Pediatric Outcomes Data Collection Instrument Scores in Ambulatory Children With Cerebral Palsy

An Analysis by Age Groups and Severity Level

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Background: The Pediatric Outcomes Data Collection Instrument (PODCI) was developed in 1994 as a patient-based tool for use across a broad age range and wide array of musculoskeletal disorders, including children with cerebral palsy (CP). The purpose of this study was to establish means and SDs of the Parent PODCI measures by age groups and Gross Motor Function Classification System (GMFCS) levels for ambulatory children with CP.

Methods: This instrument was one of several studied in a prospective, multicenter project of ambulatory patients with CP between the aged 4 and 18 years and GMFCS levels I through III. Participants included 338 boys and 221 girls at a mean age of 11.1 years, with 370 diplegic, 162 hemiplegic, and 27 quadriplegic. Both baseline and follow-up data sets of the completed Parent PODCI responses were statistically analyzed.

Results: Age was identified as a significant predictor of the PODCI measures of Upper Extremity Function, Transfers and Basic Mobility, Global Function, and Happiness With Physical Condition. Gross Motor Function Classification System levels was a significant predictor of Transfers and Basic Mobility, Sports and Physical Function, and Global Function. Pattern of involvement, sex, and prior orthopaedic surgery were not statistically significant predictors for any of the Parent PODCI measures. Mean and SD scores were calculated for age groups stratified by GMFCS levels. Analysis of the follow-up data set validated the findings derived from the baseline data. Linear regression equations were derived, with age as a continuous variable and GMFCS levels as a categorical variable, to be used for Parent PODCI predicted scores.

Conclusions: The results of this study provide clinicians and researchers with a set of Parent PODCI values for comparison to age- and severity-matched populations of ambulatory patients with CP.

Key Words: cerebral palsy, ambulatory, function, outcomes, PODCI, GMFCS

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In clinical settings, outcome tools are utilized to identify functional deficiencies, select appropriate treatment options, evaluate changes from treatment interventions, and determine whether clinical management goals are met. To be most effective, a tool should document the results of care and provide meaningful scientific evidence of clinical outcomes for patients and their families. Many different outcome measures have been developed in the past several years for administration to children and parents of children with musculoskeletal disorders.[1–12] One such tool is the Pediatric Outcomes Data Collection Instrument (PODCI).[1]

The Pediatric Outcomes Data Collection Instrument, initially known as the Pediatric Orthopaedic Society of North America questionnaire, was introduced in 1994 by a work group representing the Pediatric Orthopaedic Society of North America, the American Academy of Orthopaedic Surgeons, the American Academy of Pediatrics, and Shriners Hospitals for Children. The work group's task was the development of a pediatric patient–based instrument that could be used across a broad age range and wide array of musculoskeletal disorders.[1] The resulting 114-item PODCI yields 4 functional assessment scores: Upper Extremity Function (Upper), Transfers and Basic Mobility (Xfers), Sports and Physical Function (Sports), and Comfort/Pain (Comf/Pain). In addition, a Global Function score (Global), which is a composite of the 4 functional assessments, and a Happiness With Physical Condition score (Happiness) are calculated. Each of the functional assessments can be categorized within the International Classification of Functioning, Disability, and Health framework.[13] Most of PODCI's measures fit within the Activities and Participation component under the International Classification of Functioning, Disability, and Health Performance construct.[3]

After its initial development, Daltroy et al[1] determined that PODCI performed with reliability, validity, and sensitivity to change for pediatric orthopaedic patients with moderate to severe musculoskeletal disorders. In 2001, Haynes and Sullivan[14] collected PODCI responses from typically developing children and their parents. This study provided information useful in determining how much below typical development a patient with a defined musculoskeletal disorder functions. Since then, PODCI has been found to be a valid and useful outcome instrument when used in evaluation of children with cerebral palsy (CP).[2,4,5,15] Pediatric Outcomes Data Collection Instrument can be administered to children/patients aged 11 years or older (Child PODCI) and to the parents of patients aged 4 years and older (Parent PODCI); however, Sullivan et al[2] found that the Child PODCI may have validity weaknesses, when administered to ambulatory children with CP, and caution reliance upon the Child PODCI in this population.

