

Pain Patterns and Well-Being in Children and Adolescents with Cerebral Palsy

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AIM : To identify 5-week pain intensity trajectories and their relationship to physical and psychological well-being in children and young people with cerebral palsy (CP).

METHOD: A research study was undertaken with 101 Indian children and young people with CP, 49 of them were female. Their ages ranged from 8 to 18 years, with an overall mean age of 12 years and 11 months (SD, 3 years and 1 month). Physical and mental health (KIDSCREEN-27) were measured at baseline and after 5 weeks, as well as self-reported pain intensity (Faces Pain Scale – Revised). Latent class growth and generic linear models were used in statistical analysis.

RESULTS : All levels of the Gross Motor Function Classification System (I = 40.6%, II = 15.8 %, III = 20.8 %, IV = 13.9 %, and V = 8.9 %) were represented. There were found to be five pain intensity trajectories. Three trajectories showed mean steady pain that was either extremely low (35.4%), low (32.4%), or high (4.9%). Two trajectories saw moderate pain that changed (16.8%) and severe pain that decreased to moderate levels (10.5%), respectively. The lowest physical well-being was reported by the individuals with stable high pain (adjusted = 10.01; 95 percent confidence interval [CI] = -19.37 to -0.66). The lowest psychological well-being was found in those in the three trajectories with the highest mean baseline pain intensity (>3 out of 10) (adjusted = β -8.27, 95% CI = -14.84 to -1.70; = -6.74, 95% CI = -12.43 to -1.05; β = -5.82, 95% CI = -15.34 to 3.71).

CONCLUSION : The pain intensity trajectories of nearly one-third of subjects were moderate to severe. Lower physical and psychological well-being was linked to membership in the trajectories of greater pain intensity.

ABBREVIATIONS : CTC, Children's Treatment Centre; FPS-R, Faces Pain Scale – Revised.

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I. Introduction

A persistent, non-progressive condition known as cerebral palsy (CP) results from problems with the prenatal or infant brain's development and affects mobility and posture. 1 Despite the increasing awareness of CP-related pain, little is known about the pain trajectories and effects on well-being in children and young people with CP. With more knowledge, pain patterns may be recognized, treatments more effectively targeted, pain chronicity reduced, and well-being improved. According to the definition of pain, it is "an unpleasant sensory and emotional experience related to, or similar to, existing or potential tissue injury." 2 In both children and adults with CP, pain is one of the most often reported comorbidities. 3–6 . According to various studies, the reported prevalence of pain in a recent systematic review of children and young people ranged from 14 percent (any pain in the preceding month) to 76 percent (present pain using an observational/behavioural scale). 7 According to research, 25% of kids with CP experience moderate-to-severe chronic pain that makes daily tasks difficult. 8 There is evidence that suggests pain patterns may be present throughout childhood. 26 percent of children with CP aged 3 to 16 who reported pain at two visits had no pain, 20 percent had stable pain, 21 percent had reduced pain levels, and 33 percent had increased pain. 8. Colver et al.9 discovered in a longitudinal research that pain severity increased from childhood through adolescence. After treatments like the installation

of intrathecal baclofen pumps, some people also achieve notable long-term improvements in pain. 10 Given the clinical variability of this population, pain management in CP is difficult. Short- and long-term pain trajectories may ultimately be influenced by the underlying aetiology, as well as by availability to and effectiveness of pain therapies.

