https://doi.org/10.18666/PALAESTRA-2025-V39-I2-13102

Barriers to Physical Activity for Children with CHARGE Syndrome: A Descriptive Study

Lauren J. Lieberman
SUNY Brockport

Melanie Perreault
SUNY Brockport

Pamela Beach
Rochester Institute of Technology

Abstract

CHARGE syndrome is a low incidence multiple disability that is the most common genetic cause of deafblindness in youth. Research findings have revealed that young children with CHARGE syndrome develop their motor milestones later and perform with significantly lower scores in balance and motor competence than their sighted and hearing peers. The purpose of this study was to determine the most prevalent barriers for physical activity in children and youth with CHARGE syndrome. Fourteen children and youth with CHARGE syndrome completed The Physical Activity Barriers Questionnaire for Youth with Visual Impairment either alone or with the support of their parents. Findings indicated that youth with CHARGE syndrome faced many personal, social, and environmental barriers to physical activity. Implications illuminated the need to educate future professionals and current teachers on the needs of children and youth with CHARGE Syndrome.

Keyterms: *Adapted physical education, professional preparation, multiple disabilities*

According to the Individuals with Disabilities Education Act (2004), youth with deafblindness, concomitant hearing and vision impairments of various levels of severity, require additional services to programs for youth with deafness or blindness. The most common cause of child onset deafblindness is CHARGE syndrome. CHARGE syndrome effects between 1 per 10,000 and 1 per 15,000 infants (Deuce et al., 2012). CHARGE syndrome is a genetic condition most commonly produced from mutations of the CHD7 gene that results in a combination of unique features, such as colobomas, heart defects, atresia choanae, restricted growth and development, genital hypoplasia, and ear abnormalities (Usman & Sur, 2023). Individuals diagnosed with CHARGE syndrome are affected by numerous characteristics in addition to hearing and vision disabilities that affect motor development, including missing or malformed semicircular canals, muscle laxity, and neurological impairments (Hartshorne et al., 2011). These various characteristics are exacerbated by several environmental factors including prolonged hospital stays (Hartshorne et al., 2011), fewer opportunities to participate in physical activity (Lieberman et al., 2012), and practitioners who are not educated in teaching motor skills to children who are deafblind (Arndt et al., 2004; Lane et al., 2020) which can further contribute to their motor development delays (Lieberman & Beach, in press).

Children with CHARGE syndrome are often behind their peers without disabilities in motor competence of fundamental motor skills (Haibach-Beach et al., 2019; Perreault et al., 2021). Haibach-Beach and colleagues (2019) evaluated children with and without CHARGE syndrome on five fundamental motor skills (i.e., run, jump, slide, kick, overhand throw) from the Test of Gross Motor Development-2 (TGMD-2) and found that children with CHARGE syndrome performed with significantly lower competence on all five skills when compared to peers without disabilities. Perreault and colleagues (2021) expanded on this study by assessing children with and without CHARGE syndrome on the 13 motor skills items from the Test of Gross Motor Development-3 (TGMD-3). In this study, it was found that the participants with CHARGE syndrome scored significantly lower when compared to their peers without disabilities on all gross motor skills. The largest effects were found in the hop, underhand roll, and skip.

While deficits in fundamental motor skill competence in children with CHARGE syndrome can be attributed in part to individual structural constraints, additional constraints have also been examined. Lane and colleagues (2021) found that parents of children with CHARGE syndrome appreciated adapted physical education for their child yet were not satisfied with the knowledge of their child's physical education teacher related to CHARGE syndrome. These parents felt the teachers did not know how to modify lessons appropriately for their child. Beach and colleagues (2021) studied differences in parental perceptions and support of their children with and without CHARGE syndrome's gross motor competence. Results from this study discovered that parents of children with CHARGE syndrome assessed their child lower on all gross motor skills components compared to parents of children without disabilities. Nevertheless, these parents participated with their child in movements skills and tracked their child's gross motor skill practice on a more consistent basis than parents of children without disabilities. Haibach-Beach and colleagues (2021) expanded these findings by investigating the influence of parent perceptions and parental support on their child's actual gross motor competence. The results

suggested that parents play a vital role in the development of fundamental motor skills for children with CHARGE syndrome and other multiple disabilities and should be included in motor skill interventions (Beach et al., 2024).

