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Longitudinal trajectories and reference percentiles for the impact of health conditions on daily activities of children with cerebral palsy

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Abstract

Aims: First, to describe the average impact of health conditions on daily activities over time in children with cerebral palsy (CP) and to create age-specific reference percentiles. Second, to determine the amount of change typical over a one-year period, across Gross Motor Function Classification System (GMFCS) levels.

Method: A prospective cohort design, with 5 assessments over two years, involved 708 children with a confirmed diagnosis of CP participating in the 'On Track' study [mean age 6.0 years, SD 2.7; proportions in each GMFCS level: I- 32.1%; II-22.7%; III-11.2%; IV-18.2%; V-15.7%]. Impact of health conditions on daily activities was assessed using the *Child Health Conditions Questionnaire*. Data were analysed using mixed-effects models and quantile regression.

Results: Linear longitudinal trajectories describe the relatively stable average impact of health conditions over time for each functional level for children aged 2 to 12 years, with the lowest scores (least impact) for GMFCS level I and the highest scores (highest impact) in GMFCS level V. Percentiles were created for children in each GMFCS levels. A system to interpret magnitude of change over time in percentiles was developed.

Interpretation: Longitudinal trajectories of co-occurring health conditions assist with understanding children's prognoses. Percentiles assist in understanding a child's experience relative to children in similar GMFCS levels. Guidelines are provided to determine if children are progressing 'as expected', 'better than expected' or 'more poorly than expected' on impact of health conditions on daily activities.

Running Foot: Trajectories of health conditions in cerebral palsy

"What this paper adds"

- In childhood, the average impact of health conditions on daily activities is relatively stable
- Significant intra- and inter-individual variability for health impact exists, complicating prognosis
- Percentiles enable interpretation of health impact relative to GMFCS level
- Guidelines are available to interpret magnitude of change over time in percentiles

Occurring in 2-2.5 per 1000 live births, cerebral palsy (CP) is the most common physical disability in childhood.[1] Although CP is primarily a condition characterized by disorders of posture and movement, impairments in body functions and associated health conditions are also key components in the international consensus definition.[2] A systematic review of the frequency of co-occurring health conditions determined that children with CP experience pain (75%), intellectual impairments (50%), problems communicating (25%), epilepsy (25%), behaviour disorders (25%), problems sleeping (20%), and visual (10%) or hearing (4%) impairments.[3] Consistent with previous findings,[3] in a cross-sectional study we also found that the number of health conditions increased as functional ability decreased and, additionally, the impact of these conditions on daily activities also increased.[4] Furthermore, we corroborated that exceptions were experiences of behaviour problems and pain, which occurred with similar frequencies across children with varying functional ability levels.[4] Given the impact of associated health conditions on daily activities of children with CP, we advocate for routine assessment[4] and appropriate intervention to manage children's health and comorbidities and to minimize associated secondary impairments.[3,5] Although these are important outcomes on their own, we also found that the average impact of health conditions on daily activities was significantly inversely related to self-care performance.[6] As families of children with CP have identified independence in self-care to be a priority,[7] it is clearly prudent to focus on optimizing health.

In recognition of the importance of associated health conditions, we previously developed a parent-completed *Child Health Conditions Questionnaire* (CHCQ) to measure the number and impact of impairments in body functions and associated health conditions on daily activities experienced by children with CP.[8] Items were generated based on the international consensus definition of CP[2] in combination with the International Classification of Functioning, Disability and Health,[9] thus providing content validity. The aim of this measure is to provide clinicians with a valid, reliable, and clinically feasible measure of health conditions for children with CP across all Gross Motor Function Classification System[10] (GMFCS) levels. The form is available on the CanChild website at: http://www.canchild.ca under the On Track study webpage. In this paper, we focus on the impact of health conditions on daily activities.

Currently, the pattern and timing of change in the impact of health conditions on daily activities has not been described for children with CP of varying GMFCS levels. The purpose of this study was to document the change in impact of health conditions over time by creating longitudinal trajectories and reference percentiles for the CHCQ, including the amount of change that is typical over one year, stratified by GMFCS levels. Similar longitudinal trajectories[11] and reference percentiles[12] for gross motor function have provided useful data for clinicians for determination of prognosis of gross motor development and have allowed for more efficient intervention planning. We have purposefully selected the GMFCS for stratification because it is more reliable and valid than either type of motor disorder or distribution of involvement.[13]

Methods

This study is part of a multisite, prospective cohort study entitled 'Developmental Trajectories of Impairments, Associated Health Conditions, and Participation of Children with Cerebral Palsy' (short title: On Track Study). The full study protocol has been reported elsewhere.[14] Ethical approval for this research was granted by the Health Science Research Ethics Board at Western University as well as participating universities and sites. All parents/guardians provided written informed consent for participation and publication. Children provided assent, as appropriate and in compliance with specific ethics review boards. All committee recommendations were adhered to throughout the entire study.