We are unaware of any prior research that has prospectively assessed pain trajectories and their impact on the well-being and quality of life of children and young adults with CP. Previous research found a link between pain and quality of life 9,11. Children and adolescents who experienced pain had poorer levels of physical, psychological, and social well-being. 9 However, there was just one follow-up period in this trial, and no identifiable pain trajectories were found. Another study indicated that musculoskeletal deformity was the most significant negative factor in the relationship between pain and health-related quality of life in children aged 3 to 19 years. 12 Age, sex, Gross Motor Function Classification System (GMFCS) level, CP subtype, sleep patterns, and comorbidities including mental health issues are all factors that affect an individual with CP and their level of discomfort and well-being. 5,13,14 Additionally, young ladies with CP are twice as likely as their male counterparts to report more frequent and intense pain. 15 Hip subluxation⁵ and CP management techniques, including as donning splints and receiving injections of botulinum neurotoxin A (BoNT-A), are additional sources of discomfort that could have a negative impact on well-being. 13. We created a research study using gaps in the literature, stakeholder meetings, and our most recent pilot study 16 as our guides. First, we sought to detect short-term pain trajectories in a cohort of children and adolescents attending two Indian children's treatment facilities using self-reported pain intensity scores (CTCs). We proposed that there are five possible trajectories for pain: rising, decreasing, fluctuating, stable, and pain-free. Second, we sought to ascertain whether pain trajectories were linked to immediate physical and psychological health. We predicted that, at 5 weeks, children and young people reporting increasing, steady, or fluctuating pain trajectories would have lower physical and psychological well-being than those reporting no pain or decreasing pain trajectories.

II. Method

Design and Settings of the Study

The study was authorized by the ethics committees of Lugansk State Medical University in Ukraine. In Gangtok, Sikkim, India, where all children with CP are referred for evaluation and/or care at their regional CTCs from various parts of India, where we conducted a research study.

Sample for the Study

Participants with CP, 8 to 18 years old, categorized in any GMFCS level, ready to report their pain, and able to successfully complete a sorting activity (used to demonstrate their knowledge of ratings on a scale) were recruited between November 2021 and January 2022. Those unable to independently communicate or complete an electronic questionnaire, with or without assistance technologies or aid, were not included.

Recruitment

The previously mentioned¹⁶ recruitment tactics comprised: (1) posters and electronic signage at CTCs; (2) social media; and (3) study presentation to potential participants during outpatient clinic sessions by study staff or CTC physiotherapists. At site 1, we also made use of a call list for voluntary research, while at site 2, a list of CTC clients was used to call potential participants and mail out study flyers. To ascertain eligibility, we conducted a two-step screening procedure. First, we called clients/parents to explain the study, set up an in-person appointment, and conduct a preliminary telephone screen to identify clients 8–18 years old, diagnosed with CP, and able to talk properly to complete the questionnaires.

In accordance with COVID-19 pandemic safety measures, on-site data gathering was stopped in February 2022. Starting in August 2021, we used a safe, hospital-based virtual platform to perform the screening and baseline sessions. Parents, guardians, children, and young people were requested to give written, informed consent and/or agreement to participate if they were eligible and interested.

Data Collection

The RED Cap data gathering tools were used to distribute and complete standardised self-report baseline and follow-up questions. 17 At 7, 14, 21, 28, and 35 days after the baseline, computerized questionnaires were used for follow-ups. The data collection procedures, including pre- study stakeholder interaction and a pilot study, are shown in Figure S1. 16 At baseline and the 5-week follow-up, information on self-reported CP-related care in the previous month was also gathered.

Exposure: Participation in the pain trajectory group

In order to detect short-term pain intensity trajectories, we employed the Faces Pain Scale – Revised (FPS-R) once weekly for 5 weeks as the main scale for assessing pain intensity in the previous week. 18 This

survey is appropriate for persons with poor numeracy skills and is advised for kids and teenagers between the ages of 7 and 18. 19 It has six gender-neutral faces that range from "no pain" to "worst pain possible" and are numbered from 0 to 10. 20 It is responsive, valid in terms of both construct and content, and reliable enough. 19.

Results: physical and psychological well-being

At baseline and the 5-week follow-up, we evaluated well-being in the previous week using the KIDSCREEN-27 physical and psychological well-being domains. It is applicable to typically developing and chronically ill children aged 8 to 18 years, has acceptable internal consistency and test-retest reliability, and has been used in various settings and with children with CP.^{9,21,22} The KIDSCREEN-27 items are scored on a 5-point Likert scale (1 = not at all to 5 = very much). For comparison with a global reference population (mean = 50, SD = 10), the domains were presented as group T scores. 21 If the KIDSCREEN-27 was assessed to be too taxing based on individual aptitude, some participants had the option to complete a shortened version of the questionnaire.

