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Interrelationships of Functional Status and Health Conditions in Children With Cerebral Palsy: A Descriptive Study.

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Inter-relationships of functional status and health conditions in children with cerebral palsy: A descriptive study --Manuscript Draft--

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Abstract:	<p>Purpose: To examine the relationship among the Gross Motor Function, Manual Ability, and Communication Function Classification Systems in children with cerebral palsy and to determine the number and impact of health conditions in selected profiles .</p> <p>Methods: 671 children with CP aged 2 to 12 years (376 males; 56%) were recruited from sites in Canada and the US using convenience sampling. Analyses included cross tabulation and averages for the number and impact of health conditions and comparisons among groups.</p> <p>Results: 78 (62%) out of 125 possible classification combinations were recorded. The most frequent were III; I II I; and II II I. With lower levels of function, the number and impact of associated health conditions generally increased.</p> <p>Conclusions: The use of functional profiles across classification systems, in combination with data on the associated health conditions, provides a comprehensive picture of CP for use in clinical decision making.</p>

Response to Reviewers

We thank the reviewers for their subsequent review. Reviewer one had no additional comments. We have attended to Reviewer 2's comments. Changes are indicated in bold font. In this file, reviewers' comments are in regular font and our responses are italicized. Also, in this second resubmission, masking has been removed.

Reviewer #2: Thank you for reworking this article and resubmitting. It is much improved and a valuable addition to the literature about cerebral palsy. I feel that the inclusion of the two lower functioning groups, (IV, IV, IV) and (V, V, V), improves the generalizability and usefulness of the findings.

The Introduction and Methods sections look good.

Thank you.

Results

Page 5, line 44. The information describing the results of the Tukey's post-hoc testing is hard to follow in the text. Is it possible to put it in a Table? If not, I suggest rewriting the first part of that sentence, "Tukey's post-hoc testing revealed significant difference between (I, I, I) and (II, II, I) ($p = 0.0008$); (I, I, I) and both (IV, IV, IV) and (V, V, V) . . ." I know it is repetitive to put group (I, I, I) in an extra time but it seems more clear.

Change made as suggested.

Discussion

The first two paragraphs only discuss the three higher functioning groups. It is confusing that all 5 groups are not included. You would still be able to make the point that CP is a heterogeneous condition and it would be more consistent with the rest of the article.

Consider combining the first and second paragraphs of the Discussion as they are both talking about the variability of CP.

The first two paragraphs, which highlight the comparability of our results with those of Hidecker's group have been combined. Because we are relating our results to the available literature, only the most common combinations are described.

Page 7, line 38. Consider starting a new paragraph with "Additional efforts to group children with CP..." The topic seems to change here to focus on other types of testing that are used to develop these other five profiles of children with CP. Are these additional efforts and five profiles referring to another study (reference 19?), or to this study? Please clarify.

A new paragraph has been inserted. Reference 19 has been moved forward and wording changed to indicate that this was another study.

Page 8, line 21. Consider modifying the sentence: "Children with either all level IVs or all level Vs had a greater likelihood of problems with learning, speaking, the mouth, digesting, sleeping and epilepsy..." to improve readability.

*This has been revised to read "Children **in classifications (IV, IV, IV) or (V, V, V)** had a greater likelihood.."*

Page 8, lines 29-31. The sentence compares children with good motor abilities to fragile children, which is comparing function to health status. I recommend you compare "children with good motor abilities to children with limited motor function" so it is a clear comparison.

*This sentence now reads: "virtually all children **with CP** with good motor abilities survive into adulthood while the risk of death is highest in children **with limited motor function**."²¹*

Page 9, line 19. I believe this sentence should be written with singular rather than plural so it will agree with the sentence that comes after: "Controlling emotion and behaviour has been recognized as an unmet health need..."

This change has been made and highlighted.

Page 10, lines 9-11. The sentence beginning, "The similar development and administration..." is not needed in this paragraph.

This sentence has been deleted.

Thank you for addressing the limitation of using the Child Health Conditions Questionnaire with children who are older than the reliability and validity sample. Please explain why you think using it with older children will not change the psychometric properties, especially when you have already reported that your older sample has more health conditions than the younger sample.