Participants

A convenience sample of 708 children with CP aged 18-months up to the 12th birthday at the first assessment, across GMFCS levels, and their primary caregivers participated in this study. Recruitment occurred in sites across Canada (in British Columbia, Saskatchewan, Manitoba, Ontario, Nova Scotia, and Newfoundland), and in the United States (areas within and around Georgia, Oklahoma, Pennsylvania, and Washington states) between April 2013 and January 2015. Children had a diagnosis of CP by a physician or demonstrated impairments in movement or posture consistent with CP. Continued eligibility was confirmed and reviewed by a physiatrist (JWG) throughout the study so that the final sample represented children with CP. Children were excluded if their parents/caregivers (hereafter referred to as 'caregivers') were unable to speak and understand English, French or Spanish. Families self-identified who the primary caregiver was. Attrition was tracked across all study visits and is documented in Supplementary File 1.[14] Although we aimed to have the same primary caregiver complete the questionnaire at each visit, this did not always happen. In this event, we opted for compete data collection from the available caregiver. Demographic information of the children and their families is included in Table I.[14] The distribution of GMFCS level in our sample is comparable to incidence data from nine international CP registries [mean proportions (SD): I–34.2% (13.1), II–25.6% (11.6); III–11.5% (2.5); IV–13.6% (4.3); V–15.6% (4.3)].[15] The distribution of ages at the first study visit was as follows: 18 months up to the end of four years of age (40%), five to the end of seven years (31%) and eight to the end of 11 years (29%). A sample size of 700 children was determined to be appropriate for estimation of percentiles by age and GMFCS levels using published calculations,[16] showing adequacy of the width of the 95% CI for the 5th, 50th, and 95th percentiles. This sample size was also sufficient for the linear mixed effects (LME) analysis to produce confidence intervals on the estimated change per month of less than ± 0.005 in width for even the smallest sample size in GMFCS level III.

The Child Health Conditions Questionnaire

Using the CHCQ, caregivers first responded either 'yes' or 'no' to 16 questions asking 'does your child have problems…' about a range of health manifestations (i.e. seeing, hearing, learning, speaking, controlling behaviour, epilepsy, the mouth, teeth and gums, digestion, growth, sleeping, repeated infections, breathing, skin, heart, and pain). If the response was 'yes', they also rated 'to what extent does this problem affect your child's daily activities?' using a 7-point Likert scale (from 1 'not at all' to 7 'to a very great extent'). Scores can be obtained for number (i.e. frequency of 'yes' responses, range from 0 - 16) and impact (average of the 16 Likert scale responses, with 'no' being coded '0', range from 0 to 112) of health conditions. Of note, because of the large number of health conditions (n = 16) and the likelihood that many are reported by caregivers not to be present, the resultant average scores cannot simply be interpreted relative to the anchors of 1 (not at all) to 7 (to a very great extent). Test-retest reliability (number: ICC=0.80 (95%CI=0.63-0.90); impact: ICC= .85 (95%CI=0.72-0.93)) and known groups validity (significant differences among all GMFCS levels) have been established for children 18 months to 5 years of age.[8] Using data from 671 children in the On Track Study,[4] we confirmed significant differences for both number and impact across GMFCS levels ($F=63.81$; $df=1,4$; $p<0.001$; $F=79.60$, $df=1,4$; $p<0.001$, respectively) with Tukey post-hoc testing determining significant differences among all levels, except for II and III.

Procedures

Children participated in two (n=656) to five (n=424) assessment sessions with a physical or occupational therapist in their home or clinic settings at a time that was mutually convenient (Supplementary File 1). The therapist completed the GMFCS via consensus with caregivers.[17] The GMFCS was completed independently by both the assessor and the caregiver and then the child's classification was discussed in attempt to reach consensus. Consensus was reached 97.8% of the time, and all

disagreements were within one level.[17] Based on study protocol, the final classification used was the caregiver rating with specific rules applied to determine if the assessor classification should be used instead.[17]

Either before or during the study visit, caregivers completed the CHCQ within approximately five minutes, either independently or with assistance from the therapist assessor.

Statistical Analysis

Details of how missing data were dealt with are described elsewhere.[14] Briefly, missing data were imputed using a mixed-effects random forest method via a custom R function based on the code of Hajjem and colleagues.[18] Missing CHCQ data were minimal. Visit 1 had the highest proportion of missing CHCQ assessments with 31 of 708 (4.4%) not completed. Across all visits 2.9% assessments were missing and subsequently imputed. In previous work, we established statistically non-significant differences between girls and boys in average impact of health conditions on daily activities;[19] accordingly, analyses were completed on the sample as a whole.

