

Understanding the Impact of COVID-19 on Fatigue in Individuals with Cerebral Palsy

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Background

Cerebral Palsy (CP) “describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain” [1].

Fatigue is experienced by many individuals with CP, especially prevalent in individuals with diplegia and dyskinesia [2].

The stay-at-home restrictions and government-mandated closures to slow COVID-19 resulted in lifestyle changes, reduced socialization opportunities and the circulation of potentially incorrect health information.

The pandemic presented new challenges including social isolation, online schooling and lifestyle changes causing psychological and physical impacts to physical and mental fatigue in youth with CP that have yet to be explored.

Objective

To investigate the impact of the COVID-19 pandemic, lockdowns, and social distancing on mental and physical fatigue and life roles participation of youth with CP.

Sample Survey Questions:

“Since the start of the pandemic in March 2020...

- How has your ability to focus changed?
- How have your effective hand and arm use changed?
- How have your use of assistive changed?
- How has your need for social participation changed?
- How has your family's overall stress changed?

Study Design & Participants

The study population consisted of individuals with CP aged 7–18, given an online survey at three time points. The first and second surveys (Time 1 and Time 2) were measured roughly six months apart, starting in late August of 2018. The third and final survey (Time 3) results were collected from June 23, 2021, to July 25, 2021.

The survey included the Fatigue Impact and Severity Self-Assessment (FISSA), Child & Adolescent Scale of Participation (CASP) and the Participation and Environment Measure for Children and Youth (PEM-CY). The COVID-19 questionnaire was arranged in three parts, including 5-point Likert scale questions measuring personal opinions on the pandemic and their current social situation.

The repeated measures correlation, repeated measures ANOVA, and descriptive statistical analyses were performed in IBM SPSS Statistics, Version 27, Release 27.0.1.0.

Results

Total Sample Size	67
Male n, (%)	41, (61%)
Female n, (%)	26, (39%)
Median Age in Years (T1, T2, T3)	11, 11, 15

The results showed that total FISSA scores were not significantly different between T1 and T2, T1 and T3, or T2 and T3, $F(2, 20) = 0.308, p = 0.738$.

Another repeated measures general linear model analysis was performed on the total CASP scores between Times 1 through 3. All the tests of within-subjects and within-contrasts did not show significance at the $p=0.05$ level. The total CASP scores were not significantly different between T1 and T2, T1 and T3, or T2 and T3.

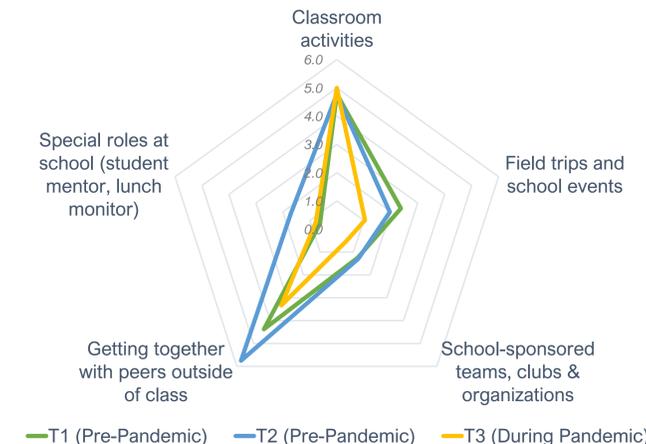
A repeated measures ANOVA was performed on the PEM-CY Community Participation sub scores. The results showed that the PEM-CY Community Participation Sub scores were significantly affected by time, $V = 0.703, F(2, 8) = 9.477, p = 0.008, \text{partial } \eta^2 = 0.867$. Furthermore, the 95% confidence interval for pairwise comparisons differences, adjusted for Bonferroni showed statistical significance between Times 1 and 3, mean difference = 0.812 and Times 2 and 3, mean difference = 0.820.

The sample size at Time 3 was 33 persons, with 55% male. The median age was 15 years. Descriptive data from the COVID-19 questionnaire showed a general decrease in social participation, with 94% of the sample reporting such a decrease. In addition, 58% agreed that staying at home influenced their mental and physical fatigue. While 88% of the sample reported that time with family had increased, 94% also reported that average time spent with friends had decreased.

Average Community PEM-CY Scores - By Activity/Environmental Feature



Average School Participation PEM-CY Scores - By Activity / Environmental Feature



Radar plots shown for the average PEM-CY Community and School Participation sub scores demonstrate change across three time points.

Higher scores indicate greater participation.

Discussion

Results from the PEM-CY Community sub scores between Time 1 and Time 3, as well as Time 2 and Time 3 demonstrated a decrease in community activity participation during the COVID-19 period. However, results from the CASP and FISSA metrics of the survey indicated that general participation, and physical and mental fatigue scores did not change between any of the time points.

Previous research similarly suggests that while the specific subtype of CP is a determinant of fatigue severity [3], the presence of fatigue at a young age persists into adulthood [4]. In our study, 55% of the sample population reported that their daily average level of fatigue had not changed since the start of the pandemic. Notably, only 58% reported that staying at home influenced physical and mental fatigue. Finally, 52% reported their self-esteem was unchanged, and 85% reported they were comfortable at home.

It is speculated that the level of social and community participation does not directly impact physical and mental fatigue, however, the specific activities involved in social and community participation may influence physical and mental fatigue instead. Given the shift towards unstructured physical activities and increased family time while maintaining classroom activities virtually, a decrease in social participation levels does not influence physical and mental fatigue.

70% of participants reported an increase in their family's overall stress, while 67% believed their access to healthcare services had been impacted by the pandemic.

Limitations & Next Steps

The use of the FISSA and CASP may be unsuitable for measuring a change in fatigue and participation in longitudinal studies. While the FISSA at construction had adequate test-retest reliability, the evaluative validity of the FISSA has not been tested. The validation of the FISSA or creation of a new metric that can accurately gauge fatigue longitudinally and can reliably predict fatigue levels at a future date will be needed. Likewise, the CASP possesses strong internal consistency, but may not have adequate responsiveness to change, as it reflects general participation areas in comparison to measuring participation in discrete activities. Finally, the current sample size of 67 persons in total from Time 1 to Time 3, may be insufficient to examine changes over time in a heterogeneous CP population.

Results from this study can give insight into potential coping and fatigue management strategies for youth with CP, in the event of another grand scale pandemic.

References

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