Possible Comorbidities

Possible comorbidities on the basis of the prior scientific literature and clinical experience, were identified. Sex, age, GMFCS level, CP subtype, sleep disorders, mental health issues, and socioeconomic position were among them.

Socio-demographic information

Age, sex, and socioeconomic status—linked census data on median household income and postal code—were all taken into account at the outset.^{23–25}

CLINICAL DATA

Clinical data from electronic health records were collected, including CP subtype, GMFCS level, mental health disorders, and other comorbid conditions (epilepsy and seizure disorders, gastrointestinal conditions).^{26,27} The PROMIS Sleep Disruption Questionnaire (Short Form, v1.0-4a) was used to collect sleep characteristics, which were then reported as standardised T scores. 28.

SAMPLE SIZE

We took into account scenarios based on various numbers of trajectories and participant distribution across trajectories when estimating sample size using the method of effect size for latent class analysis.²⁹ A likelihood ratio test comparing a k-1 model solution to a k model solution was included in the analysis. Based on the tables Dziak et al.²⁹ created using Monte Carlo simulations, it was determined that a sample size of 90 to 100 individuals was estimated to be adequate sufficient to identify five pain trajectories with power = 0.80 and = 0.05.

STATISTICAL ANALYSIS

Descriptive statistics were reported using means, medians, and proportions.

OBJECTIVE NO 01

Various pain trajectories were identified using latent class growth modeling³⁰. Based on which participant had the best probability of joining a particular trajectory, that trajectory was given to that participant. Beginning with a one-cluster model, latent class models were constructed one after the other. Linear, cubic, and quadratic terms were first introduced to each model. A trajectory group was added by each subsequent model until k = 5. (1)The Bayesian information criterion and the (2) Akaike information criterion were compared and the model with the lowest criterion value was selected as the ideal one. We removed linear, cubic, and quadratic terms that did not differ significantly from zero from the model's parameters in order to ensure parsimony. To investigate individual variance among the trajectories, spaghetti plots were made for participants assigned to each trajectory in the final model (Figures S2–S6).

OBJECTIVE NO 02

To assess the basic relationship between short-term pain trajectories and well-being at 5 weeks, we employed general linear models. Potential confounders were incorporated into bivariate models. The final multi-variable models included any confounders that satisfied the change in estimate approach ($\pm 10\%$ change from the crude model).³¹

ASSESSMENTS OF SENSITIVITY

In order to determine whether the cross-sectionality of measuring pain and well-being on the same day had an impact on trajectory shape and group membership, we used latent class growth modelling to run sensitivity analyses on the first four weeks of pain measurement. By excluding participants who were pain-free, we also tested the models' sensitivity to people who were not experiencing any pain. (SAS Institute, Cary, NC, USA) provided its SAS software, version 9.4. From <http://www.andrew.cmu.edu/user/bjones/>, we downloaded the traj application³².

III. Results

To find 100 participants, we had to get in touch with 260 of the 550 suitable ones we had found (Figure S7). 190 of the 260 people who were contacted during stage 1 screening were qualified to attend in-person screening. 111 people underwent in-person screening at stage 2. Overall, 102 out of 190 participants (53.7%) met the inclusion requirements and gave their agreement to participate. Before completing the baseline survey, one child withdrew. At all times, the follow-up rate was greater than 90%. Eight participants (three withdrew at baseline and five completed the short-form surveys) did not complete the KIDSCREEN-27 at 5 weeks, yielding 93 responses for the final KIDSCREEN-27. Imputation was not done because there were not many missing data points. Participants' ages ranged from 8 to 18, and 48.5% were female. (Table 01).