Longitudinal Trajectories

The average impact of health conditions from all 5 visits were analyzed using linear mixed-effects models[20] to create longitudinal trajectories describing change in the impact of health conditions with respect to age, separately for each GMFCS level. The strategy of treating levels of GMFCS as separate clinical populations permits flexible modeling of the individual variability in trajectories as well as the average trajectory, and it is consistent with the typical goals in clinical decision-making that does not emphasize comparisons between GMFCS levels. Based on inspection of the raw data, linear models were fit and age was centered at 60 months so that the intercept parameter reflected the average impact of health conditions at five years of age. LME estimates were obtained by restricted maximum likelihood. Random effects were estimated for the intercepts, slopes, and their correlation. Models were fit using the nlme package in R.[21]

Reference Percentiles

The impact of health conditions data from the first, 12-month, and 24-month visits were analyzed via quantile regression (QR) to construct cross-sectional reference percentiles for each functional classification level. Therefore, to maximize the sample size, the analysis included up to 3 assessments from each child, treated as cross-sectional. By including only one measure per year per child the influence of the correlation among repeated observations is attenuated because the splines used in the quantile regression operate over small age ranges. The quantregGrowth package in R was used, which constrains the percentiles to be non-crossing.[22] These reference percentiles describe the distribution of the impact of health conditions at each age by GMFCS level.

In addition, the amount of change in each child's percentile score at baseline and 12-month visits was calculated and the distribution of 12-month change scores was used to estimate bands that encompass 50% and 80% of changes. These bands quantify the amount of change in percentiles that is typical in children with CP. Following Hanna et al.,[12] we recommend that children whose percentile changes are within the 80% limits can usually be described as 'progressing as expected' for their age and GMFCS levels, whereas children who change more or less than the central 80% can be described as 'more' or 'less' than expected.

Results

Descriptive data for the impact of health conditions are presented in Table II. There was no evidence that the impact of health conditions on daily activities increased with age for children in any GMFCS level. Longitudinal trajectories for the impact of health conditions by GMFCS level are shown in Figure 1 with the accompanying model parameters contained in Table II.

Figure 2 shows the estimated reference percentiles for each GMFCS level, plotted at the 3rd, 5th, 10th, 25th, 50th, 75th, 90th, 95th, and 97th percentiles. Additional versions of these figures and the tabulated percentiles are available on the On Track study website: https://www.canchild.ca/en/research-in-practice/current-studies/on-track.

Table III provides the mean and standard deviation of the change in percentile score over a one-year period (plus or minus three months) by GMFCS level, along with the range of the central 50% and 80% of change scores. We recommend using the range of the central 80% of scores to ascertain that children are progressing 'as expected'. This is follows a recommendation used in Hanna et al (2008) that presented reference centiles for the Gross Motor Function Measure. Feedback from users of this paper suggests that clinicians find the 80% interval a useful cutoff, but others are certainly possible. The 80% central interval has been useful because it emphasizes that large changes in percentile are very common. Given that higher scores on the CHCQ represent greater impact, changing to a much higher percentile is interpreted as progressing 'less' (or 'more poorly than expected'). Conversely, dropping significantly in percentiles is interpreted as progressing 'more' (or 'better than expected'). Consistent with the evidence from the longitudinal trajectories, the average change in percentile is not statistically significant for any GMFCS level.

Discussion

Parents and caregivers wish to know about their individual children's prognoses, strengths and limitations, and some wish to understand their health status relative to children with CP of similar functional levels.[23] As has been previously available for motor function,[11,12] information from this study now allows clinicians to complete periodic 'check-ups' and health monitoring with children with CP and, in collaboration with families, to develop efficient and effective plans for intervention.

Longitudinal trajectories are useful for clinicians and families to discuss how well children are doing with respect to impact of health conditions in relation to the average values of other children with CP of similar GMFCS levels and their prognosis for impact of health conditions on daily activities 2 to 12 years of age. The trajectories for the impact of health conditions for children in all GMFCS levels are linear, with all slopes being close to zero (all 95% confidence intervals for slope for the fixed effects contain '0'). Thus, on average, the impact of health conditions on daily activities from ages 2 to 12 years is expected to be stable. Given that high scores reflect a greater impact, the lines for the GMFCS levels are in the order expected, with health conditions having a lower impact for children in GMFCS level I than children in level V. Despite the stability of the average trajectories, the random effects highlight significant intra- and inter-individual variability (based on residual and intercept results), especially for children in GMFCS levels IV and V. The positive slope/intercept correlations suggest that for children in all GMFCS levels but III, those with greater impact at age 5 years will likely experience even greater impacts as they continue to age, especially children in levels II and V. Conversely, for children in GMFCS level III, those with greater impact at 5 years will experience less impact over time.

Tracking children's status and change over time with the reference percentiles enables comparison of a child relative to peers of the same ability level and of a similar age. A single assessment permits an

understanding of a child's individual strengths and limitations with respect to impact of health conditions. The reference percentiles are useful in identifying the consequences of health conditions as potential areas for intervention or, conversely, to indicate that, relative to peers, overall health is a strength and thus a basis for strengths-based intervention planning. The distribution of percentiles of the impact of health conditions across GMFCS levels show a floor effect for all levels except level V (Figure 2). Specifically, values start at the 25th, 10th, 10th, 5th and 3rd percentiles for GMFCS levels I, II, III, IV and V, respectively. Note that 25 percent of children at level I reportedly have no impact of health conditions on their daily activities, whereas very few children at level V do not experience an impact. The greatest variation in percentiles of impact of health conditions across all ages occurs in GMFCS levels IV and V. For children at level II, there is greater variability as children age.

