence in their balance even during common everyday activities of daily living (such as standing up, reaching at eye level, and dressing) than did the sighted participants in the control group. Self-efficacy of balance has been correlated with the increased risk of falls and with decreased participation in physical activities (Ray et al., 2007; Stuart, Lieberman, & Hand, 2006). Although the balance of typically developing children improves on a variety of tasks throughout childhood and adolescence (Assaiante & Amblard, 1995; Charpiot et al., 2010; DeOreo & Wade, 1971; Schmid, Conforto, Lopez, Renzi, & D'Alessio, 2005), balance performance was not correlated with age in the participants with CHARGE syndrome.

Limitations

Maintaining the attention of some of the participants with CHARGE syndrome was particularly difficult for the tasks that instructed them to maintain a position for 30 seconds. It is possible that some of them could have physically held these positions longer, but had difficulty maintaining their focus to continue the tasks longer. We used some distracting techniques, such as asking the participants questions and counting with them to help them continue the tasks longer. The descriptive information of the participants was limited by the self-reports from the parents, with some parents stating that they had limited knowledge of their children's diagnoses. Self-report questionnaires are also limited by the understanding and attention of the participants, which is why the ABC scale was completed with the assistance of the parents.

In addition, this was a convenience sample because of the low incidence (1 in 10,000 babies born; Sanlaville & Verloes, 2007) of the syndrome. Assessing a large-enough sample of children with CHARGE syndrome who were not at the conference would have required extensive time, money, and travel. Given these limitations, these data still fill critical gaps in the literature on children with CHARGE syndrome. They provide descriptive information on objective static and dynamic balance, which were also correlated with self-efficacy of balance. Future research should examine effective interventions to improve balance in children with CHARGE syndrome.

Conclusion

Research has shown that children with CHARGE syndrome have balance difficulties for a variety of physiological reasons (Girardi, 2009). It is likely that the more opportunities children have to improve their balance in a variety of contexts with supports from teachers and caregivers, the better the children will perform. Future research should examine the benefits of increased physical activity, specifically activities that help children with CHARGE syndrome to improve their balance. We expect that a greater focus on balance and movement would improve the children's performance in all the tasks in the PBS, as well as the children's ABC scores. Balance is a critical component of daily living because it affects all our movements and our ability to function independently.

In summary, our study examined balance and self-efficacy of balance in a group of children with CHARGE syndrome. Over half (57%) the participants were at a medium to high risk of falling. Most participants also reported low ABC scores, which were significantly correlated with their PBS scores. It is essential that parents and physical educators emphasize activities that can improve balance and provide additional opportunities for physical activities by children with CHARGE syndrome, so these children can improve their balance across the critical developmental years.

References

Assaiante, C., & Amblard, B. (1993). Ontogenesis of head stabilization in space during locomotion in children: Influence of visual cues. *Experimental Brain Research, 93*, 499–515.

Assaiante, C., & Amblard, B. (1995). An ontogenetic model for the sensorimotor organization of balance control in humans. *Human Movement Science, 14*, 13–43.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychology Review, 84*, 191–215.

Brown, D. (2005). CHARGE syndrome "behaviors": Challenges or adaptations? *American Journal of Medical Genetics A, 133A*, 268–272.

Cantell, M., Crawford, S., & Doyle-Baker, P. (2008). Physical fitness and health indices in children, adolescents and adults with high or low motor competence. *Human Movement Science*, *27*, 344–362.

Cawley, J. C., & Spiess, C. K. (2008). Obesity and skill attainment in early childhood. *Economics and Human Biology*, *6*, 388–397.

Casselbrant, M. L., Mandel, E. M., Sparto, P. J., Redfern, M. S., & Furman, J. M. (2007). Contribution of vision to balance in children four to eight years of age. *Journal of Ontology, Rhinology & Laryngology, 116*, 653–657.

Charpiot, A., Tringali, S., Ionescu, E., Vital-Durand, F., & Ferber-Viart, C. (2010). Vestibulo-ocular reflex and balance maturation in healthy children aged from six to twelve years. *Audiology and Neurotology, 15*, 203–210.

Dammeyer, J. (2012). Development and characteristics of children with Usher syndrome and CHARGE syndrome. *International Journal of Pediatric Otorhinolaryngology, 76*, 1292–1296.

Delorme, A., Frigon, J. Y., & Lagace, C. (1989). Infants' reactions to visual movement of the environment. *Perception, 18*, 667–673.

DeOreo, K., & Wade, M. G. (1971). Dynamic and static balancing ability of preschool children. *Journal of Motor Behavior, 3*, 326–335.

Foster, E. C., Sveistrup, H., & Woollacott, M. H. (1996). Transitions in visual proprioception: A cross-sectional developmental study of the effect of visual flow on postural control. *Journal of Motor Behavior, 28*, 101–112.

Franjoine, M. R., Gunther, J. S., & Taylor, M. J. (2003). Pediatric balance scale: A modified version of the Berg Balance Scale for the school-aged child with mild to moderate motor impairment. *Pediatric Physical Therapy*, *15,* 114–128.