*We have revised the final sentence in this paragraph to read: "**We do not know if the psychometric properties would differ significantly when parents use it with their school-aged children.**"*

Inter-relationships of functional status and health conditions in children with cerebral palsy:

A descriptive study

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Short Title: Inter-relationships of Functional Status

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Figures / Tables 5/5

References 34/30

Sept 19, 2017

Dr. Linda Fetters,
Editor-in-Chief, Pediatric Physical Therapy

Dear Dr. Fetters,

Thank you so much for shepherding this 'orphan' manuscript through the review process! This is the second resubmission of the manuscript now numbered PED-PT-D-17-001111. We thank the reviewers for their final comments and look forward to the next stages. Please note that two of my co-authors questioned the shortened title (previously "Inter-relationships of functional status of children with cerebral palsy: A descriptive study and an extension of previous work" – alluding to Hidecker's work; shortened to "... A descriptive study and extension". I wonder if a revised title of "Inter-relationships of functional status and health conditions of children with cerebral palsy: A descriptive study" might be considered?

Sincerely,



Doreen Bartlett, BSc (PT), PhD
Professor Emerita

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4 **Abstract**
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9 **Purpose:** To examine the relationship among the Gross Motor Function (GMFCS), Manual Ability (MACS),
10 and Communication Function Classification (CFCS) Systems in children with cerebral palsy (CP) and to
11 determine the average number and impact of health conditions in selected profiles using the Child Health
12 Conditions Questionnaire.
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18 **Methods:** 671 children with CP aged 2 to 12 years (376 males; 56%) were recruited from sites in Canada
19 and the US using convenience sampling. Analyses included cross tabulation and averages for the number
20 and impact of health conditions and comparisons among groups.
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25 **Results:** 78 (62%) out of 125 possible classification combinations were recorded. The most frequent were
26 GMFCS I, MACS I, CFCS I; GMFCS I, MACS II, CFCS I; and GMFCS II, MACS II, CFCS I. Aiming for
27 some representation across the GMFCS levels, we also explored profiles of children in levels IV and V for
28 all three systems. With lower levels of function, the average number and average impact of associated
29 health conditions generally increased.
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38 **Conclusions:** The use of functional profiles across classification systems, in combination with data on the
39 associated health conditions, provides a more comprehensive picture of CP for use in clinical decision
40 making, than any single classification or measure alone.
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Introduction

There are two commonly used systems for classifying children with cerebral palsy (CP): systems based on anatomy or physiology versus function. Functional classification systems focus on what the child typically does instead of classifying based on impairments (such as distribution of involvement or type of movement disorder). The integration of the International Classification of Functioning, Disability and Health (ICF) framework¹ into health care has helped to emphasize children's functional abilities and their typical performance in day-to-day life, rather than impairments.² These concepts have been incorporated and used in classification systems by researchers, clinicians, and families to describe performance in mobility, handling objects, and communication. The Gross Motor Function Classification System (GMFCS),³ the Manual Ability Classification System (MACS),⁴ and the Communication Function Classification System (CFCS)⁵ are three functional classification systems designed for children with CP to portray reliably their mobility habits, how they handle objects in daily life, and their communication skills with familiar and non-familiar partners, respectively. These classification systems can be accessed at the following sites: (https://www.canchild.ca/system/tenon/assets/attachments/000/000/058/original/GMFCS-ER_English.pdf); (http://www.macs.nu/files/MACS_English_2010.pdf); and (http://cfcs.us/wp-content/uploads/2014/02/CFCS_universal_2012_06_06.pdf).

As there is no singular classification system for children with CP, combining various classifications encompassing functional components of a child's life is important.⁶ Hidecker and colleagues described functional profiles established from the three complementary classification systems (i.e. the GMFCS, the MACS, and the CFCS).⁷ Although their study described a more comprehensive picture of children with CP than when classified using a single system, they did not concurrently describe impairments in body functions and associated health conditions, which are included in key components in the definition of CP.⁸

It is important to ascertain the frequency and impact of impairments in body functions and associated health conditions to provide a more complete picture of the functional profiles for children with