During the past 10 years, PODCI has gained popularity among researchers studying children with CP.[15,16] Although the work of Haynes and Sullivan[14] established PODCI scores representative of typically developing children, expected scores for patients with CP, stratified by age groups and Gross Motor Function Classification System (GMFCS) levels,[17] are needed for effective utilization of PODCI in this patient population. The scores would allow direct comparisons between a specific patient and a matched cohort, assisting clinicians in the creation of comprehensive and individualized management plans. Understanding functional levels relative to other children with CP, both preoperatively and postoperatively, potentially provides insights into the benefits and liabilities of specific treatment modalities. Therefore, the purpose of this study was to establish means and SDs of the Parent PODCI measures by age groups and GMFCS levels for ambulatory children with CP.

METHODS

This study is part of a larger prospective multicenter project evaluating functional assessment tools and measures utilized in ambulatory patients with CP, consisting of baseline and follow-up data sets. Participants were recruited from outpatient clinics or motion analysis laboratories of 7 pediatric orthopaedic facilities. Institutional review board approval was obtained at each site, with appropriate consent and Health Insurance Portability and Accountability Act forms signed by each participant and parent.

Study inclusion criteria were a diagnosis of CP, a GMFCS level of I through III, aged between 4 and 18 years, and literacy in English. The ability to walk a minimum of 15 ft independently with or without assistive devices for no less than 3 trials was also required, so that temporospatial parameters could be captured for the multicenter project. Subjects excluded were those with lower extremity musculoskeletal surgery within the previous year, botulinum toxin A injections in the prior 6 months, an operational baclofen pump, or prior selective dorsal rhizotomy. Recruitment and data collection occurred between February 2002 and October 2005.[3]

Baseline PODCI data consist of 559 participants: 338 boys and 221 girls. These data were used as the primary data set of the study; for validation purposes, a follow-up secondary data set was analyzed. Mean age of the baseline data set was 11.1 years (range, 4.1–18.7 years), with 241 classified as GMFCS level I, 196 as level II, and 122 as level III. By pattern of involvement, 370 were diplegic, 162 hemiplegic, and 27 quadriplegic. By ethnicity, 465 were white, 41 Hispanic, 37 African American, 6 Asian, and 10 other. Of the 559 subjects, 260 reported lower extremity orthopaedic surgery in prior years, ranging from isolated tendo Achilles lengthening to simultaneous, multiprocedure surgeries, which could include procedures at the hips, knees, ankles, and feet. This baseline cohort is consistent with a population of children often seen in centers treating patients with CP.

All participants who completed the baseline phase were invited via phone, mail, or clinic visit to participate in the follow-up phase. There were 373 (67%) completed Parent PODCI responses: 224 boys and 149 girls. The parent who responded to study questions at baseline was chosen as the respondent at follow-up. Mean age at follow-up was 12.3 years (range, 5.2–20.5 years), with 175 classified as GMFCS level I, 121 as level II, and 77 as level III. The follow-up assessment was scheduled at least 9 months subsequent to baseline, with no upper limit. Average time between assessments was 1.3 years (range, 0.7–3.0 years).

In the follow-up cohort, 228 of the 373 subjects received lower extremity musculoskeletal surgery either before baseline, between baseline and follow-up, or both. Surgical intervention during the study period was defined as lower extremity orthopaedic procedures, either soft tissue and/or bony, but excluded serial casting, hardware removal, and botulinum toxin A injections. Between baseline and follow-up, participants received community-based standard-of-care management, which may have included observation, physical therapy, serial casting of contractures, botulinum toxin A, and/or musculoskeletal surgery. Follow-up assessments were administered no earlier than 9 months after surgery.

Although a battery of questionnaires and functional measures were administered to patients and parents during the multicenter project,[2,3] this study focuses on responses to the Parent PODCI. At baseline, there were missing responses such that 11 of the 559 Happiness scores could not be calculated. At follow-up, 4 of the 373 Happiness scores could not be calculated. Pediatric Outcomes Data Collection Instrument scores for the functional measures were complete. Responses to PODCI at both baseline and follow-up were collected via touchscreen monitors.