The above findings illuminate a clear deficit in motor competence for children with CHARGE syndrome. However, at this time it is not known what specific barriers children with CHARGE syndrome face related to physical activity participation. Although research with parents has shed some light on environmental influences on physical activity engagement of children with CHARGE syndrome, there have been no studies that focus on the perspectives of the children with CHARGE syndrome in relation to their own physical activity involvement. Thus, the purpose of this study was to determine the most prevalent barriers for children and youth with CHARGE syndrome related to physical activity by surveying the children themselves.

Methods

Participants

Ethical approval for this study was attained from the institutional review board of the lead researcher's institution. Consent and assent were obtained from all parents and children prior to the start of the study. Parents were included in the study to provide support for their child completing the questionnaire, if needed. The sample included 14 children and youth with CHARGE syndrome and four parents (3 mothers and 1 father) who provided support for their child completing the questionnaire. Within the sample of children and youth with CHARGE syndrome, the average age was 15 years (SD=3.5 years). There were more females (n=10) than males (n=4), and the majority identified as White (n=12).

Instrument

The instrument utilized in this study was the Physical Activity Barriers Questionnaire for Youth with Visual Impairments (PABQ-VI). This instrument has been shown to have good psychometric properties (Martin et al., 2021). The PABQ-VI comprises 23 questions representing three subscales: personal, social, and environmental barriers. Participants responded to each statement on a 5-point Likert scale that ranged from a 1 (strongly disagree) to 5 (strongly agree). Subscale scores were determined by taking the average score throughout the items representing each subscale. Higher scores indicated the barrier was less problematic while lower scores indicated the barrier is more of an issue. Additionally, there were two open-ended questions: "Is there anything else that you can think of that might stop you from doing physical activity, or that keeps you from doing the physical activities that you would like to do?", and "Is there anything that you can think of that would help you do physical activities or be more physically active?"

Procedures

A demographics questionnaire and the PABQ-VI were distributed in person at a large conference for families of individuals with CHARGE syndrome. Participants who had clear communication and were between 10-20 years old were recruited. Participants completed the questionnaires with their parents' help at the conference. Large print copies of the questions were provided to participants who asked for them.

Data Analysis

Descriptive statistics were analyzed for the PABQ-VI subscales and individual items. Means and standard deviations were determined due to the low number of participants. For the open-ended questions, the responses were reviewed and coded for themes separately by two of the lead researchers. Thematic analysis was used to analyze the data using a six-stage inductive process (Braun et al., 2016). This data analysis method is recommended for analyzing people's experiences in various life experiences. Initially, the researchers immersed themselves into the original data by reading and re-reading the data generated from the open-ended questions. Secondly, they generated initial codes of common experiences that arose. This step was to develop a clear understanding and familiarity with the data. Thirdly, they created common themes from the codes, and fourth, reviewed the themes together for comparison and refinement. The fifth step was to define and name each theme with agreement. Agreement on the themes occurred during each subsequent stage before moving forward to ascertain the accuracy and placement of the data. Lastly, the sixth step was writing up the findings section. The coding resulted in themes with corresponding salient elements nested within the larger organizational structures.

Results and Findings

The descriptive analysis for the subscales revealed that participants had more environmental barriers (M=3.62, SD=.70) than personal (M=3.94, SD=.72) and social barriers (M=3.93, SD=.62), which were very similar to one another. Descriptive statistics for individual items for each subscale are presented in Tables 1-3.

The findings for the open-ended questions provided more depth to the quantitative results. Three themes emerged from the analyses of the open-ended questions: (1) Communication Issues, (2) CHARGE Syndrome Characteristics, and (3) Community Access.