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4 CP. The primary purpose of this study was to replicate Hidecker's work⁷ to identify frequently occurring
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6 functional profiles for children with CP by examining the inter-relationships among the GMFCS, the MACS,
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8 and the CFCS. We hypothesized that there would be a relatively small proportion of frequently occurring
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10 profiles in children with CP, as CP is a very heterogeneous condition. Secondly, we explored the number
11
12 and impact of impairments in body functions and associated health conditions in frequently occurring and
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14 additional selected functional profiles and differences among them.
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18 19 Methods

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21 This study is part of a five-year prospective cohort study: Developmental Trajectories of
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23 Impairments, Associated Health Conditions, and Participation of Children with CP (the On Track study).⁹
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25 Ethical approval for this research was granted by the Health Science Research Ethics Board of Western
26
27 University, as well as participating universities and sites in Canada and the United States. All ethical
28
29 recommendations have been adhered to and written, informed consent for participation and publication was
30
31 obtained from all legal guardians; assent was provided by children older than 7 years.
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35 36 Participants

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38 Children participating in the On Track study who had been diagnosed with CP or were suspected
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40 to have CP at the time of recruitment and who were between the ages of 18 months and 12 years were
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42 eligible to participate in the larger study. Ongoing eligibility was maintained throughout the study so that the
43
44 final data set for analysis represented children with CP. Therapist assessors provided detailed information
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46 for consideration of eligibility of seventy-one unique cases either before or after recruitment. A physiatrist
47
48 (JWG) reviewed and made recommendations to the team about any queries relating to eligibility. As a
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50 result, 11 cases were excluded. Families were excluded from the On Track study if they did not speak
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52 English, French, or Spanish. A convenience sampling approach was used to recruit participants for the
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54 study using various methods from clinical sites across Canada and the United States, including children
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56 from urban, rural, and suburban areas (see site descriptions at: <https://www.canchild.ca/en/research-in->
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4 [practice/current-studies/on-track](#)). Recruitment and the first data collection point took place between April
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7 2013 and January 2015. Children in the original On Track sample of N=711 were excluded from this sub-
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9 study if they were under 24 months at the first visit (N=34) or if consensus information was not available for
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11 one or more of the classifications (N=6). A total of 671 children were included in this descriptive sub-study.
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13
14 Child and caregiver respondent characteristics are described in Table 1.

16 Measures

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19 The GMFCS,^{3,10} the MACS,⁴ and the CFCS⁵ classification systems were used to determine the
20
21 appropriate levels of functional ability in the areas of gross motor, manual ability, and communication for
22
23 each child with CP. The three systems have a similar parallel structure and design concept, examining
24
25 children's performance in everyday life by placing them into one of five levels forming an ordinal scale from
26
27 level I (most functional) to level V (least functional). The three classification systems were all developed
28
29 through the use of nominal group and the Delphi survey consensus methods. The GMFCS, the MACS,
30
31 and the CFCS all have evidence of reliability, validity, and stability.^{3-5, 10-15} These properties are
32
33 summarized in Table 2.
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38 The Child Health Conditions Questionnaire consists of 16 items pertaining to various impairments
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40 in body functions and health conditions of children with CP.¹⁶ Items were generated based on the
41
42 international definition of CP⁸ and most were framed based on the body functions component of the ICF¹
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44 (e.g. *does your child have problems seeing, hearing, learning / understanding, speaking / communicating,*
45
46 *and so on*). Data can be reported on both number of health conditions and impact of health conditions
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48 (from 1 = not at all to 7 = to a very great extent) to describe the extent to which the conditions affect the
49
50 child's daily activities. Test-retest reliability was established for number (ICC = 0.80) and the average
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52 impact (ICC = 0.85) of health conditions for children between 18 months and 5 years of age.¹⁶ This
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54 questionnaire is available at:
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60 https://canchild.ca/system/tenon/assets/attachments/000/000/470/original/move_play_health_conditions_q
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4 [uestionnaire_dec2012.pdf](#) . Data obtained from the parent data collection booklets were used to describe
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6 the sample.

