# Concurrent Validity and Reliability of Retrospective Scoring of the Pediatric National Institutes of Health Stroke Scale

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***Background and Purpose***—The Pediatric National Institutes of Health Stroke Scale (PedNIHSS), an adaptation of the adult National Institutes of Health Stroke Scale, is a quantitative measure of stroke severity shown to be reliable when scored prospectively. The ability to calculate the PedNIHSS score retrospectively would be invaluable in the conduct of observational pediatric stroke studies. The study objective was to assess the concurrent validity and reliability of estimating the PedNIHSS score retrospectively from medical records.

***Methods***—Neurological examinations from medical records of 75 children enrolled in a prospective PedNIHSS validation study were photocopied. Four neurologists of varying training levels blinded to the prospective PedNIHSS scores reviewed the records and retrospectively assigned PedNIHSS scores. Retrospective scores were compared among raters and to the prospective scores.

***Results***—Total retrospective PedNIHSS scores correlated highly with total prospective scores ($R^2$=0.76). Interrater reliability for the total scores was "excellent" (intraclass correlation coefficient, 0.95; 95% CI, 0.94–0.97). Interrater reliability for individual test items was "substantial" or "excellent" for 14 of 15 items.

***Conclusions***—The PedNIHSS score can be scored retrospectively from medical records with a high degree of concurrent validity and reliability. This tool can be used to improve the quality of retrospective pediatric stroke studies. **(*Stroke*. 2012;43:341-345.)**

**Key Words:** arterial ischemic stroke ■ pediatric ■ NIH Stroke Scale



The National Institutes of Health Stroke Scale (NIHSS), a reliable quantitative measure of acute stroke severity in adults,[1] predicts stroke outcome at 7 and 90 days.[2] The adult NIHSS is the primary examination used for adult stroke research and acute treatment trials. This scale has enabled multicenter studies because the clinical stroke severity of various patients can be compared easily, even by practitioners other than neurologists.[3] Furthermore, the reliability and concurrent validity of estimating the adult NIHSS score from medical records retrospectively was first demonstrated using 39 subjects[4] and has been replicated.[5–8] These studies have been extremely useful, allowing researchers to quantify stroke severity when a prospective NIHSS score was not recorded.[9,10]

Children were not included in the initial validation study of the NIHSS. A study to determine the validity and utility of a

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pediatric adaptation of the NIHSS, the Pediatric NIH Stroke Scale (PedNIHSS), closed its enrollment in 2009. Modification of the NIHSS for pediatric use is crucial because the neurological examination of children varies significantly by age and development. The PedNIHSS has the same examination elements as the adult scale including 11 neurological domains and 15 scored items. The PedNIHSS (for children aged 2–18 years) adapts the tasks the child performs so that they are appropriate for the child's age and development. The total score for the PedNIHSS ranges from 0 (least severe) to 42 (most severe).[11]

The PedNIHSS validation study was prospective with scores determined during hospitalization for the acute stroke.[11] Many studies on pediatric stroke, including population-based studies from which stroke incidences in developed countries have been estimated, are retrospective. Retrospective pediatric stroke studies are limited because comparison of children's clinical stroke severity across centers and even within centers cannot be done quantitatively. The ability to assess the PedNIHSS score retrospectively would allow investigators to use this quantitative measure even when a study design is retrospective or when the PedNIHSS score is missing during prospective studies, thereby improving the validity of study findings. However, the concurrent validity and reliability of calculating the PedNIHSS score retrospectively using medical records are untested.

## Materials and Methods

### Study Design

This was a cross-sectional study comparing PedNIHSS scores derived retrospectively from neurological examinations documented in the medical record with PedNIHSS scores assigned prospectively in the parent study.[11]

### Inclusion Criteria

All sites participating in the parent study were invited to participate in the current study, and all subjects enrolled in the parent study with a neurological examination documented in the medical record were eligible for the current study. The methods of the parent study are described elsewhere, and consent from the parent or legal guardian of the child was obtained.[11] Enrollment in the parent study required definite arterial ischemic stroke based on criteria for the International Pediatric Stroke Study. The criteria consist of an acute neurological deficit and corresponding imaging findings of focal infarct conforming to an established arterial territory.[12] This study was approved by the local Institutional Review Board at each site.

### Study Population and Sites

The population for the current study was comprised of 75 children enrolled from the following 9 sites: Children's Medical Center Dallas (Dallas, TX, 26), The Children's Hospital of Philadelphia (Philadelphia, PA, 16), The Hospital for Sick Children (Toronto, Ontario, Canada, 13), The Cleveland Clinic Children's Hospital (Cleveland, OH, 5), Nationwide Children's Hospital (Columbus, OH, 4), The Children's Hospital (Denver, CO, 4), The Children's Hospital of Pittsburgh (Pittsburgh, PA, 4), Alberta Children's Hospital (Calgary, Alberta, Canada, 2), and The Johns Hopkins Children's Center (Baltimore, MD, 1). All sites are tertiary care centers affiliated with universities and have established pediatric stroke programs. All prospective PedNIHSS scores were performed by a study pediatric stroke neurology attending physician or stroke fellow. The Children's Hospital of Philadelphia was the coordinating center.

