Impact of Covid-19 on Adults with Cerebral Palsy among Cohort of the Cerebral Palsy Adult Transition Longitudinal Study

Hyun Kim1, Meredith Lewis2,3, Patricia C. Heyn1,5, Alex Tagawa2,3, Zhaoxing Pan1,3, James Carollo2,3,4

1University of Colorado School of Medicine, 2Center for Gait and Movement Analysis (CGMA), Children’s Hospital Colorado, 3Musculoskeletal Research Center (MRC), Orthopedics Institute, Children’s Hospital Colorado, 4Physical Medicine & Rehabilitation Department, University of Colorado Anschutz Medical Campus, 5Center for Optimal Aging (COA), Marymount University

Background

• Cerebral Palsy (CP) describes a group of chronic, non-progressive conditions affecting body movement and muscle coordination, caused by damage or injury to one or more specific areas of the brain that occurs during fetal development, perinatal period, or infancy.1
• CP is the most common physical disability in children, occurring in approximately 3.5 individuals per 1,000 live births.4

Methods

• This study is reporting interview data collected through phone interviews. Covid-19 vaccination status, changes in physical, mental health, access to healthcare, daily routine, and socialization status were obtained during the interviews.

Survey

• An informed verbal consent procedure at each interview was deployed. Each participant was asked to complete a Medical History Questionnaire and Coronavirus Disability Survey (COV-DIS). The phone interview included an additional and optional standardized survey, PROMIS-57. Each participant was asked to complete and return the survey electronically. Each phone interview took approximately 45 minutes.

Results

Background

• More research is needed to determine the impact of CP on indicators of socioeconomic status, such as isolation, poverty, and marginalization as compared to the non-CP population; these indicators may be exacerbated by outside influences, such as the global novel coronavirus disease (COVID-19).

• There is little research reporting the impact of the pandemic on adults with CP; to this end, we conducted a study with individuals with CP with the goal to inform and improve the current state of research about the impact of the COVID-19 pandemic on adults with CP.

• This case series aims to evaluate the lived experiences and health status of participants from the Cerebral Palsy Adult Transition Study (CPAT) cohort during the COVID-19 pandemic from 2019-2021.

Sample Case Presentation

• The following case series presentation seeks to elucidate the lived experiences of each participant but is only a glimpse of what the population of adults with CP have experienced during the COVID-19 pandemic.

Case 1: This participant is able to walk mostly without assistance but reports needing nitrates for long hikes. She frequently falls but does not hit her head and has never been significantly hurt. Her CP-related chronic arthritis has been progressing for the last 16 years, but she is not currently receiving treatment. This participant has non-congenital hip dysplasia and underwent a hip replacement procedure in 2020. She enjoys skiing, hiking, and weightlifting at least 3 times a week. She works as a healthcare worker and has experienced significant mental and emotional health changes due to the COVID-19 pandemic. The pandemic caused her a significant amount of stress and anxiety. For example, she had surgery in 2020 and was not allowed any visitor and this was a mentally and emotionally challenging event. She experienced decreased access to healthcare due to encounters switching to telehealth and reports that it was occasionally difficult to reach physicians as necessary. She lives with her husband and reports that she feels much more isolated now than before the pandemic. She takes care of daily activities alone. She reports she has been at home more, has started using grocery delivery, and has started connecting with family and friends more by computer phone. She is currently working part-time with an annual household income between $30,000-59,000 and has not reported experiencing financial troubles as a result of the COVID-19 pandemic; however, other than difficulty obtaining food, she has not experienced many changes.

Positive

• Lost significant amount of weight
• Increase in mobility due to decreased daily activities
• Fell more healthy and had less viral illnesses
• Spent more time with family

Negative

• Infected with COVID-19
• Fell very isolated
• Increased stress and anxiety, especially due to the news reporting about the COVID-19 pandemic
• Decreased access to in-person primary care visits

Discussion

• As a group of individuals with a significant physical disability, it was speculated that these individuals would struggle significantly due to isolation during the COVID-19 pandemic. Some of the expected and demonstrated changes that the participants faced were negative, including with COVID-19, other illness, feelings of anxiety, changes in access to appointments (particularly, primary care visits). These were expected changes as the rest of the world experienced significant negative effects of the COVID-19 pandemic.

• In addition, although 66.7% of the participants had a reported annual household income of less than $30,000, only 1 participant (6.67%) reported some difficulty paying rent, obtaining food, and paying for gas since the start of the COVID-19 pandemic. This finding was intriguing with the rising cost of rent, food, and gas, it would have been expected to see more individuals in this population struggling to afford them with an annual income of less than $30,000. This may be associated with some of these individuals living with family members but reporting their household income separate from the support they receive from family members.

• However, an unexpected outcome was the positive impact that a few of the participants reported. The participant in Case 2 reported that he experienced a positive physical change due to the pandemic because he lost 10 lbs, noticed an increase in his mobility due to decreased daily activities in the setting of isolation, and felt overall healthy due to the associated decrease in exposure to the public and environment. He also reported a positive emotional and mental change because he was able to spend more time with his family after his caregiver quit in the midst of the pandemic. Case 11 was also unique in that he reported feeling much healthier now than before the pandemic without specific indication thereof. As the COVID-19 pandemic forced a transition to lockdown, the lived experiences of some individuals with CP may have become more “normalized” amongst the non-CP population. The increase in use of delivery services, the isolation of leaving the house less, and increased access to healthcare via telehealth are some of the changes that may have felt difficult for individuals without CP. But this may more clearly resemble the day-to-day of individuals with CP. Thus, the pandemic lockdown may have been a positive change for this population as suggested by the 3 participants who reported that they feel much less isolated now than before the pandemic on the COV-DIS survey. Due to limited mobility, individuals with CP often experience isolation from the public and are at risk for morbidity associated with sedentary lifestyle.

• These were positive changes that were unexpected before the results of the study. They would indicate that the pandemic may have brought about some positive health changes for a portion of this population, but the factors that brought these changes can only be speculated and cannot be identified with clarity in this time. This cohort represents only a small sample of the CP population and thus it is impossible to generalize these outcomes to the overall CP community.

Limitations

• Low response rates. One of the possible factors may be the significant temporal gap between the previous study and the current case series. There has been no active contact with the cohort since the end of the previous study in 2018.
• Timing of the data collection. These phone interviews were initiated two years into the pandemic when the mask mandate was starting to loosen, rather than being conducted the year prior during the peak of the quarantines.

References