Participants' ages, sexes, histories of prior surgeries (PriorSxYN), GMFCS levels, and patterns of involvement were examined as potential predictors of differences in PODCI scores. Toward developing age-based mean and SD scores, 4 age groups were created: younger than 7, 7–10, 11–14, and 15 years or older. The break between younger than 7 and 7 to 10 represents the time by which a mature gait pattern typically develops.[18] The break between 7 to 10 and 11 to 14 differentiates children before and after their preadolescent growth rate acceleration. The final break between 11 to 14 and 15 years or older distinguishes achievement of skeletal maturity. Because of the large number of P values examined and the reasonably sized sample, statistical significance was set at

TABLE 1. *P* Values of 5-Way ANCOVAs for Each of the 6 Parent PODCI Scores*

Parent PODCI Measures	Upper	Xfers	Sports	Comf/Pain	Global	Happiness
Age	***0.000***	***0.000***	0.281	0.079	***0.009***	***0.002***
GMFCS	0.021	***0.000***	***0.000***	0.484	***0.000***	0.519
Pattern	0.030	0.418	0.526	0.601	0.665	0.974
Sex	0.079	0.182	0.266	0.939	0.165	0.180
PriorSxYN	0.425	0.027	0.495	0.667	0.391	0.914
GMFCS × age	0.464	***0.000***	0.345	0.177	0.164	0.387
Pattern × age	0.365	0.826	0.399	0.829	0.676	0.926
Sex × age	0.115	0.306	0.170	0.673	0.133	0.098
PriorSxYN × age	0.486	0.011	0.229	0.577	0.304	0.754

*Statistically significant *P* values are bolded and italicized. *P* values reported as ***0.000*** represent values less than 0.0005.

$P < 0.01$. SPSS version 13.0 (SPSS Inc, Chicago, Ill) was used for data analysis.

RESULTS

The first analyses were 5-way analyses of covariance (ANCOVAs) for each of the 6 baseline PODCI scores, using GMFCS level, pattern of involvement, sex, and PriorSxYN as categorical variables and age as a covariate. All main effects and all 2-way interactions containing the age covariate were examined (Table 1). Gross Motor Function Classification System level is a significant predictor for Xfers, Sports, and Global. Age is a significant predictor of Upper, Xfers, Global, and Happiness. Pattern of involvement, sex, and PriorSxYN did not demonstrate statistical significance for any

TABLE 2. Parent PODCI Mean and SD Scores Stratified by Age Groups and GMFCS Levels*