76.2 % of people reported experiencing pain in the week before, and the mean baseline pain intensity (FPS-R) was 2.8 (2.6). Eighty percent of those surveyed said they had performed CP-related exercises at home in the month prior, while 67.3 % wore a brace, 24.8% underwent physiotherapy, 17.8% practiced yoga, and 9% received massage therapy. Pharmacological interventions that might help with pain management included BoNT-A, gabapentin, omeprazole, and cannabidiol oil. These interventions varied by trajectory group and included: group 1 = 10 out of 34 (BoNT-A only); group 2 = 11 out of 34 (BoNT-A only); group 3 = 10 reports among 17 individuals (BoNT-A = 7, gabapentin = 2, cannabidiol oil = 1, not exclusive to each person (BoNT-A only).

The electronic health records contained information on a wide range of reported mental health illnesses or symptoms as well as developmental and behavioural issues. There were 17 reports of anxiety, 7 of depression, 15 of ADHD/ADHD, 5 of autistic spectrum disorder, 2 of obsessive-compulsive disorder, and 1 each of bipolar disorder, oppositional defiant disorder, high stress, and self-harm behaviours. Constipation ($n = 19$), gastro-oesophageal reflux ($n = 7$), having a gastrostomy tube ($n = 3$), epilepsy/seizures ($n = 11$), and other comorbid conditions like scoliosis ($n = 9$), reactive airway disorder ($n = 2$), ventriculo-peritoneal shunt ($n = 2$), and kidney stones ($n = 1$) were all potential sources of pain.

TRAJECTORIES OF PAIN INTENSITY

5 trajectories were determined to be the ideal number through latent class growth modelling (Figure 1). While trajectories 3 and 4 had both quadratic and linear terms, trajectories 1, 2, and 5 solely used intercept terms (constant average pain across time). The greatest participant assignment probabilities to specific trajectories ranged from 0.85 to 1.0, showing unique categorization. The Bayesian information criteria for this model was -1227.05, and the Akaike information criterion was -1208.74 (Table S1).

The final model trajectories are described as: trajectory 1: no or very mild stable mean pain ($n = 34, 35.4\%$), with a constant pattern and estimated mean weekly pain of 0.69 (95% confidence interval [CI] = 0.24–1.15); trajectory 2: mild stable mean pain ($n = 34, 32.4\%$), with a constant pattern and estimated mean pain intensity of 1.99 (95% CI = 1.49–2.49); trajectory 3: moderate changing mean pain ($n = 17, 16.8\%$), with moderate pain intensity at baseline, plateauing to above 5 out of 10 at weeks 2 and 3, then decreasing below the mean estimated baseline level at week 5 (3.93, 95% CI = 3.12–4.75); trajectory 4: high to decreasing moderate mean pain ($n = 11, 10.5\%$) with high mean pain intensity at baseline (estimated mean = 7.47 95% CI = 6.32–8.62) improving over time (week 5 estimated mean = 3.25, 95% CI = 2.16–4.33); trajectory 5: high stable mean pain ($n = 5, 4.9\%$), with a constant pattern and estimated mean of 7.33 (95% CI = 6.54–8.11). Using spaghetti plots, individual participant variability within each trajectory group was represented, and it largely took the form of the designated group (Figures S2–S6).

Physical and Psychological Well-Being

In the rough model, participation in a trajectory group was related to both psychological and physical health (Table 2). The highest level of physical well-being was reported by those in trajectory group 1. Based on membership in the trajectory group, the crude model depicted a gradient of declining physical health. Members of the other trajectory groups had poorer mean physical well-being compared to group 1, which had a mean physical well-being (model intercept) of 55.31 (95% CI = 52.03–58.78). In the final physical well-being model, we adjusted for baseline physical well-being, GMFCS level, CP subtype, and median family income using the change in estimate approach (Table 2). Although relationships for all groups were weaker, the gradient persisted.

The highest physical well-being difference from trajectory 1 was related with participation in trajectory 5, with estimates for all other groups being lower than those for trajectory group 1 ($\beta = -10.01$, 95% CI = 19.37 to -0.66).