Completing a second CHCQ after an interval of one year (± 3 months) provides an understanding of change in impact of health conditions on daily life over time. This comparison of percentiles allows clinicians and families to determine if a child with CP is progressing 'as expected', 'more than expected', or 'less than expected' over time. Relative percentile standing can be much more variable than the measured changes in impact of health conditions that underlie them, leading to relatively large changes in percentiles being interpreted as progressing 'as expected.' Decisions about management should also consider a child's CHCQ raw scores for each health manifestation and further clinical evaluation, as needed. Whereas the CHCQ provides an overview assessment, a thorough medical history and physical examination, combined with additional specific questionnaires, tools, and more advanced and objective methods may be used to evaluate the health issue. For example, when the CHCQ may show that sleep appears to impact a child's daily activities, sleep quality and quantity should be evaluated, as a recent review indicates that sleep is an under-reported and under-recognized health issue in children with CP.[24] Furthermore, the CHCQ has not been designed to evaluate the effectiveness of specific interventions. More specific and sensitive measures are required for this purpose.

To illustrate the application of these data to practice, consider Julia, whose gross motor function was classified as level II and tested at age 6 years 9 months and then again at age 8 years. At the first study visit, her average health impact score was 1.6. Looking at Figure 1, one can readily see that she is above the average trajectory for children at level II. On the second study visit, her score increased to 3.1, indicating that she experienced a greater impact in health conditions than predicted by the flat trajectory. Using the reference percentiles, she was determined to be at the 80th percentile at the first visit and >97th at the second. This increase of >17 percentiles is more than +15 (Table 3), indicating that she is progressing 'less' or 'more poorly' than expected with respect to impact of health conditions for a child at level II. Furthermore, her change of 1.5 is well over the standard error of measurement, which is 0.3 (95%CI±0.6).[25] Over the period of 15 months, Julia had increased health impact scores in seeing, hearing, controlling emotions, seizures, skin, and pain, and new concerns with digestion and sleep. Clearly Julia has significant health concerns that require examination and management. Over the interval, she also dropped in performance in self-care percentiles from the 20th to the 10th, interpreted to be progressing 'as expected'. However, with the reported association between impact of health conditions and self-care,[6] monitoring health manifestations and treating her health conditions might prevent Julia from a decrease in self-care functioning and potentially could improve self-care outcomes. Notably, children with CP with problems learning, seizures, and digestion (all problems that were impactful for Julia) had lower self-care scores than similar children without these problems.[6]

This case illustrates the importance of comprehensive care that may be required for children with CP and medical complexity.[26] In a related paper, we identified areas of health of children with CP that require special attention, specifically, problems with the mouth, teeth, and gums, with digestion, growth and

sleep, problems controlling emotion and behaviour, and pain.[4] Because of co-existing health issues, children and adolescents with CP are seen by a number of different healthcare providers, indicating a need for care co-ordination and adequate information sharing among treating clinicians.[27] Children with CP are at risk for more visits to the emergency department or multiday hospitalizations, in particular in those with greater severity and complexity (GMFCS levels V).[28,29] Meehan et al, recommended CP registers to routinely collect information on comorbidities, in particular neurological, respiratory, musculoskeletal, and digestive diseases as these conditions accounted for most admissions.[28] We believe that all children with CP could potentially benefit from having the CHCQ completed annually.

Limitations of this work include lack of knowledge of the reliability of parent report of impact of health conditions on daily activities for children older than 5 years, as well as lack of knowledge of the effect of different caregivers completing the CHCQ. Second, it is possible that the data reported here under-estimate the average impact of health conditions because children with acute health conditions would not have had a study visit when ill. Third, the On Track Study sample is one of convenience. Although the proportion of children in each of the GMFCS levels is comparable to a compilation of nine international CP registries, this sample under-represents non-white, lower socioeconomic and less educated families. The likelihood that these factors might influence the impact of co-occuring health conditions on daily activities as children grow up will need further consideration and advocacy. Further research with under-represented subpopulations is required.

Conclusion

When used appropriately to monitor progress and change over time for children with CP, the CHCQ and the impact of health conditions on daily activities trajectories and percentiles should assist clinicians' and families' collaborative interaction to proactively plan services and intervention to support optimal overall health and self-care performance for children with CP.

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Table I. Child and Parent Demographics (Reprinted from[14])