Communication Issues

Due to the variety of hearing needs of youth with CHARGE syndrome, it was not surprising that communication was a major theme. One challenge raised was the ability to communicate in the water without a Bone Anchored Hearing Aid (BAHA) hearing devices. One participant said

Table 1
Personal Subscale Items in Order from Greatest Barrier to Least Barrier

Item	M	SD
I feel confident to try new sports and physical activities.	3.07	1.14
I feel motivated to do physical activity.	3.79	1.12
Physical activity and sports are fun.	4.07	0.73
I believe physical activity is important.	4.14	1.17
I believe I can do physical activity even though I have a visual impairment.	4.28	0.91
I know ways that I can be physically active.	4.28	0.73

Table 2
Social Subscale Items in Order from Greatest Barrier to Least Barrier

Item	M	SD
My teachers expect me to do physical activity just like everyone else.	3.29	1.20
I know other children who will do physical activity with me.	3.57	1.09
My classmates include me in games and physical activities during recess.	3.57	0.94
My parents can afford for me to do sport and physical activities.	3.93	1.07
My parents encourage me to do physical activity.	4.00	1.04
My PE teacher encourages me to do physical activity.	4.07	0.92
Physical activity is important to my parents.	4.29	0.91
My PE teacher includes me in games and physical activities.	4.29	0.61
My parents have a way to get me to places to do sport or physical activity.	4.36	1.08

Table 3
Environmental Subscale Items in Order from Greatest Barrier to Least Barrier

Item	M	SD
My school has sport teams and physical activity clubs that I can join if I want to.	2.86	1.29
There are sports programs that I can join which are close to home.	3.21	1.19
Sports clubs in my community will allow me to join even though I have a visual impairment.	3.21	0.98
There are places in my community that are safe for me to do physical activity.	3.57	1.09
I know about opportunities to do physical activity in my community.	3.64	0.93
There are sport programs or physical activities available in my community.	3.86	0.77
I have sports equipment at home that I can use to be physically active.	4.21	1.05
There are spaces at home that are safe for me to do physical activity.	4.36	1.08

"Can't get an interpreter in the water with me for swimming lessons. I can't wear my glasses or BAHA's in the water and need the interpreter close." A parent shared

> The only thing that will stop her because she's non-verbal. She has some signs but not fully signed and she's hearing and vision impaired. She does wear a BAHA for her left ear, but if she hears too much noise that stimulation will make her act out, her behavior will go haywire.

These statements make it clear that communication can be a problem. Another family said that they do not have access to an interpreter. These barriers related to communication directly relate to environmental barriers.

CHARGE Syndrome Characteristics

Some of the barriers found specifically related to various CHARGE characteristics. For example, one participant wrote "I have had a retinal detachment, and I am at risk for it to detach again." This response illuminates the fear of further damaging their vision from participating in physical activity. Another comment related to vision was "I have a hard time seeing at night. I need to wear my transition glasses. I have a hard time running." Another participant mentioned challenge due their proprioceptive system "She loves working out, but sports like baseball/softball, football are challenging, (balance, depth perception)." Participants also indicated that participation in exercise was difficult due to low energy from frequent illnesses. The lack of ability to be active can affect

endurance as one participant said "stamina" was the barrier to their participation.

Community Access

Engaging in physical activity in the community is an enjoyable and positive experience for most children and youth. However, it was clear in some of the quotes that access to typical community sports and recreation activities were a barrier for children and youth with CHARGE syndrome. One participant said, "Social inclusion with local sports and physical activity in community. Always need to drive at least 20 minutes to find inclusive sports."

A child's ability to engage in a typical sports or recreation program can be challenging due to the many unique characteristics of CHARGE syndrome. A parent shared about their child, "He likes swimming, and we have him in adapted swim classes. He likes jogging and we would need to find a safe place for that." This clearly shows their child's desire to be physically active, however, there are safety concerns that need to be addressed. One participant expressed difficulty with support to participate in physical activity, "It's disappointing because I cannot get my mother to walk with me."

Some participants recommended additional opportunities in the community to engage in physical activity, sports, and recreation. One parent suggested, "We would like to see an increase in inclusive community sports programs within our city." Another participant shared "Safe running/ jogging space". Lastly, one participant expressed, "Have coaches help me one-on-one, and I need to tell them what I need."

Discussion

Youth with CHARGE syndrome face many personal, social, and environmental barriers to physical activity; however, this is the first study to examine these barriers. Individuals with CHARGE syndrome exhibit a variety of characteristics affecting their sensory and motor domains that include, but not limited to, visual impairment, deafness, vestibular underdevelopment, and muscle laxity (Hartshorne et al., 2011). Medical treatments and hospitalizations further prevent individuals with CHARGE syndrome from being physically active and remove them from socialization opportunities. The findings from this study provide some initial empirical data to support the challenges that youth with CHARGE syndrome face regarding physical activity and indicate potential strategies to further support them to have a physically active lifestyle.