When compared to group 1, those in groups 3 and 5 had the lowest mean psychological well-being according to the crude model of psychological well-being ($\beta = 56.40$, 95 % CI = 53.07–59.74). (Table 2). We took into account baseline psychological well-being, mental health, sleep disturbances, and median household income in the adjusted model (Table 2). When confounders were taken into account, the connection between the estimated mean psychological well-being and group 1 remained nearly unaltered for members of groups 2 and 4, while it was weaker for those in groups 3 and 5. A lower mean level of psychological well-being was linked to participation in trajectory groups 3 (-6.74; 95 % CI = 12.43 to -1.05), 4 (-8.27; 95% CI = 14.84 to -1.70), and 5 (-5.82; 95% CI = 15.34 to 3.71).

TABLE 1 Baseline Characteristics of the Study Participants (*n* = 101)

Characteristic	Full sample (<i>n</i> = 101)	Trajectory group 1 (<i>n</i> = 34)	Trajectory group 2 (<i>n</i> = 34)	Trajectory group 3 (<i>n</i> = 17)	Trajectory group 4 (<i>n</i> = 11)	Trajectory group 5 (<i>n</i> = 5)
Age Year Months						
Mean (SD)	12:10(3:1)	13:3 (3:3)	12:8 (3:1)	13:1(2:10)	11:10(3:7)	13:2 (2:7)
Median (IQR)	13:0 (6)	13:0 (5)	12:0 (6)	13:0 (5)	11:0 (7)	13:0 (2)
Female, n (%)	49 (48.5)	11 (32.4)	19 (55.9)	12 (70.6)	3 (27.3)	4 (80.0)
CP type, n (%)			(<i>n</i> = 33)			
Spastic	69 (68.3)	27 (79.4)	22 (66.7)	12 (70.6)	4 (36.4)	4 (80.0)
Dyskinetic	13 (12.9)	1 (2.9)	4 (12.1)	3 (17.7)	5 (45.5)	0
Mixed (spastic and dyskinetic)	14 (13.9)	6 (17.7)	3 (9.1)	2 (11.8)	2 (18.2)	1 (20.0)
Ataxic	3 (3.0)	0	3 (9.1)	0	0	0
Unknown	2 (2.0)	0	1 (3.0)	0	0	0
GMFCS level, n (%)						
I	42 (41.6)	18 (52.9)	14 (41.2)	6 (35.3)	2 (18.2)	2 (40.0)
II	15 (14.9)	3 (8.8)	5 (14.7)	5 (29.1)	2 (18.2)	0
III	21 (20.8)	6 (17.7)	9 (26.5)	3 (17.7)	2 (18.2)	1 (20.0)
IV	14 (13.9)	7 (20.6)	4 (11.8)	0	1 (9.1)	2 (40.0)
V	9 (8.9)	0	2 (5.9)	3 (17.7)	4 (36.4)	0
Average Pain Intensity (FPS-R) (n= 100)						
Mean (SD)	2.8 (2.6)	0.9 (1.3)	2.0 (1.7)	3.7 (1.3)	7.5 (1.6)	6.8 (1.1)
Median (IQR)	2.0 (4)	0 (2)	2.0 (2)	4.0 (2)	8.0 (2)	6.0 (2)
KIDSCREEN-27, mean T score(SD)						
(<i>n</i> = 96)		(<i>n</i> = 33)	(<i>n</i> = 32)	(<i>n</i> = 16)	(<i>n</i> = 9)	
Physical well being	50.0(11.1)	52.2 (10.3)	49.7 (7.4)	47.4(12.4)	52.8 (19.9)	39.9 (5.9)
Psychological well-being	51.0(10.1)	53.8 (10.5)	49.6 (7.7)	45.6 (8.7)	51.8 (10.4)	41.7 (5.9)

Abbreviations: CP, cerebral palsy; FPS-R, Faces Pain Scale – Revised; GMFCS, Gross Motor Function Classification System; IQR, interquartile range.

SENSITIVITY ANALYSIS

The results were not skewed by the cross-sectional evaluation of pain and well-being. With 74 out of 101 participants in the same trajectory groups in both FPS-R models, pain reported at 5 weeks did not affect trajectory membership compared to trajectory membership at 4 weeks. The 4-week and 5-week models had slightly different trajectory shapes.