		Participants		
		Baseline Completed n=708 (%)	**12-Month Completed n=656 (%)**	**24-Month Completed N=424 (%)**
Child age, years	Mean (SD)	6.0 (2.7)	7.1 (2.7)	8.0 (2.7)
	Minimum - Maximum	1.5 – 11.9	2.4 – 13.1	3.1 – 14.0
Child Gender	Male	396 (56)	369 (56)	242 (57)
	Female	312 (44)	287 (44)	182 (43)
Child GMFCS Level	I	227 (32)	217 (33)	135 (32)
	II	161 (23)	147 (22)	97 (23)
	III	80 (11)	73 (11)	48 (11)
	IV	129 (18)	116 (18)	75 (18)
	V	111 (16)	103 (16)	69 (16)
Child Distribution of Involvement* Baseline (n = 707) 12-Month (n = 655) 24-Month (n = 424)	Monoplegia	8 (1)	8 (1)	6 (1)
	Hemiplegia	198 (28)	184 (28)	114 (27)
	Diplegia	184 (26)	172 (26)	114 (27)
	Triplegia	39 (6)	38 (6)	20 (5)
	Quadriplegia	278 (39)	253 (39)	170 (40)
Child race* Baseline (n = 699) 12-Month (n = 649) 24-Month (n = 419)	American Indian/Alaska Native	15 (2)	11 (2)	3 (1)
	Asian	40 (6)	37 (6)	18 (4)
	Black/African American	60 (8)	56 (8)	45 (11)
	White	503 (72)	472 (73)	310 (74)
	Multi	81 (12)	73 (11)	43 (10)
Child ethnicity* Baseline (n = 703) 12-Month (n = 653) 24-Month (n = 422)	Hispanic	49 (7)	43 (7)	32 (8)
	Non-Hispanic	654 (93)	610 (93)	390 (92)
	Aboriginal	31 (4)	26 (4)	9 (2)
	Non-Aboriginal	672 (96)	627 (96)	413 (98)
Parent respondent race* Baseline (n = 698) 12-Month (n = 648) 24-Month (n = 419)	American Indian/Alaska Native	15 (2)	12 (2)	4 (1)
	Asian	51 (7)	45 (7)	22 (5)
	Black/African American	56 (8)	52 (8)	42 (10)
	White	550 (79)	517 (80)	339 (81)
	Multi	26 (4)	22 (3)	12 (3)
Parent respondent ethnicity* Baseline (n = 701) 12-Month (n = 651) 24-Month (n = 420-421)	Hispanic	32 (5)	30 (5)	20 (5)
	Non-Hispanic	669 (95)	621 (95)	400 (95)
	Aboriginal	20 (3)	16 (3)	5 (1)
	Non-Aboriginal	681 (97)	635 (97)	416 (99)

Parent respondent age, years* Baseline (n=694) 12-Month (n = 644) 24-Month (n = 415)	Mean (SD)	37.8 (7.9)	37.9 (8.0)	37.4 (7.1)
Parent respondent relationship to child* Baseline (n = 704) 12-Month (n = 654) 24-Month (n = 423)	Mother Father Other	628 (89) 51 (7) 25 (4)	578 (88) 51 (8) 25 (4)	382 (90) 26 (6) 15 (4)
Parent respondent education* Baseline (n = 700) 12-Month (n = 650) 24-Month (n = 420)	High School or less Community College / Associate's Degree University	160 (23) 212 (30) 328 (47)	147 (23) 196 (30) 307 (47)	92 (22) 114 (27) 214 (51)
Family Income* Baseline (n = 594) 12-Month (n = 553) 24-Month (n = 363) (CAD or USD)	≥$75,000 $60,000 - $74,999 $45,000 - $59,999 $30,000 - $44,999 ≤$30,000	306 (52) 78 (13) 50 (8) 58 (10) 102 (17)	293 (53) 72 (13) 47 (8) 49 (9) 92 (17)	190 (52) 43 (12) 34 (9) 35 (10) 61 (17)
Family Composition Baseline (n= 667) 12-Month (n = 620) 24-Month (n = 404)	Adults (mean, SD) Children (mean, SD)	2.1 (0.7) 2.3 (1.1)	2.1 (0.7) 2.3 (1.1)	2.1 (0.7) 2.3 (1.1)
Country	Canada United States	347 (49) 361 (51)	330 (50) 326 (50)	137 (32) 287 (68)

GMFCS= Gross Motor Function Classification System Level
CAD = Canadian Dollars
USD = United States Dollars
SD = standard deviation
* report based on the available information
Notes: 'mother' includes mother, adoptive mother, foster mother, or custodial mother; 'father' includes father, adoptive father, or step father; 'other' includes grandparent, nursing supervisor, or aunt.

Table II: Descriptive Data and Longitudinal Model Parameters by Gross Motor Function Classification System Level.

	Level I	Level II	Level III	Level IV	Level V
Number of Children	227	161	80	129	111
Number of Observations	874	611	298	487	443
Mean number of Observations per Child	3.9	3.8	3.7	3.8	4
Fixed Effects					
Intercept*	0.57	0.92	0.92	1.40	2.21
(95% CI)	(0.49, 0.65)	(0.81, 1.03)	(0.76, 1.07)	(1.25, 1.56)	(2.03, 2.40)
Slope: change with Age (months)	0.000	0.002	-0.003	0.000	0.001
(95% CI)	(-0.002, 0.002)	(0.000, 0.005)	(-0.006, 0.000)	(-0.004, 0.003)	(-0.002, 0.005)
Random Effects (SD)					
Residual	0.26	0.28	0.28	0.33	0.46
Intercept	0.54	0.62	0.60	0.79	0.86
Slope	0.006	0.009	0.004	0.01	0.003
Slope/Intercept correlation	0.10	0.46	-0.17	0.15	0.67

* The age variable was centered at 60 months so the intercept represents the expected average impact of health conditions at five years of age.