All the personal barriers that were mentioned in the open-ended questions were related to issues corresponding directly to their CHARGE characteristics. The higher scores found for the personal barrier items related to the importance of a physically active lifestyle, understanding how to be physically active, and belief in being physically active with a visual impairment are very encouraging. However, the results suggest that youth with CHARGE syndrome lack the confidence and motivation to try new sports and physical activities. An individuals' perception of their physical strength, capability for movement, and fitness levels (Fox & Corbin, 1989), termed perceived motor competence (PMC), is important for participation levels in physical activity. Brian and colleagues (2016) found that children with visual impairments have low levels of PMC and their PMC is associated with their physical activity levels. Children with lower levels of PMC find participating in physical activity less enjoyable and participate in less physical activity (Stodden et al., 2008). Participating in physical activity at a young age is particularly important as research indicates that PMC and participation in physical activity decreases with age (Brian et al., 2016). The open-ended responses indicated that lower participation in physical activity was also related to safety concerns and lower physical conditioning.

The results related to the social barriers indicated challenges with teachers, peers, and parents. The qualitative and quantitative findings provided some mixed results. Subset items with the lowest scores included "My teachers expect me to do physical activity just like everyone else," "I know other children who will do physical activity with me, and 'My classmates include me in games and physical activities during recess." Conversely, one of the highest subset items was "My physical education teacher includes me in games and physical activities." The results regarding the parents indicated high parental involvement for their child with CHARGE syndrome with high scores for "Physical activity is important to my parents," and "My parents have a way to get me to places to do sport or physical activity." Similarly, positive associations between parental perceptions and motor performance of children with CHARGE syndrome were found such that parents who were more involved with their child's gross motor skill development positively influenced their child's motor competence (Haibach-Beach et al., 2021). It should be noted that the parents were involved in completing the questionnaire, which likely impacted these responses. It is also important to acknowledge that all participants were recruited from an International CHARGE syndrome conference. Parents who bring their child with CHARGE syndrome to an international conference are likely more involved in their child's health and well-being or at least are likely to have more opportunities than parents of youth with CHARGE syndrome who do not attend international conferences for their child. Parental encouragement is a very important factor for physical activity levels for youth with visual impairments (Stuart et al., 2006). Thus, while these results should be examined with caution, they are encouraging.

The responses to the open-ended questions related to environmental barriers reiterated the items included in the environmental subscale, such as access to community sport and physical activity programs. The lowest item on the subscales with a mean of 2.86 was "My school has sport teams and physical activity clubs that I can join if I want to." This

showed a clear barrier to engagement in after school sports and activities. This issue could relate back to social barriers as it is likely to be due to the lack of knowledge of the PE teachers and coaches in knowledge related to the needs of children with CHARGE syndrome.

Limitations

The most obvious limitation to this study was the low number of participants. Yet, the depth of information we gained from these participants was rich and informative. Another limitation was that the participants were recruited from an international CHARGE syndrome conference. Therefore, their families had the ability and means to get them to the conference and may not represent all families with children with CHARGE syndrome. Yet, this was a natural opportunity to recruit families that fit our demographic for the study. Lastly, this questionnaire was validated for children and youth with visual impairments. Children with CHARGE syndrome typically have disabilities beyond just visual impairment. Therefore, this questionnaire may not have detected some of the unique barriers that may be experienced by a child with a visual impairment and additional disabilities.

Implications

In this study, the major barrier was the CHARGE characteristics and the lack of inclusion in school and community physical activity. The obvious remedy would be to train current and future teachers about the abilities of children and youth with CHARGE syndrome. Perkins School for the Blind (Perkins.org) and Camp Abilities (campabilities.org) have educational materials that can train educators about the needs of youth with CHARGE syndrome and strategies to teach them motor skills and physical activity.

Another important concept that must be addressed is for coaches and administrators to understand the needs of the children and youth with CHARGE syndrome. This education and training may be done by the parent, Deafblind specialist, or the adapted physical education teacher. Each state has a Deafblind (DB) Project and a local representative from the State DB Project can be asked to help with the training of the teachers and community members. Lastly, teaching the children and youth themselves how to self-advocate can ensure they get what they need related to communication, vision needs, and adaptations (Lieberman & Childs, 2020).