9 Procedures

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11 Data were collected at the first data collection point of the On Track study during a one-hour
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13 assessment completed by a trained therapist and completion of a separate booklet by the parent or
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15 caregiver. Both the assessing therapist and parent or caregiver classified the child's level of involvement
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17 and consensus was reached on the level for each system. Decision algorithms and flow charts provided by
18
19 all three systems³⁻⁵ were included in all study kits to aid with decisions on levels between therapists and
20
21 the parent or caregiver if a consensus was not initially reached. In cases where consensus was not
22
23 reached, we developed guidelines to come up with final classifications.¹⁷ All completed data collection
24
25 booklets were entered into a common database for analysis.

31 Statistical Analysis

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33 Inter-relationships among the GMFCS, the MACS, and the CFCS classification systems (reported
34
35 in this order) were explored using nested cross tabulations, producing 125 possible combinations of
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37 functional cells. The average number and average impact of each associated health condition were
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39 calculated in selected cell combinations. Differences among the selected cell combinations was determined
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41 using a one-way ANOVA and the Kruskal-Wallis k independent samples test (and appropriate post hoc
42
43 testing) for the average number and average impact of associated health conditions, respectively.
44
45 Frequencies and proportions of each of the 16 health conditions was determined for the selected cells. A
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47 Chi Square test was used to determine the significant difference in proportion of health conditions among
48
49 the profiles. A p value was set at 0.05 for most inferential analyses, with Bonferroni's correction being used
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51 to compare differences in the 16 health conditions among the selected groups ($p < 0.003$).
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57 Results

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4 The inter-relationships among the GMFCS, the MACS, and the CFCS are displayed in Table 3 representing
5
6 the functional profiles. Of the possible 125 cell combinations available, 78 combinations were present among the
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8 children in this study, representing approximately 62% of all possible combinations that could have arisen. From
9
10 Table 3, the frequency of the occurrence of the same level of classification in all three systems was determined. Of
11
12 the 671 children 157 (23%) were found to be the same level in all three classification systems. The most common
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14 same level classification was GMFCS level I, MACS level I, and CFCS level I (n = 71, 11%). Sequentially all level IIs
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16 represent 4% (n = 26), all level IIIs 1% (n = 5), all level IVs 4% (n = 26), and all level Vs 4% (n = 29).
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20 The most frequent functional profiles were considered to be those that represented 5% or more of
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22 the 671 participants and accounted for 27% of the total sample. The most frequent functional cell
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24 combinations were (I, I, I) representing 11% (n = 71) of the total sample, followed by (I, II, I) representing
25
26 10% (n = 65), and (II, II, I) representing 6% (n = 37). To round out the exploratory portion of this sub-study,
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28 we selected two additional groups: all level IV and all level V, each representing about 4% of the sample.
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30 We selected the additional lower functioning groups as a complement to allow for greater variability in
31
32 number and impact of health conditions to be described and interpreted.
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37 The average number and average impact of associated health conditions was described for both
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39 frequent and selected (hereafter referred to as selected) functional profiles (Table 4). A significant
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41 difference in the number of associated health conditions was determined among the 5 groups ($F = 81.32$, df
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43 $= 4$, $p < 0.001$). Tukey's post-hoc testing revealed significant differences between (I, I, I) and (II, II, I) ($p =$
44
45 0.008); (I, I, I) and both (IV, IV, IV) and (V, V, V) ($p < 0.001$); between (I, II, I) and both (IV, IV, IV) and (V, V,
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47 V) ($p < 0.001$); between (II, II, I) and both (IV, IV, IV) and (V, V, V) ($p < 0.001$); and between (IV, IV, IV) and
48
49 (V, V, V) ($p = 0.001$). Differences for average number of health conditions exceeded the minimal
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51 detectable difference at the 95% CI (MDC₉₅) of 3.4 (calculated from¹⁶) between the three most frequent
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53 profiles and each of the two additional selected profiles. Significant differences in the average impact were
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55 determined among groups (Chi Square = 117.29, $df = 4$, $p < 0.001$). Post hoc testing using the Mann
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4 Whitney U test and a Bonferroni correction of 0.01, established differences between (I, I, I) and (II, II, I), (IV,
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7 IV, IV) and (V, V, V) (all $p < 0.001$); between (I, II, I) and (II, II, I) ($p = 0.001$), as well as for (IV, IV, IV) and
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9 (V, V, V) (both $p < 0.001$); between (II, II, I) and (IV, IV, IV) and (V, V, V) (both $p < 0.001$); and finally
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11 between (IV, IV, IV) and (V, V, V) ($p < 0.001$). Again, differences for average impact of health conditions
12
13 exceeded the MDC_{95} of 0.8 (also calculated from¹⁶) between the three most frequent profiles and each of
14
15 the two additional selected profiles.
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19 The number and proportion of individual associated health conditions in each of the selected
20
21 functional profiles are recorded in Table 5. Using a Bonferroni correction of 0.003, the Chi square tests
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23 show differences among the five groups for problems seeing, hearing, learning, speaking, the mouth, the
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25 teeth and gums, digestion, growth, sleeping, repeated infections, breathing and with seizures.
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28 Discussion