	GMFCS Level			
	I	II	III	TD†
<7 y				
Upper	(31) 66.5 ± 16.9	(30) 64.5 ± 20.7	(17) 56.3 ± 14.7	(16) 95.5 ± 7.4
Transfers	(31) 82.7 ± 11.9	(30) 72.6 ± 14.2	(17) 46.3 ± 18.7	(17) 98.8 ± 3.2
Sports	(31) 60.0 ± 14.8	(30) 46.1 ± 15.4	(17) 27.4 ± 13.9	(17) 90.2 ± 13.7
Comf/Pain	(31) 82.5 ± 19.0	(30) 83.6 ± 17.1	(17) 83.4 ± 14.4	(17) 94.6 ± 18.1
Global	(31) 72.9 ± 12.5	(30) 66.6 ± 12.4	(17) 53.4 ± 10.7	(16) 94.8 ± 7.0
Happiness	(26) 90.3 ± 11.2	(27) 80.6 ± 20.0	(16) 89.5 ± 10.6	(12) 84.3 ± 20.7
7–10 y				
Upper	(83) 81.8 ± 15.0	(73) 75.1 ± 16.0	(50) 67.2 ± 18.2	(12) 96.2 ± 11.0
Transfers	(83) 90.2 ± 8.7	(73) 82.2 ± 10.6	(50) 62.2 ± 16.2	(12) 99.5 ± 1.2
Sports	(83) 69.4 ± 16.2	(73) 53.0 ± 16.5	(50) 36.9 ± 17.5	(12) 94.0 ± 9.7
Comf/Pain	(83) 81.5 ± 17.6	(73) 79.8 ± 19.8	(50) 82.2 ± 19.7	(12) 88.2 ± 20.9
Global	(83) 80.7 ± 10.2	(73) 72.5 ± 11.2	(50) 62.2 ± 13.2	(12) 94.4 ± 7.4
Happiness	(82) 76.5 ± 16.4	(73) 77.4 ± 18.5	(49) 78.5 ± 19.8	(12) 89.2 ± 18.9
11–14 y				
Upper	(80) 86.6 ± 11.0	(59) 77.6 ± 18.6	(32) 72.2 ± 18.0	(14) 98.9 ± 3.3
Transfers	(80) 91.7 ± 7.8	(59) 85.6 ± 9.2	(32) 70.5 ± 15.3	(14) 99.4 ± 1.3
Sports	(80) 68.5 ± 17.4	(59) 52.7 ± 16.6	(32) 35.2 ± 14.4	(14) 92.8 ± 10.9
Comf/Pain	(80) 78.8 ± 23.4	(59) 77.0 ± 25.3	(32) 74.8 ± 22.0	(14) 90.5 ± 15.3
Global	(80) 81.3 ± 11.3	(59) 73.3 ± 11.8	(32) 63.2 ± 12.0	(14) 95.4 ± 7.0
Happiness	(80) 72.9 ± 19.7	(59) 72.6 ± 17.6	(32) 74.5 ± 21.0	(14) 86.1 ± 18.9
15+ y				
Upper	(47) 90.9 ± 8.7	(34) 85.1 ± 13.8	(23) 79.6 ± 17.7	(14) 100 ± 0.0
Transfers	(47) 94.3 ± 7.1	(34) 81.9 ± 9.7	(23) 71.8 ± 17.4	(14) 100 ± 0.0
Sports	(47) 68.5 ± 17.6	(34) 46.0 ± 16.7	(23) 34.2 ± 18.5	(14) 98.1 ± 2.2
Comf/Pain	(47) 86.2 ± 17.6	(34) 73.5 ± 26.1	(23) 71.8 ± 25.0	(14) 91.7 ± 13.0
Global	(47) 85.0 ± 9.1	(34) 71.6 ± 12.0	(23) 64.3 ± 13.9	(14) 97.4 ± 3.5
Happiness	(47) 78.2 ± 16.5	(34) 70.9 ± 21.1	(23) 67.0 ± 22.4	(14) 92.1 ± 12.0

*The number of Parent PODCI scores available (n) are in parentheses. SDs follow the ± symbol.
†Data from Haynes and Sullivan[14] reanalyzed to fit the age categories of this study.
TD indicates typically developing children.

TABLE 3. Spearman ρ Correlations Between GMFCS Levels and Parent PODCI Scores

	ρ	P*
Upper	−0.305	***0.000***
Xfers	−0.609	***0.000***
Sports	−0.609	***0.000***
Comf/Pain	−0.072	0.087
Global	−0.525	***0.000***
Happiness	−0.001	0.981

*Statistically significant *P* values are bolded and italicized. *P* values reported as *0.000* represent values less than 0.0005.

of the PODCI measures at $P < 0.01$ and were not further analyzed. The GMFCS level × age interaction for Xfers was statistically significant, which suggests that the Xfers scores vary across ages at rates that are different for each of the 3 GMFCS levels. To appreciate differences in age groups and GMFCS levels, means and SDs for the baseline PODCI scores were stratified by these 2 variables (Table 2).

Using the follow-up data set, the linear mixed model was used to validate the reliability of the mean and SD baseline scores reported in Table 2. A time variable was created and coded as 1 for the 559 baseline evaluations and 2 for the 373 follow-up evaluations. Each of the 6 PODCI measures was assessed separately with time analyzed as a repeated measure; sex, GMFCS level, pattern of involvement, and PriorSxYN as fixed predictor variables; and age as a covariate. All main effects and all 2-way interactions with time were included in the analyses. The time main effects and interactions were the statistical tests of interest, with any statistical significance suggesting that results would have been different had the follow-up data set been used as primary. When the 6 time main effects and the 30 time 2-way interactions were examined, none were statistically significant (all $P > 0.01$), implying that the descriptive statistics, as reported in Table 2, are reliable. These results should not be interpreted as suggesting that there were no functional effects from surgical interventions, as this was not the intent nor the design of this study.

To examine the degree of sensitivity that PODCI exhibited in detecting different levels of severity, Spearman ρ correlations were produced between the GMFCS levels and baseline PODCI scores (Table 3), with Upper, Xfers, Sports, and Global exhibiting statistical significance. The list of significant PODCI measures is somewhat different from the list associated with GMFCS level as a predictor from the ANCOVAs because with the Spearman ρ calculation GMFCS level is treated as ordinal rather than categorical, and the analysis is bivariate as opposed to multivariate.