Conclusion

The findings from this study offer valuable insights into the physical activity challenges faced by children and youth with CHARGE syndrome, highlighting the specific barriers they encounter and suggesting potential strategies to encourage a more active lifestyle. By addressing these challenges and implementing targeted support measures, practitioners of youth with CHARGE syndrome can help improve their motor competence, engagement in physical activities, and overall well-being.

References

Arndt, K. L., Lieberman, L. J., & Pucci, G. (2004). Communication during physical activity for youth who are deafblind. *Teaching Exceptional Children Plus, 1*(2), Article 1.

Beach, P., Lieberman, L. J., & Grenier, M. (2024). Parents of children with visual impairments and additional disabilities perceptions on physical education. *PALAESTRA, 38*(2), 24–31.

Beach, P., Stribing, A., Perreault, M., & Lieberman, L. (2021). Parent perceptions of movement skills in children with and without CHARGE syndrome. *European Journal of Adapted Physical Activity, 14*, 13. https://doi.org/10.5507/euj.2021.005

Braun, V., Clarke, V. & Weate, P. (2016). Using thematic analysis in sport and exercise research. In B. Smith & A. C. Sparkes (Eds.). *Routledge handbook of qualitative research in sport and exercise* (pp. 191–2005). Routledge.

Brian, A. S., Haegele, J. A., & Bostick, L. (2016). Perceived motor competence of children with visual impairments: A preliminary investigation. *British Journal of Visual Impairment, 34*(2), 151–155. https://doi.org/10.1177/0264619616628575

Clancy, C., Jackson, B., Dimmock, J. A., & Thornton, A. L. (2017). Parents and the Pygmalion Effect: Exploring relations between parent efficacy beliefs and children's fundamental movement skills. *Journal of Sport & Exercise Psychology, 39*, S56–S56.

Clark, J. E., & Metcalfe, J. M. (2002). The mountain of motor development: A metaphor. In J. E. Clark & J. H. Humphrey (Eds.), *Motor development: Research and reviews* (Vol. 2, pp. 163–190). National Association for Sport and Physical Education.

Deuce, G., Howard, S., Rose, S., & Fuggle, C. (2012). A study of CHARGE Syndrome in the UK. *The British Journal of Visual Impairment, 30*(2), 91-100.

Fox K. R., & Corbin C. B. (1989). The physical self-perception profile: Development and preliminary validation. *Journal of Sport & Exercise Psychology, 11*, 408–430.

Haibach-Beach, P., Perreault, M., Foster, E., & Lieberman, L. (2019). Gross motor skill performance in children with and without CHARGE syndrome: Research to practice. *Research in Developmental Disabilities, 91*, 103423. https://doi.org/10.1016/j.ridd.2019.05.002

Haibach-Beach, P., Perreault, M., Lieberman, L., & Foster, E. (2020). Independent walking and balance in children with CHARGE Syndrome. *British Journal of Visual Impairment*. doi: 10.77/026419620946068

Haibach-Beach, P., Perreault, M., Lieberman, L. J., & Stribing, A. (2021). Associations between parent perspectives and motor competence in children with CHARGE syndrome. *Journal of Motor Learning and Development, 9*(2), 313–326. https://doi.org/10.1123/jmld.2020-0057

Hartshorne, T. S., Hefner, M. A., Davenport, S. L. H., & Thelin, J. W. (Eds.). (2011). *CHARGE syndrome*. Plural Publishing.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)

Jackson, B., Whipp, P. R., Chua, K. P., Pengelley, R., & Beauchamp, M. R. (2012). Assessment of tripartite efficacy beliefs within school-based physical education: Instrument development and reliability and validity evidence. *Psychology of Sport and Exercise, 13*(2), 108–117. https://doi.org/10.1016/j.psychsport.2011.10.007

Lane, K., Lieberman, L. J., Haibach-Beach, P., Perreault, M., & Columna, L. (2021). Parental perspectives on physical education services for children with CHARGE syndrome. *Journal of Special Education, 55*(2), 90–100. https://doi.org/10.1177/0022466920942769

Lieberman, L. J., & Beach, P. (in press). Deafblindness and physical activity. In T. Hartshorne, M. Janssen, & W. Wittich (Eds.), *Oxford handbook on deafblindness*. Oxford Press.