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31 Alone there is no singular classification system to describe all aspects of a child's life with CP. On
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33 their own the GMFCS,^{3,10} the MACS,⁴ and the CFCS⁵ are reliable and valid classification systems that
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35 describe a child's body movement, hand function, and communication abilities in everyday life, respectively.
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37 When these three classification systems are reported together they provide a more comprehensive picture
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39 of a child with CP than with any single classification. Functional profiles of the three systems have been
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41 observed by one other study. Hidecker and colleagues⁷ also observed that the most common profile was
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43 children in all level I, representing 10% their total sample, **a value that is similar to ours (11%)**. The
44
45 Hidecker group also found profile (II, II, I) to be a common profile representing 5% of the sample, which is
46
47 **also** similar to our results (6%). Hidecker's study was not as diverse as our study as their study filled 50%
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49 of the possible cell combinations in comparison to 62% in our study. Nonetheless, when one considers the
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51 distribution of involvement in various samples, one would not expect to see all 125 possible combinations
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53 as some are functionally unlikely.¹⁸ The fact that 73% of the sample fell into cells with fewer than 5% of the
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55 children highlights the heterogeneity of the cerebral palsy phenotype.
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4 Co-occurring impairments in body functions and health conditions were also reported in this study
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6 as they are included in the definition of CP.⁸ Overall, among the selected functional profiles, we found that
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8 as the levels increased (i.e. function decreased) in one or more of the classification systems the average
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10 number and average impact of associated health conditions also increased. A report on preschool
11
12 children with CP found similar results regarding the number and impact of associated health conditions.
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14 Wong and colleagues reported a slightly lower frequency and average impact compared to this study,
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16 which might be explained by the younger age of the participants and the age in which associated health
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18 conditions become apparent.¹⁶
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24 Additional efforts to group children with CP more comprehensively than with the three classification
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26 systems and health conditions alone **involved** using measures of spasticity, balance, distribution of
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28 involvement, strength, range of motion, endurance and impact of health conditions.¹⁹ Five 'profiles' of
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30 functioning were established using both a summative, quintile approach and cluster analysis. Although
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32 average function decreased from the most to least functional groups, similar to the observations reported in
33
34 this manuscript, there was significant variability in scores on individual measures within each of the five
35
36 groups, with considerable overlap between groups, a finding that has been observed by others
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38 investigating measurement scores among children at different GMFCS levels.²⁰ We suggest that aiming for
39
40 a single comprehensive classification is not useful as this over simplifies the complexity of health issues.
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42 Instead, we advocate for routine assessment with a 'suite' of measures or classification systems being
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44 interpreted separately, and in combination with each other, to understand individual children's functional
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46 and health profiles with their relative strengths and limitations, and then to plan interventions based on
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48 collaborative decisions with families (see [https://www.canchild.ca/en/research-in-practice/current-
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65](https://www.canchild.ca/en/research-in-practice/current-studies/on-track) studies/on-track).

