

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

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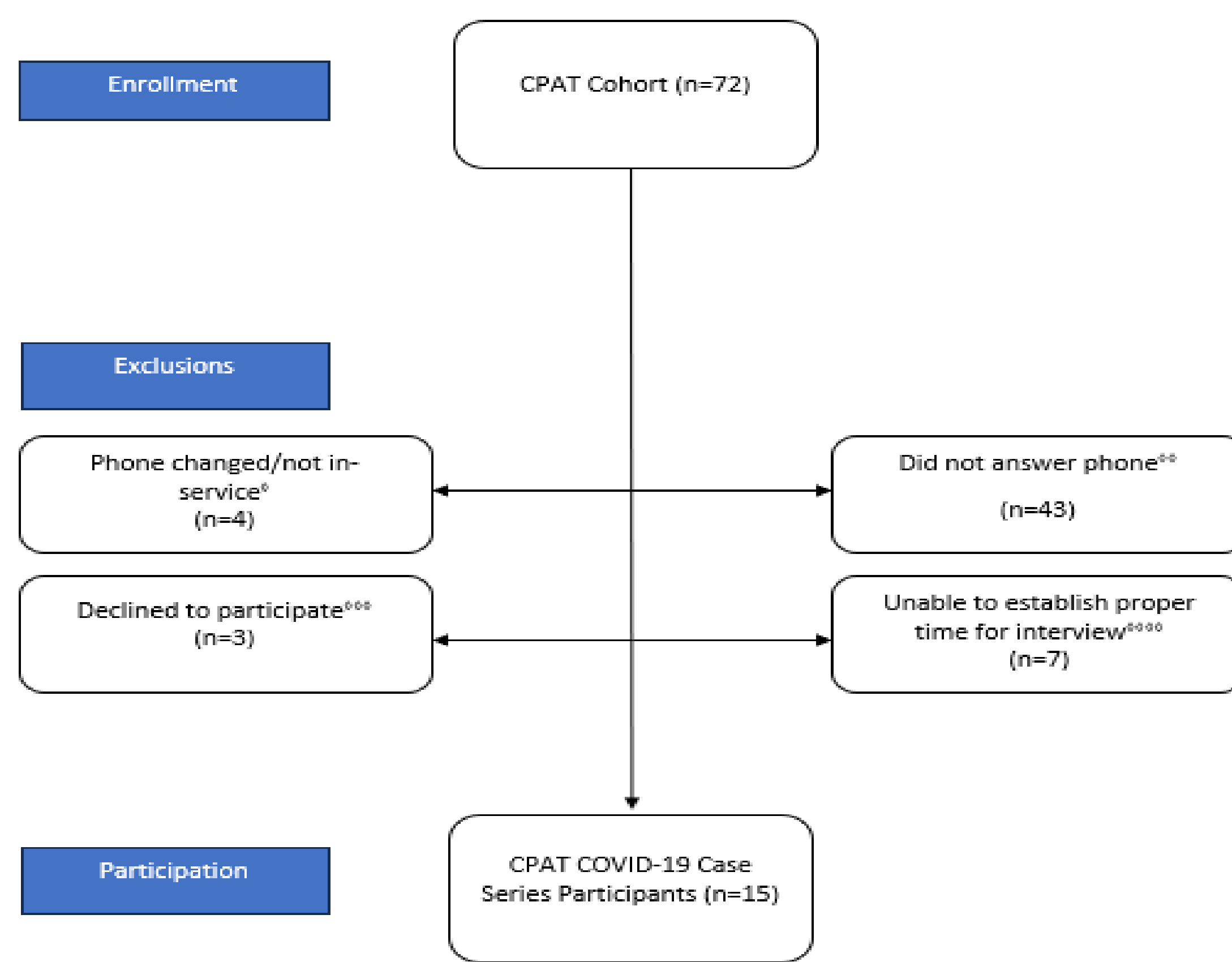
Background

- 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, the perinatal period, or infancy.^{1,2}
- CP is the most common physical disability in children, occurring in approximately 3.5 individuals per 1,000 live births³;
- Individuals living with CP have lower Health-Related Quality of Life (HRQOL), report difficulty engaging with peers socially, and face higher barriers to accessing the care they need in adulthood than the non-CP population.^{22,23,24}
- 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 participants during the COVID-19 pandemic from 2019-2021.

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.
- 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. The data was collected and managed using the REDCap Database platform¹¹. Participants were not compensated for their time.
- Participants Selection Process:

Figure 1. Participant Eligibility Flow Diagram.



Footnotes:
*: Participants were unable to be reached due to change in phone numbers or phone number currently not in service.
***: Phone number either rang until voicemail box was reached or directed straight to voicemail box.
****: Participants did not want to participate at the time of phone call nor in the future.
*****: Participants were reached with the correct phone number and appointments were made for the interview. When the participants were called again, they did not answer. They did not answer on other subsequent calls after the first contact.

- Survey instruments: Medical history survey, COVID-19 pandemic history survey, Coronavirus Disability Survey (COV-DIS), PROMIS-57

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 crutches 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/or 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, other than some difficulty obtaining food needed during the pandemic.

Results

COVID-19 Pandemic History Survey	Responses Total n=15 (n, percent)			
Did you experience any physical health changes due to the COVID-19 pandemic?	Yes (4, 26.7%)	No (11, 73.3%)	Positive changes (1, 6.67%)	Negative changes (3, 20.0%)
Did you experience any mental/emotional health changes due to the COVID-19 pandemic?	Yes (9, 60.0%)	No (6, 40.0%)	Positive changes (1, 6.67%)	Negative changes (6, 53.3%)
Did you experience a change in your access to healthcare due to the COVID-19 pandemic?	Yes (6, 40.0%)	No (9, 60.0%)	Positive changes (1, 6.67%)	Negative changes (5, 33.3%)
Have you received both doses of the COVID-19 vaccination?	Yes (14, 93.3%)	No (1, 6.7%)		
Have you been diagnosed with PTSD as a result of this memory?	Yes (0, 0%)	No (15, 100%)		

Summarized Impacts of COVID-19 Pandemic

Positive

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

Negative

- Infected with COVID-19
- Felt 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; infection with COVID-19, other illness, feelings of isolation, increased stress and anxiety, and decreased access to healthcare (particularly, in-person primary care visits). These were expected changes as the rest of the world experienced similar negative effects of the COVID-19 pandemic²¹.
- In addition, although 66.7% of the participants have a reported annual household income of less than \$30,000, only 1 participant (6.67%) reported some difficulty with paying rent, obtaining food, and paying for gas since the start of the COVID-19 pandemic. This was an interesting finding; 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 the 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 reports 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 increase in access to healthcare via telehealth are some of the changes that may have felt difficult for individuals without CP, but this may more closely 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 lifestyle².
- 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 clear certainty at this time. This cohort represents only a small sample of the CP population and thus it is impossible to generalize these changes to the overall CP community.

Limitations

- Low response rate. 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 quarantine.

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