Lieberman, L. J., Beach, P., Perreault, M., Brian, A., & Bebrisa-Fedotova, L. (2021). Feasibility of a home motor skill intervention for children with CHARGE syndrome. *Research, Advocacy, and Practice for Complex and Chronic Conditions, 40*(1), 4–23. https://doi.org/10.14434/rapcc.v40i1.31710

Lieberman, L. J., & Childs, R. (2020). Steps to success: A sports focused self-advocacy program for children with visual impairments. *Journal of Visual Impairments and Blindness*. doi: 10.1177/0145482X20971960

Lieberman, L. J., Haibach, P., & Schedlin, H. (2012). Physical education and children with CHARGE Syndrome: Research to practice. *Journal of Visual Impairment and Blindness, 106*(2) 106–119.

Martin, J. J., Snapp, E. E., G. Moore, E. W. G., Lieberman, L. J., Armstrong, E., & Mannella, S. (2021). Factor structure of the barriers to physical activity scale for youth with visual impairments. *Adapted Physical Activity Quarterly*. https://doi.org/10.1123/apaq.2020-0243

Pagon, R.A., Graham Jr., J.M., & Zonana, J.Y.S.L. (1981). Coloboma, congenital heart disease, and choanal atresia with multiple anomalies: CHARGE association. *Journal of Pediatrics, 99*, 223–227.

Perreault, M., Haibach-Beach, P., Lieberman, L., & Foster, E. (2021). Motor competence in children with CHARGE syndrome. *Research and Practice for Persons with Severe Disabilities, 46*(2), 67–76. https://doi.org/10.1177/1540796921998011

Seefeldt, V. (1980). Developmental motor patterns: Implications for elementary school physical education. In C. Nadeau, W. Holliwell, K. Newell, & G. Roberts (Eds.), *Psychology of motor behavior and sport* (pp. 314–323). Human Kinetics.

Stodden, D., Goodway, J. D., Langendorfer, S., Roberton, M., Rudisill, M., Garcia, C., & Garcia L. (2008). A developmental perspective on the role of motor skill competence in physical activity: An emergent relationship. *Quest, 13*(1), 16–26.

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

Ulrich, D. (2019). *Test of gross motor development*: Examiner's manual (3rd ed). PRO-ED.

Usman, N., & Sur M. (2023). *CHARGE Syndrome*. [Updated 2023 Mar 6]. In: StatPearls [Internet]. StatPearls Publishing. https://www.ncbi.nlm.nih.gov/books/NBK559199/

Lauren J. Lieberman, PhD, is a Distinguished Service Professor at SUNY Brockport. She teaches Adapted Physical Education at the undergraduate and graduate level in the Kinesiology, Sport Studies and Physical Education department. She is the founder and director of Camp Abilities Brockport. She is the co-director of the Institute on Movement Studies for Individuals with Visual Impairment or Deafblindness. She is a Global Fulbright Scholar, and has authored over 225 articles and 25 books in the field. She most recently was recognized with the Lifetime Achievement Award from the Association for Education and Rehabilitation of the Blind Physical Activity and Sport Division.

Melanie Perreault is an associate professor of Motor Behavior and Interim Chair of the Department of Kinesiology, Sport Studies, and Physical Education at SUNY Brockport. Her main area of research focuses on motor development in children with low vision, blindness, and deafblindness.

Pamela Beach is a professor of Motor Behavior and associate dean of Academic Affairs for the College of Health Sciences and Technology at the Rochester Institute of Technology. She is also a co-founder and co-Director of the Institute on Movement Studies for Individuals with Visual Impairments (IMSVI). Pamela publishes and presents nationally and internationally on her research in motor behavior and balance in individuals across the lifespan with sensory impairments and CHARGE syndrome. In addition, she published Gross Motor Development Curriculum: For Children with Visual Impairment with the American Printing House for the Blind and three editions of the undergraduate textbook Motor Learning and Development which have been widely adopted. Pamela has also produced numerous educational and training videos for parents and practitioners of youth with visual impairments and deafblindness. She currently serves as the Vice President of the National Consortium for Physical Education for Individuals with Disabilities.