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61 Among the functional profiles selected for this study, children with all level V on the GMFCS,
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63 MACS and CFCS had the highest proportion of problems seeing, hearing, with teeth and gums, as well as
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4 with repeated infections and breathing. Children **in classifications (IV, IV, IV) or (V, V, V)** had a greater
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6 likelihood of problems with learning, speaking, with the mouth, with digestion and sleeping, as well as
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8 epilepsy, than children in the three more functional profiles. These results are not surprising as it is known
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10 that virtually all children **with CP** with good motor abilities survive into adulthood while the risk of death is
11
12 highest in children **with limited motor function**.²¹ Nonetheless, our findings do suggest that
13
14 comprehensive care coordination and additional services may be required for children CP and medical
15
16 complexity to manage their many (and often impactful) associated impairments and health conditions.²²
17
18 Nonetheless, even children at GMFCS level I have been observed to have a greater number of health
19
20 conditions with greater impact on their lives than children without CP;¹⁶ therefore, all children with CP could
21
22 potentially benefit from having the Child Health Conditions Questionnaire completed on a routine basis, at
23
24 least once a year.
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31 Several areas of health are worth highlighting. Problems with the mouth and teeth and gums occur
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33 more frequently as functional profiles are more limited. Given that children with CP are at an increased risk
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35 for tooth decay,²³ early oral hygiene care from appropriately trained professionals is required. Problems
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37 with digestion, growth and sleep also increase as functional profiles decrease. We agree with colleagues
38
39 who have suggested that all care providers working with children with CP should comprehensively assess
40
41 and manage physical activity, nutrition and sleep to promote health across the lifespan, suggested to be
42
43 particularly important for children with lower functional abilities.²⁴ A comprehensive review and analysis of
44
45 sleep disturbances in children with CP, including guidelines for assessment and management, is a valuable
46
47 resource for front-line clinicians.²⁵
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52
53 The most commonly occurring health condition in the three most functional profiles, with no
54
55 significant difference among the five selected profiles, was controlling emotions and behaviour. Controlling
56
57 emotions and behaviour has been recognized as an unmet health need in children with CP compared to
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59 typically developing children.^{26,27} This health condition has previously received attention as having an
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4 impact on children's lives.²⁸⁻³⁰ As others have found,³¹ the frequency and impact of pain does not differ by
5
6 functional ability. Accordingly, all children with CP warrant early detection and prevention of chronic pain,
7
8 where possible. Guidelines are available for assessment³² and management
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10
11 (<https://hollandbloorview.ca/TeachingLearning/EvidencetoCare/knowledgeproducts/PainToolbox>) of
12
13 pain in children with CP.
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15
16 The increase in research on CP over time has made it more challenging for health care
17
18 practitioners to stay up to date on appropriate assessment and intervention across the spectrum of needs
19
20 for children with CP. Recognition of unmet health needs can lead to changes in how health care
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22 practitioners are caring for children with CP. Although physical therapists are not responsible for
23
24 management across the range of impairments in body functions and health conditions reported here, we
25
26 suggest routine use of the Child Health Conditions Questionnaire. It is psychometrically sound and readily
27
28 completed with parents in five minutes. Integration of this questionnaire in examinations can lead to
29
30 appropriate referral, monitoring, and care for early intervention and health promotion.³³ Completion of this
31
32 questionnaire with parents indicates that therapists are interested in the whole child and his or her overall
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34 health and well-being.
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41 It is important to note that while the functional aspects of the child's life are portrayed using the
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43 three classification systems, functional aspects of associated health conditions also impact the lives of
44
45 children with CP. The additional information on the associated health conditions can help health care
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47 practitioners and families to better estimate what to expect and how to better deal and plan for these
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49 associated health conditions. Together the combination of functional profiles and associated health
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51 conditions gives a more comprehensive profile for children with CP, than with the classification systems
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53 alone.
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57 A limitation to the On Track study is the method in which the sample was obtained. Although not a
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59 population-based sample of children with CP, the distribution of GMFCS in this large prospective cohort
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4 sample of 671 participants is comparable to incidence data reported in the literature. Reid and colleagues
5 reported mean proportions (SD) in each GMFCS level in nine international CP registries: GMFCS I - 34.2%
6 (13.1); GMFCS II – 25.6% (11.6); GMFCS III – 11.5% (2.5); GMFCS IV – 13.6% (4.3); GMFCS V - 15.6%
7 (4.3).³⁴ The proportion of children in each GMFCS level in our sample is: GMFCS I – 31.7%; GMFCS II –
8 23.1%; GMFCS III – 11.3; GMFCS IV – 18.3%; GMFCS V – 15.5%. Another limitation to the study is that
9 although this study determined differences among five selected functional classifications systems and the
10 associated health conditions, there is so much more that contributes to each individual child with CP. As
11 alluded to earlier,¹⁹ clinical practice needs to incorporate all of the heterogeneous features of children with
12 CP. Finally, the Child Health Conditions Questionnaire has been validated for use with parents of
13 preschool children with CP and not with parents of older children. **We do not know if the psychometric
14 properties would differ significantly when parents use it with their school-aged children.**