Girardi, M. M. (2009, July). Balance: What is it and how does it work? Paper presented at the Ninth International CHARGE Syndrome Conference, Bloomingdale, IL.

Haibach, P., Lieberman, L. J., & Pritchett, J. (2011). Balance in adolescents with and without visual impairments. *Insight Journal, 4,* 112–121.

Harter, S. (1989). Causes, correlates and the functional role of global self-worth: A lifespan perspective. In J. Koligan & R. Stennberg (Eds.), *Perceptions of competence and incompetence across the lifespan* (pp. 136–182). New Haven, CT: Yale University Press.

Holbrook, M. C., & Koenig, A. J. (2007). *Foundations of education*. New York: AFB Press.

Houwen, S., Hartman, E., & Visscher, C.

(2009). Physical activity and motor skills in children with and without visual impairments. *Medicine & Science in Sports & Exercise, 41*, 103–109.

Issekutz, K., Graham, J. G., Jr., Prasad, C., Smith, I. M., & Blake, K. (2005). An epidemiological analysis of CHARGE syndrome: Preliminary results from a Canadian study. *American Journal of Medical Genetics, 133A*, 309–318.

Lieberman, L. J., Haibach, P., & Schedlin, H. (2012). Physical education and children with CHARGE syndrome: Research to practice. *Journal of Visual Impairment & Blindness, 106,* 106–119.

Pagon, R. A., Graham, J. M., Zonana, J., & Young, S. L. (1981). Congenital heart disease and choanal atresia with multiple anomalies. *Journal of Pediatrics, 99*, 223–227.

Powell, L. E., & Myers, A. M. (1995). The Activities-Specific Balance Confidence (ABC) Scale. *Journal of Gerontology A: Biological Sciences and Medical Sciences, 50A*, M28–M34.

Ray, C., Horvat, M., Williams, M., & Blasch, B. (2007). Kinetic movement analysis in adults with vision loss. *Adapted Physical Activity Quarterly, 24*, 209–217.

Ribadi, H., Rider, R. A., & Toole, T. (1987). A comparison of static and dynamic balance in congenitally blind, sighted, and sighted blindfolded adolescents. *Adapted Physical Activity Quarterly, 4*, 220–225.

Salem-Hartshorne, D., & Jacob, S. (2005). Adaptive behavior in children with CHARGE syndrome. *American Journal of Medical Genetics, 133A*, 262–267.

Sanlaville, D., & Verloes, A. (2007). CHARGE syndrome: An update. *European Journal of Human Genetics, 15*, 389–399.

Schmid, M., Conforto, S., Lopez, L., Renzi, P., & D'Alessio, T. D. (2005). The development of postural strategies in children: A factorial design. *Journal of NeuroEngineering and Rehabilitation, 2*, 29–39.

Smith, K. G., Smith, I. M., & Blake, K. (2010). CHARGE syndrome: An educator's primer. *Education and Treatment of Children, 33*, 289–314.

Sobsey, D., & Wolf-Schein, E. (1996). Children with sensory impairments. In F. P. Orelove & D. Sobsey (Eds.), *Educating children with multiple disabilities: A transdisciplinary approach* (3rd ed., pp. 411–450). Baltimore, MD: Paul H. Brookes.

Stuart, M. E., Lieberman, L., & Hand, K. E. (2006). Beliefs about physical activity among children who are visually impaired and their parents. *Journal of Visual Impairment & Blindness, 100*, 223–234.

Sundermier, L., Woollacott, M. H., Roncesvalles, N., & Jensen, J. (2001). The development of balance control in children: Comparisons of EMG and kinetic variables and chronological and developmental groupings. *Experimental Brain Research, 136*, 340–350.

Vellas, B. J., Wayne, S. J., Romero, L. J., Baumgartner, R. N., & Garry, P. J. (1997). Fear of falling and restriction of mobility in elderly fallers. *Age and Ageing*, *26*, 189–193.

Wagner, M., & Haibach. P. (2012, March). *Motor development assessment—Children with visual impairments using the TGMD-II.* Paper presented at the national consortium of the American Alliance for Health, Physical Education, Recreation, and Dance, Boston.

Williams, G. L., & Hartshorne, T. S. (2005). Understanding balance problems in children with CHARGE syndrome. *Deaf-Blind Perspectives, 12*(2), 5–7.

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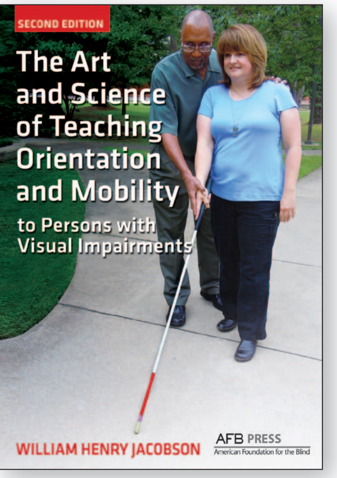
The Art and Science of Teaching Orientation and Mobility to Persons with Visual Impairments, *Second Edition*



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