There were some variations in group membership when participants who reported no pain (*n*=13) were excluded, but the general trajectory shapes remained the same (Appendix S1).

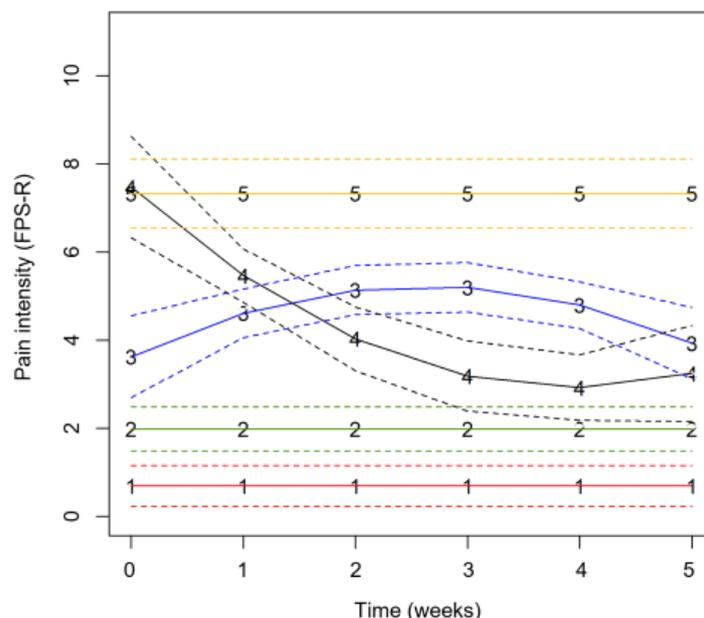


FIGURE 1 : Model for trajectory group membership for pain intensity measured by the Faces Pain Scale – Revised (FPS-R) over 5 weeks (n = 101). The dashed lines represent the 95% confidence intervals. Group percentages: 1 = 35.4%, 2 = 32.4%, 3 = 16.8%, 4 = 10.5%, 5 = 4.9%.

IV. Discussion

The clinical trajectory of pain intensity in children and young people with CP was a new discovery from this investigation. This was defined as the degree of discomfort felt in the previous week, regardless of whether it was caused by their CP or not. Five different categories are described by the short-term pain trajectory model. Three groups displayed consistent trajectories and different mean pain levels. Of these, two (groups 1 and 2) included people with no or low stable mean pain intensity (representing 67.8% of participants), and the third (group 5) had participants with high stable mean pain intensity (representing 5% of participants). 16.8% of those in trajectory group 3 experienced varying moderate intensity pain. They may have experienced more erratic pain intensity, which needs to be substantiated with more extensive follow-ups. People in trajectory group 4 (10.5 %) experienced significant early pain that gradually subsided. It is disconcerting that approximately one-third of children were in trajectories with moderate-to-high pain intensity levels.

To our knowledge, this is the first study to identify short-term pain intensity trajectories in children with CP. Past research assessed how pain changes in children with CP using two time points spanning several months to years. 8,9. By characterizing short-term pain trajectories in children with CP, future studies may focus on identifying factors that have an impact on or improve pain trajectories. Studies of pain trajectories in other pediatric chronic conditions, such as rheumatoid arthritis and sickle cell anaemia, reported similar results. 33,34 . Although they were measured every 6 months for 5 years, juvenile rheumatoid arthritis patients also categorized into concerning pain trajectories, including chronically moderate and increasing or decreasing pain trajectories. 33 Over the course of a week, children who were hospitalized for sickle cell vaso-occlusive crises had pain that decreased slowly, moderately, and quickly. 34.