31 Conclusion

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33 This study demonstrates that functional profiles can be established for children with CP by
34 observing their GMFCS, MACS, and CFCS levels and providing a more comprehensive profile by
35 considering impairments in body functions and associated health conditions (both number and impact on
36 daily life). This research represents a more comprehensive picture of children with CP, however it is
37 important to remember that CP is a heterogeneous condition and more developmental domains should be
38 taken into consideration when planning intervention to optimize outcomes within each child's prognostic
39 potential.
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Table 1. Child and Caregiver Respondent Characteristics

Child Characteristics	Total (n = 671)
Age – years	
Mean	6.3
Standard Deviation (SD)	2.6
Gender – n (%)	
Boy	376 (56)
Girl	295 (44)
Limb Distribution – n (%)	n = 669
Unilateral	194 (29)
Monoplegia	5 (1)
Hemiplegia	189 (28)
Bilateral	475 (71)
Diplegia	179 (27)
Triplegia	37 (5)
Quadriplegia	259 (39)
Caregiver Respondent Characteristics	
Age – years	(n = 656)

Mean	38
Standard Deviation (SD)	7.8
Relationship to child – n (%)	n = 665
Mother/Adoptive Mother	585 (88)
Father/Adoptive Father/Stepfather	48 (7)
Other (Aunt, Foster Mother, Grandmother, Grandfather, nurse in LTC)	32 (5)

Notes: SD = Standard Deviation; LTC = Long Term Care

Table 2. Summary of the Psychometric Properties of the Classification Systems

Classification System	Reliability	Validity	Stability
GMFCS	Inter-rater for children over 2 years of age (K = 0.75) ¹⁰	Correlation with GMFM scores (r = -0.91) ¹¹	Yes ¹²
MACS	Inter-rater (ICC = 0.97) ⁴ Test retest (ICC = 0.97) ⁴	Content validity established ¹³ Correlation with Functional Independence Measure for children (r = - 0.78) ¹⁴	Yes ¹⁵
CFCS	Intra-rater (K = 0.82) ⁵ Inter-rater (K = 0.66) ⁵	Content validity ⁵	Not at this point

Notes: GMFCS = Gross Motor Function Classification System; MACS= Manual Ability Classification System; CFCS = Communication Function Classification System, GMFM = Gross Motor Function Measure, K (Kappa co-efficient), ICC (Intraclass Correlation Co-efficient)

Table 3: Inter-relationships of all Three Functional Classifications (N=671)

GMFCS level I (n = 213)		CFCS level					Row totals
		I	II	III	IV	V	
MACS level	I	71	13	3	1	1	89
	II	65	26	16	6	0	113
	III	1	4	2	2	0	9
	IV	0	0	1	1	0	2
	V	0	0	0	0	0	0
	Column totals	137	43	22	10	1	213

GMFCS level II (n = 155)		CFCS level					Row totals
		I	II	III	IV	V	
MACS level	I	20	8	2	2	0	32
	II	37	26	18	10	0	91
	III	5	7	6	6	0	24
	IV	1	1	1	4	1	8
	V	0	0	0	0	0	0

Column totals 63 42 27 22 1 155

GMFCS level III (n = 76)

Row totals

CFCS level

		I	II	III	IV	V	
MACS level	I	10	1	0	0	0	11
	II	16	11	9	2	0	38
	III	7	4	5	3	1	20
	IV	1	0	2	3	0	6
	V	0	0	0	0	1	1
	Column totals	34	16	16	8	2	76

GMFCS level IV (n = 123)