Linear regression equations for each of the Parent PODCI scores using age as a continuous variable and GMFCS level as a categorical variable were derived (Table 4). These equations can be used to calculate sets of predicted PODCI scores. A child's age and GMFCS level are inserted, with solutions representing that child's predicted scores for the Parent PODCI. The standard error of the estimate for each equation can be used as the SD, which, along with the predicted score, establishes a range in which the actual Parent PODCI score for the child may reside.

DISCUSSION

The intent of this study is to provide data which will allow clinicians to address the question, "How does a particular ambulatory child with CP compare to others of a similar age and level of severity on measures of real life function and happiness with physical state?" The Pediatric Outcomes Data Collection Instrument assesses the issues in question and is widely recognized for its contributions in assessing outcomes of children with CP.[2,4,5,15] The instrument yields scores representing 4 specific aspects of real life function, a composite score of function, and a score assessing happiness with the physical state. Each of the numeric measures is scaled such that the highest achievable value is 100. In an attempt to answer the above question, data in the form of means and SDs for the Parent PODCI measures by age group and GMFCS levels I through III are derived (Table 2).

This study represents a cross-sectional analysis of Parent PODCI scores for a population of children with GMFCS levels I through III. The subject group is considered consistent with that seen in centers caring for children with CP—some with prior musculoskeletal surgery and some without. Longitudinal Parent PODCI data were collected as a part of a much larger multifocus, multicenter study; however, the follow-up data were not used in the present study for comparisons of functional changes over time, but were used as a secondary cross-sectional data set for statistical validation of the primary PODCI scores.

For children without disabilities, Haynes and Sullivan[14] found that, for the 4 measures of function, typical scores from Parent PODCI reports range from the high 80s to the high 90s.

TABLE 4. Linear Regression Equations*

Upper	$63.061 + \text{Age} \times 1.772 - G_2 \times 6.631 - G_3 \times 13.004$	SEE = ±15.7
Xfers	$78.375 + \text{Age} \times 1.069 - G_2 \times 8.460 - G_3 \times 26.037$	SEE = ±11.9
Sports	$65.376 + \text{Age} \times 0.204 - G_2 \times 16.961 - G_3 \times 32.973$	SEE = ±16.7
Comf/Pain	$88.220 - \text{Age} \times 0.518 - G_2 \times 3.391 - G_3 \times 3.439$	SEE = ±21.0
Global	$73.768 + \text{Age} \times 0.614 - G_2 \times 8.840 - G_3 \times 18.819$	SEE = ±11.6
Happiness	$90.001 - \text{Age} \times 1.114 - G_2 \times 2.392 - G_3 \times 1.114$	SEE = ±18.5

*Age = actual age in years with decimal fraction, G_2 = GMFCS level II (0 = no, 1 = yes), G_3 = GMFCS level III (0 = no, 1 = yes). There is no G_1 since GMFCS level I is the default for the equations.

SEE indicates standard error of the estimate.

With respect to children with CP, before this study, expected ranges for PODCI measures and differences in scores attributable to age and severity level had not been reported. Sullivan et al[2] identified validity weaknesses with the Child PODCI when used in the population of ambulatory patients with CP; therefore, only Parent PODCI reports are examined in this analysis. In a recent work by Oeffinger et al,[3] which had no consideration of age differences, the Parent PODCI reports of Upper, Xfers, Sports, and Global for a large group of CP patients demonstrated direct relationships with changes in GMFCS levels I through III. A follow-up study by Bagley et al[4] found large effect size differences among GMFCS levels I through III for Sports and Global.

In the present analysis, GMFCS level is a significant predictor of Parent PODCI Xfers, Sports, and Global; and age is a significant predictor of Upper, Xfers, Global, and Happiness. In reference to Table 2, in which Parent PODCI scores are stratified by age groups and GMFCS levels, Upper and Xfers scores tend to increase for advancing age groups within each GMFCS level. The PODCI Sports measure appears to peak in the 11- to 14-year age bracket, declining thereafter, irrespective of GMFCS level. A possible explanation may be that, because of increased metabolic demands and general physical state, children with CP no longer are able to compensate sufficiently and therefore lack the capacity to stay abreast of their uninvolved peers as sporting activities advance in skill, strength, and endurance requirements.[19] It is also possible that parents of younger children may be imparting their emotion-laden expectations of sports function rather than more direct responses to PODCI Sports questions.