The pain intensity trajectory model presented in this study is not based on an inception cohort. Instead, it provides a 5-week snapshot of pain trajectories and serves as a starting point for future work. Participants in the high and moderate pain intensity trajectories had lower physical well-being compared to those in the low pain intensity trajectories; the effect was larger the higher the pain intensity. Participants in the trajectories with higher mean baseline pain intensities and changing pain intensities had lower psychological well-being compared to those in the stable, lower pain intensity trajectories. Patterns in the crude models, such as lower psychological well-being in trajectory groups 3 to 5 compared to group 1, were maintained although diminished in the adjusted models. Children in lower pain trajectories may experience less impact on daily activities leading to higher psychological well-being. Furthermore, some children may cope better with stable pain levels than unanticipated changes or fluctuations. Also, given that children/young people in three trajectory groups had constant pain levels, there may be a cross-sectional relationship with well-being versus an association with the trajectories. However, this was tested in our sensitivity analyses and any impact was minimal.

Strengths of the current study include frequent follow-ups in a short time period, control of confounders, low attrition, and validated questionnaire instruments. Questionnaires were self-completed and participants were classified in all GMFCS levels, CP subtypes, and a wide age range. Our study has some limitations. First, uncertainties remain regarding the psychometric properties of the FPS-R when used in children/young people with chronic pain; it is possible we may be assessing chronic versus acute pain episodes.¹⁹ Second, the small sample size of some trajectory groups led to greater variability around the point estimates. Future work to identify pain trajectories should ensure a sufficient sample size for each trajectory group, thereby leading to greater statistical power. Third, mis-classification bias is possible by using the postal code as an indicator for income and socioeconomic status. Fourth, we attempted to be inclusive of all GMFCS levels by including participants who could not verbalize (but could vocalize, or use eye gaze or communication devices) or complete questionnaires independently (could direct someone else to fill in their electronic responses). However, we excluded some individuals based on their inability to complete a sorting task and individuals in GMFCS levels IV and V may be over-represented in this group. Thus, our results may not be representative of individuals with lower functional status or severe comorbidities. Fifth, we did not consistently record limb involvement during data collection, which is a limitation because this helps to better assess the generalizability of results to specific CP subtypes. Finally, it is probable that residual confounding exists in our well-being models.

Some of the trajectory shapes differed from our hypotheses. No trajectories had increasing pain or no pain. Although we measured pain over a short period, future work should assess if trajectory patterns change over longer periods (e.g. up to 1 year), measure ethnic, cultural, and sex differences, be repeated in other jurisdictions to assess generalizability, and importantly include qualitative data collection to help identify pain triggering and relieving factors. The next step of our work will be to analyse how pain interference, a more complex and multidimensional construct, is associated with both pain and well-being scores. Continued measurement of socioeconomic status of individuals with CP is important. This was a confounder in both the physical and psychological well-being models. Lower socioeconomic status is associated with higher level of motor impairment (GMFCS), intellectual impairment, and additional comorbidities.³⁵

Furthermore, those who are economically and socially disadvantaged may have greater difficulty accessing care for their children, which may have an impact on pain experiences and well-being. Health assessments could also help determine pain aetiology. Identifying not only pain intensity but its aetiology and types of pain management will be important in future work to better understand pain trajectories. For instance, many children and young people with hip joint displacement may experience significant and prolonged pain. Equally, children and young people with CP who have dystonia, muscle contractures, or experience constipation may have very different pain trajectories than those who do not have these conditions. This is especially true for children and young people in GMFCS levels IV and V who often experience multiple sources of pain. Lastly, future work should consider the use of proxies to respond on behalf of children/young people with CP with lower functional ability or cognitive impairments. Proxies can provide important information regarding pain and well-being for which there is currently little reported in this subgroup.

TABLE 2 : Association between trajectory group membership (FPS-R) and physical and psychological well-being (KIDSCREEN-27), controlling for confounders.