Row totals

CFCS level

		I	II	III	IV	V	
MACS level	I	3	0	1	0	0	4
	II	8	5	4	4	0	21
	III	7	9	13	12	3	44
	IV	0	2	16	26	4	48
	V	1	0	0	3	2	6

		Column totals	19	16	34	45	9	123
GMFCS level V (n = 104)								Row totals
			CFCS level					
			I	II	III	IV	V	
MACS level	I		0	0	0	0	0	0
	II		0	0	1	1	0	2
	III		1	0	2	0	0	3
	IV		1	1	13	23	10	48
	V		1	0	7	14	29	51
	Column totals		3	1	23	38	39	104

**Notes: GMFCS = Gross Motor Function Classification System; MACS = Manual Ability Classification System; CFCS = Communication Function Classification System*

Table 4: Average Number and Average Impact of Selected Associated Health Conditions

(GMFCS, MACS, CFCS) levels	Number of Associated Health Conditions		Impact of Associated Health Conditions	
	mean (SD)	median (min, max)	mean (SD)	median (min)(max)
(I, I, I) (n = 70)*	2.0 (2.0)	2 (0, 8)	0.4 (0.4)	0.3 (0.0, 1.9)
(I, II, I) (n = 65)	2.5 (2.3)	2 (0, 11)	0.4 (0.4)	0.3 (0.0, 1.8)
			(n = 63)*	
(II, II, I) (n = 37)	3.7 (2.3)	4 (0, 10)	0.7 (0.6)	0.7 (0.0, 2.6)
			(n = 35)*	
(IV, IV, IV) (n = 26)	7.5 (2.9)	7 (3, 14)	2.1 (1.1)	1.9 (.3 – 5.5)
(V, V, V) (n = 29)	10.0 (2.8)	10 (3-14)	3.1 (1.1)	3.2 (.8 , 4.7)
			(n = 27)*	

notes: GMFCS = Gross Motor Function Classification System;

MACS=Manual Ability Classification System;

CFCS = Communication Function Classification System;

* notes that the numbers are not the same as in Table 1 as some of the

health conditions data were missing

Table 5: Frequency and Proportion of Each Associated Health Condition in the Selected Groups

(Bonferroni corrected p value bolded if significant (i.e. < 0.003))

Health Condition – n (%)	(I, I, I)	(I, II, I)	(II, II, I)	(IV, IV, IV)	(V, V, V)	p value
	(n = 70)	(n = 65)	(n = 37)	(n = 26)	(n = 29)	(X ² test)
Seeing	16 (23)	20 (31)	12 (32)	9 (35)	26 (90)	< 0.001
Hearing	2 (3)	3 (5)	1 (3)	5 (19)	17 (59)	< 0.001
Learning/ understanding	15 (21)	21 (32)	11 (30)	22 (85)	28 (97)	< 0.001
Speaking/ communicating	3 (4)	9 (14)	1 (3)	24 (92)	29 (100)	< 0.001
Emotions/behaviour	26 (37)	24 (37)	20 (54)	18 (69)	11 (39)	0.03
					(n = 28)	
Seizures/epilepsy	1 (1)	10 (15)	8 (22)	13 (50)	22 (76)	< 0.001
Mouth	1 (1)	8 (12)	9 (24)	24 (92)	27 (96)	< 0.001
					(n = 28)	
Teeth/gums	0 (0)	3 (5)	4 (11)	6 (23)	14 (50)	< 0.001
					(n = 28)	

Digestion	12 (17)	14 (22)	15 (41)	20 (77)	28 (97)	< 0.001
Growth	7 (10)	7 (11)	7 (29)	11 (42)	15 (54)	< 0.001
		(n = 64)				
Sleeping	12 (17)	7 (11)	6 (16)	15 (58)	20 (68)	< 0.001
Repeated infections	2 (3)	4 (6)	7 (19)	3 (12)	13 (45)	< 0.001
Breathing problems	9 (13)	6 (9)	12 (32)	7 (27)	17 (59)	< 0.001
Skin problems	15 (21)	11 (17)	5 (14)	6 (23)	6 (21)	0.83
Heart problems	5 (7)	5 (8)	2 (5)	3 (12)	4 (14)	0.73
Pain	17 (24)	10 (15)	15 (41)	9 (35)	13 (45)	0.01

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