Table III. Mean and Standard Deviation of Change in Percentile Score Over a One-year Period by GMFCS Level

	GMFCS				
	Level I	Level II	Level III	Level IV	Level V
N	217	147	73	116	103
Mean Centile Change	-2.1	-4.8	-5.0	-2.0	0.2
SD Centile Change	19.2	17.4	22.5	17.6	17.7
Range 25-75% Change Scores	-13, +5	-13, +4	-15, +5	-10, +4	-12, +9
Range 10-90% Change Scores	-28, +21	-25, +15	-28, +17	-22, +17	-20, +26

Figures and Supplementary Files

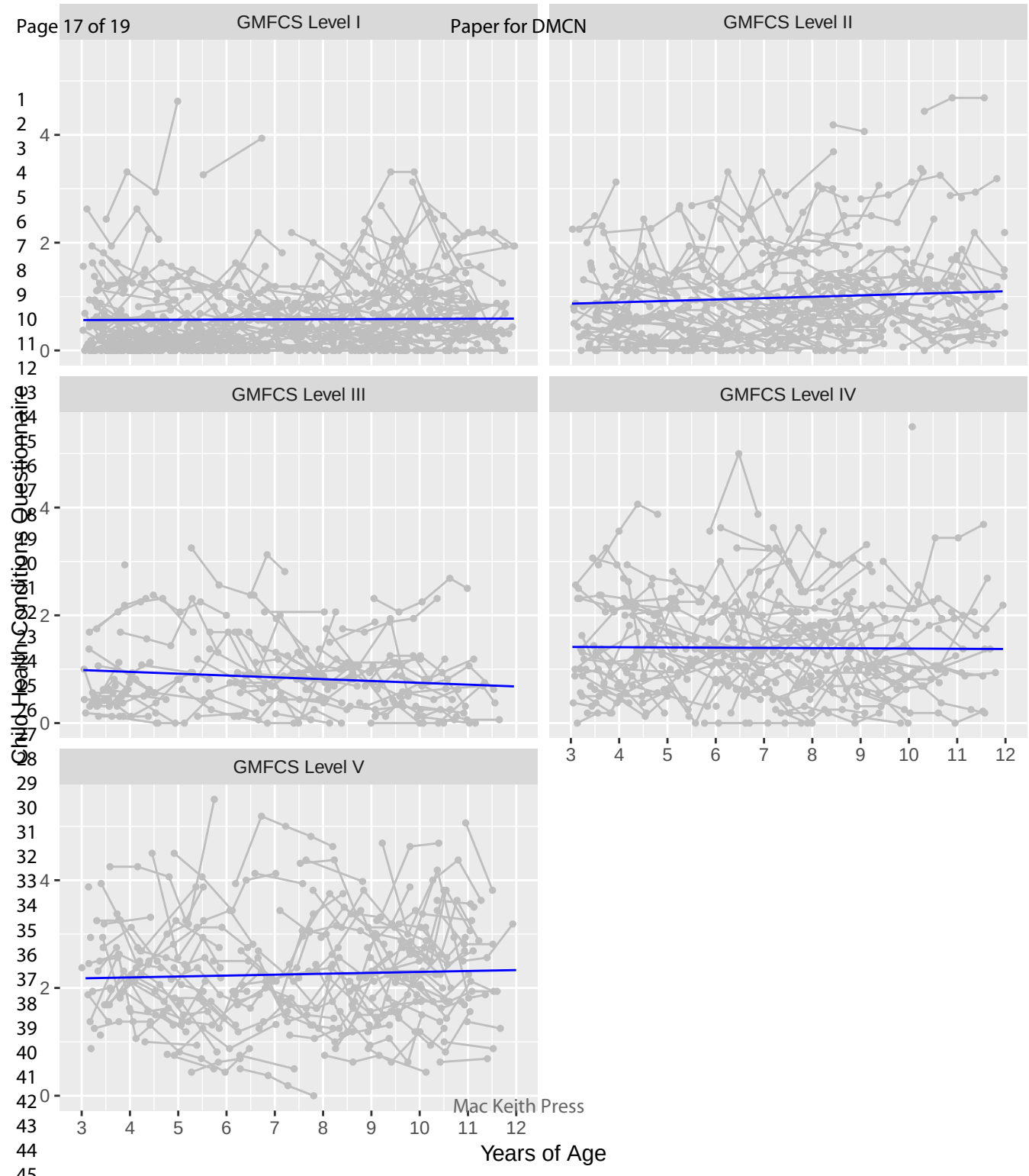
Figure 1. Longitudinal Trajectories of the Impact of Health Conditions by Gross Motor Function Classification System (GMFCS) Level