Comf/Pain scores show little change with advancing age, except for level III in which a steady decline occurs. Happiness scores decline with each advancing age group for all 3 GMFCS levels, except for level I at the group 15 years or older. Both observations are reflected by the negative signs for the age terms in the linear regression equations, as seen in Table 4. One could speculate that diminishing Happiness scores partially reflect the emotional turmoil often seen in typical children as they enter the preadolescent and adolescent age groups; however, this trend is not supported by data reported by Haynes and Sullivan[14] for their cohort of typically developing children. Another possible explanation is that, as children with CP age, they are struggling with the realities of their own physical performances as compared with their typically developing peers.[19] Perhaps, a more likely explanation is that, as expectations of functional improvements subside with each passing year, parents project their unhappiness over the realization that their children may have reached the upper limits of physical capacity.

Overall, the changes observed by age group in this study of children with CP mirror those observed by Daltroy et al[1] in their original report on the reliability, validity, and sensitivity to change of PODCI. These consistencies are notable, given that their study population was a heterogeneous group of patients, encompassing 138 different primary diagnoses affecting the musculoskeletal system. Age gradation in the 4 PODCI measures of function may represent true differences in the children's physical capacities or an age bias, in that activities assessed by PODCI may be more easily performed by older children. Daltroy et al also observed large SDs for all of the Parent PODCI measures in each of their 4 age groups. The same holds true in the present study with one difference: within the 4 measures of function, the reported SDs do not decrease with advancing age groups. The large SDs suggest a broad heterogeneity of functional abilities among the children within the different age brackets and GMFCS levels.

Pattern of involvement was analyzed as a potential predictor of function in this study, but it did not demonstrate statistical significance for any of the Parent PODCI measures at $P < 0.01$. A prior investigation by Damiano et al[20] compared functional profiles of children with hemiplegic CP and those with diplegic CP using PODCI as one of their studied outcome tools. Differences were noted between the 2 patient groups within GMFCS levels I ($P = 0.001$) and II ($P = 0.012$), in that the children with hemiplegia scored significantly lower in Upper function than did children with diplegia. Interestingly, pattern of involvement was not significantly related to levels of function in the present study ($P = 0.030$), although it would have been significant had statistical significance been set at $P < 0.05$.

Multivariate analyses were performed in this study, using age, GMFCS level, sex, PriorSxYN, and pattern of involvement as potential predictors of function, which test the effect of each potential predictor after the effects of other predictors have been removed (controlled). Combinations of other tested predictors may have partially accounted for PODCI score changes reported in the Damiano et al[20] study. The results of the present study indicate that, for the Parent PODCI responses, pattern of involvement is less important when attempting to compare functional levels with an age- and GMFCS-matched group of children.

For each of the measures related to physical function (Upper, Xfers, and Sports), the predicted scores decrease within individual age groups as the GMFCS level of severity increases, but Comf/Pain and Happiness scores change little within age groups with increasing GMFCS levels. Daltroy et al[1] also found that the measures related to physical function were sensitive to changes in severity gradation. From this, they speculated that the measures were sensitive to changes in function for individual patients. Using a correlational approach, the present study also found that the measures were sensitive to changes in severity gradation (as assessed by the GMFCS, limited to levels I through III).

Utilizing the results of this study as a comparative baseline, clinicians can be confident in using the Parent PODCI as an outcome tool for ambulatory children with CP. A limitation of this study is the exclusion of patients with CP at GMFCS levels IV and V; comparative baseline scores for the minimally and nonambulatory CP population would also be useful to the clinician. For clinicians, a data set of predicted Parent PODCI mean scores, stratified by age and GMFCS level, aids in determining how a given child should score as compared with his or her peers with CP. Outlier scores become evident and may trigger patient reassessment to determine potential causes and courses of action. Future study considerations may include the comparison of ambulatory children with CP who had surgical intervention to well-matched patients who received conservative treatment, using Parent PODCI scores as an assessment of outcomes.

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