Variable	Crude models(n= 93)		Adjusted models (n = 91)	
	β a (SE)	95% CI	β a (SE)	95% CI
Physical well being				
Group 1 (ref)	55.31 (1.65)	52.03 to 58.78	33.79 (5.02)	23.81 to 43.77
Group 2	-6.19 (2.38)	-10.93 to -1.46	-4.48 (2.30)	-9.06 to 0.09
Group 3	-8.35 (2.97)	-14.26 to -2.44	-6.76 (2.71)	-12.16 to -1.36
Group 4	-8.42 (3.60)	-15.57 to -1.28	-7.87 (3.41)	-14.65 to -1.08
Group 5	-16.30 (5.07)	-26.38 to -6.22	-10.01 (4.70)	-19.37 to -0.66
Baseline physical well-being	-	-	0.41 (0.09)	0.24 to 0.58
GMFCS levels I and II (ref)	-	-	-	-
GMFCS levels III and IV	-	-	-2.04 (1.94)	-5.90 to 1.82
CP subtype -spastic (ref)	-	-	-	-
CP subtype – other b	-	-	-1.11 (2.06)	-5.21 to 3.00
Household income(ref) \geq Can\$100	-	-	-	-

000c				
Household income Can\$75 000 to <\$100 000c	-	-	1.03 (2.39)	-3.71 to 5.77
Household income <Can\$75 000c	-	-	2.68 (2.27)	-1.83 to 7.19
R2	0.17		-	
Psychological well-being				
Group 1 (ref)	56.40 (1.68)	53.07 to 59.74	32.44 (5.38)	21.74 to 43.14
Group 2	-3.31 (2.43)	-8.13 to 1.52	-3.25 (2.30)	-7.82 to 1.33
Group 3	-10.53 (3.03)	-16.55 to -4.50	-6.74 (2.86)	-12.43 to -1.05
Group 4	-8.40 (3.67)	-15.69 to -1.11	-8.27 (3.30)	-14.84 to -1.70
Group 5	-12.38 (5.17)	-22.65 to -2.10	-5.82 (4.79)	-15.34 to 3.71
Baseline psychological well-being	-	-	0.43 (0.10)	0.24 to 0.61
Mental health disorder: none reported (ref)	-	-	-	-
Mental health disorder: reported	-	-	-0.71 (2.34)	-5.38 to 3.95
Sleep disturbance: lower median T score≤55.8 (ref)c	-	-	-	-
Sleep disturbance: higherd	-	-	-2.41 (1.93)	-6.25 to 1.44
Median T score>55.8				
Household income (ref)≥Can\$100 000c	-	-	-	-
Household income Can\$75 000 to <Can\$100 000c	-	-	2.97 (2.38)	-1.77 to 7.70
Household income<Can\$75 000c	-	-	3.46 (2.25)	-1.02 to 7.93
R2	0.16		-	

aβ, un-standardized parameter estimate b. Includes dyskinetic, mixed, ataxic, and unknown. C Median household income using the 2016 India census data. D PROMIS Sleep Disturbance Short Form Questionnaire 4a.

Abbreviations: CI, confidence interval; CP, cerebral palsy; FPS-R, Faces Pain Scale – Revised; GMFCS, Gross Motor Function Classification System; ref, reference group; SE, standard error.

IMPLICATIONS

Children with CP frequently experience intense pain on a recurring basis as a result of routine tasks and numerous procedures such as BoNT-A injections, bracing, casting, and rehabilitation. 13 Effective treatments may not be given to lessen the long-term effects of pain without appropriate understanding of how pain varies in the short term. To lessen the detrimental effects on physical and psychological well-being and avoid pain hyper sensitization, acute pain must be recognized and reduced. Functional or structural neuroplastic alterations have the detrimental impact of amplifying pain and causing it to become chronic. 36 People may be at risk for developing chronic pain as adults if their pain interferes with their ability to function and/or becomes persistent. They may also have decreased well-being, participation restrictions, and a higher prevalence of mental health problems. The discovery of effective pain preventive measures, the prevention of pain chronicity, and the maintenance or enhancement of well-being are all possible outcomes of repeated pain assessments, which can also identify those at risk for worrying pain trajectories.

V. Conclusion

This study identified five pain trajectories in CP children and adolescents and found that, for 68% of them, the estimated mean pain was primarily stable over a 5-week period. Low physical well-being is associated with trajectory groups that have high steady pain intensity. Higher baseline pain intensity individuals in the trajectory groups had lower psychological well-being. Future studies should investigate the effect of pain trajectories on involvement and incorporate longer-term follow-ups.

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CONFLICTS OF INTERESTS

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