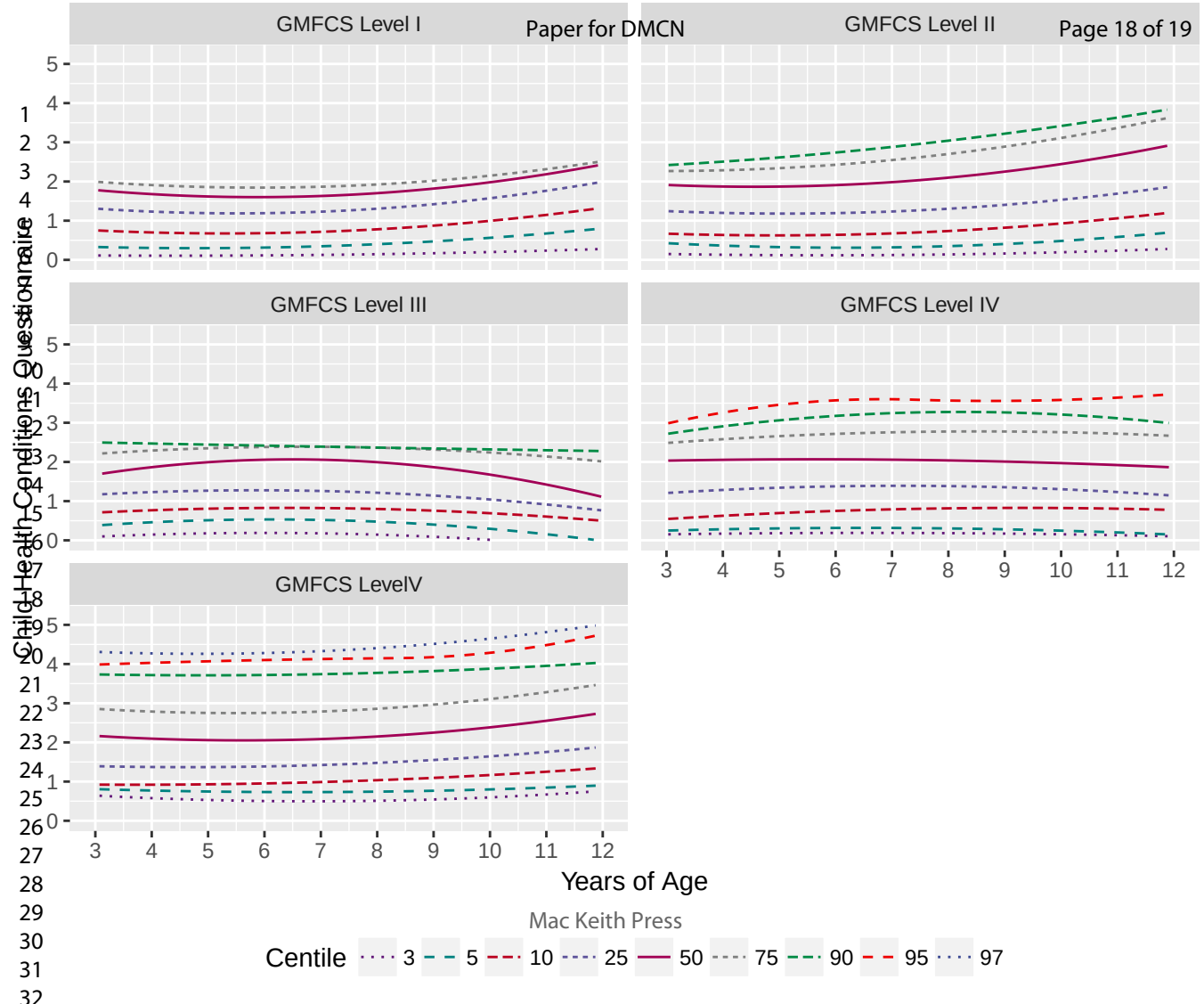
Figure 2. Reference Percentiles of the Impact of Health Conditions by Gross Motor Function Classification System (GMFCS) Level

Supplementary File 1. On Track Study Participant Flow Diagram (Reprinted with permission[14])

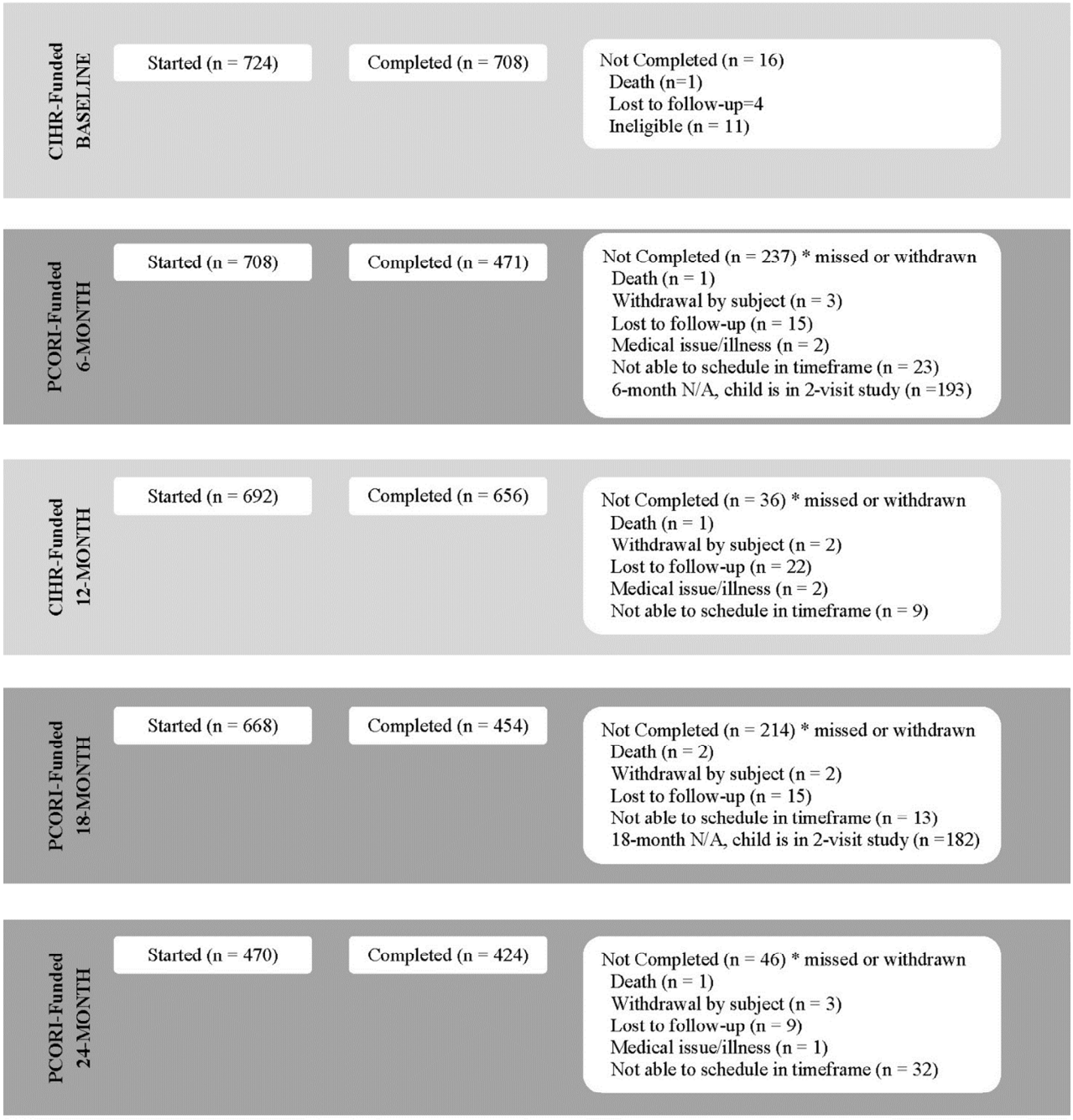
Appendix: Additional Members of the On Track Study Team

We acknowledge additional On Track Study Team members including academic researchers: Sally Westcott McCoy, Lisa Chiarello, Robert Palisano, Alyssa Fiss,; Canadian project coordinator Barb Galuppi; US project coordinator Monica Smersh; and parent researchers: Lisa Diller, Paula Drew, Nancy Ford, Marquitha Gilbert, tina hjorngaard, Kimberly Rayfield, and Barbara Sieck Taylor. We thank the participating children and families, whose continued involvement made this study possible. We also acknowledge the important contributions of the regional coordinators as well as the 90 therapists across North America who assessed children during the course of the study.


GMFCS Level I
GMFCS Level II
GMFCS Level III
GMFCS Level IV
GMFCS Level V
Child Health Conditions Questionnaire
Years of Age
Mac Keith Press


GMFCS Level I
GMFCS Level II
GMFCS Level III
GMFCS Level IV
GMFCS LevelV
Child Health Conditions Questionnaire
Years of Age
Mac Keith Press
Centile 3 5 10 25 50 75 90 95 97

Supplementary File 1: On Track Study Participant Flow Diagram (Reprinted with permission[14])



Included in Longitudinal Curves Analysis (n = 708): Using all available data points. Cases in analysis with 1 visit = 27, 2 visits = 198, 3 visits = 18, 4 visits = 89, 5 visits = 376.

Included in Percentiles Analysis (n = 708): Using Baseline, 12- and 24- Month data points with no repeated measurements on a child within an age group.
Cases in analysis with 1 visit = 42, 2 visits = 252, 3 visits = 414.

Included in the Six-Minute Walk Test Longitudinal Curves Analysis (n=456): Using all available data points.
Cases in analysis with 1 visit = 33, 2 visits = 136, 3 visits = 29, 4 visits = 71, and 5 visits = 187.

Included in the Activity Performance Sub-Study Longitudinal Curves Analysis:
Actigraph (n=79): Using all available data points. Cases in the analysis with 1 visit = 4, 2 visits = 6, 3 visits = 25, 4 visits = 25, 5 visits = 19.
StepWatch (n=50): Using all available data points. Cases in the analysis with 1 visit = 4, 2 visits = 4, 3 visits = 15, 4 visits = 18, 5 visits = 9.