### Study Procedure

#### *Medical Record Preparation*

A study coordinator at each site photocopied the first neurological examination documented by a neurologist or neurologist-in-training. Of the 75 subjects in this study, 36 neurological examinations documented in the medical record (48%) were performed by a general pediatric neurologist who was not the stroke neurologist performing the prospective PedNIHSS score, and 39 (52%) were performed by the pediatric stroke neurologist who also performed the prospective PedNIHSS. Of the 36 subjects in whom the neurological examination was performed by a general neurologist and not the stroke neurologist who performed the prospective PedNIHSS score, 22 (29% of all subjects) were performed before the subject was enrolled in the parent study**.** Identifying patient information was removed at the enrolling site. The Children's Hospital of Philadelphia study coordinator (R.A.B.) read through each neurological examination, removed any references to the prospectively assigned scores, and photocopied the examination for each of the 4 raters. A random number generator was used to order the subject neurological examinations, so each rater scored the 75 examinations in the same order to limit variability for each subject due to rater experience. The initial PedNIHSS score from the parent study served as the reference criterion for each subject in the concurrent validity analysis.

#### *Rater Training*

Four raters from The Children's Hospital of Philadelphia and The University of Pennsylvania Neurology Departments with varying levels of clinical training were blinded to the prospectively assigned PedNIHSS scores. The raters included a pediatric stroke attending (S.E.S.), an adult stroke attending (M.T.M.), a pediatric stroke fellow (L.A.B.), and a child neurology resident (M.P.K.). The raters attended a training session with the principal investigator of the parent study (R.N.I.). Detailed instructions on how to translate information from the medical record into scores were provided at the training session. If an item was not recorded in the medical record, it was scored as 0 (normal) as was done in past adult studies (see Online Appendix; http://stroke.ahajournals.org).[5] Every rater recorded whether each item was documented. Study data were entered into a database by L.A.B. and were reviewed for accuracy by The Children's Hospital of Philadelphia study coordinator (R.A.B.).

### Statistical Analyses

Descriptive statistics were performed using frequency distributions and proportions for categorical variables and means with SDs or medians with interquartile ranges for continuous variables. Linear regression was performed to determine the correlation of the estimated PedNIHSS scores with the prospectively assigned scores clustered by subject because the 4 estimates obtained by the 4 raters for each subject were not independent. The parameter $R^2$ was reported as the measure of concurrent validity. Age at the time of the stroke and the time difference between the prospective scores and neurological examination recorded in the medical record were examined as covariates. Linear regression analysis was also done for each rater. A subanalysis was performed to assess the correlation of the estimated PedNIHSS scores with the prospectively assigned scores for the 22 subjects in whom the neurological examination was documented by a nonstroke neurologist before the subject was enrolled in the parent study. Using a predetermined threshold based on categorizations in the original adult retrospective NIHSS scoring study,[4] the sensitivity and specificity for correctly scoring a total PedNIHSS that had been prospectively scored as $\leq 5$ were calculated with their 95% CIs using MedCalc Version 11.5.1 (MedCalc Software, Mariakerke, Belgium). Since the total NIHSS score is generally used as a continuous measure, interrater reliability of the estimated total scores was determined by the calculation of an intraclass correlation coefficient (ICC) using 1-way analysis of variance. A subanalysis was performed to assess the reliability of the 4 raters' retrospective scores for the 22 subjects in whom the neurological examination was documented by a nonstroke neurologist before the subject was enrolled in the parent study. Subanalyses

were performed on the 15 items' scores using a weighted $\kappa$ statistic because the item scores are categorical using SAS 9.2 macro (SAS Institute Inc, Cary, NC). A $\kappa$ or ICC was considered moderate agreement if 0.41 to 0.60, substantial agreement if 0.61 to 0.80, and almost perfect (excellent) if 0.81 to 1.00.[13] A 2-sided probability value of $<0.05$ was considered significant. STATA Version 11.1 (STATA Corporation, College Station, TX) was used for regression analysis and ICC analysis.

## Results

### Subject Characteristics

Nine of 15 centers (60%) participating in the parent prospective study agreed to enroll their subjects in the current study. All subjects from the 9 centers were enrolled in the current study with the exception of 1 subject for whom the neurological examination in the medical record could not be located. Therefore, 75 of 113 children (66.4%) from the parent study (66.4%) were included. Forty-five subjects (60%) were male. Racial distribution was 56 white (8 Hispanic), 11 black or African American, 6 Asian, 1 mixed race, and 1 of unknown race (Hispanic). The mean and median ages of the participants were 9.7 years (SD, 5.5 years) and 9.2 years (interquartile range, 4.5–15.6 years), respectively. There were no significant differences between the 75 subjects enrolled in the study and the 38 subjects who were not enrolled on the basis of median prospective PedNIHSS total score, age at presentation, or sex (data not shown).

### Concurrent Validity of Retrospective Scores With Prospective Scores

The mean and median total prospective and retrospective PedNIHSS scores were not different for the 75 subjects ($P=0.49$ Student $t$ test; $P=0.37$ Wilcoxon rank sum). The mean prospective total PedNIHSS score for the 75 participating children was 8.2 (SD, 7) with a median of 6 (interquartile range, 3–12), and the mean total retrospective PedNIHSS score was 7.6 (SD, 7) with a median of 5 (interquartile range, 3–11). In regression analysis, $R^2$ for the retrospective estimations of the total scores and the prospectively assigned total scores was 0.76, slope 0.87 (95% CI, 0.77–0.97), intercept 1.62, and $P<0.001$. The mean and median time difference between the performance of the prospective PedNIHSS score and the neurological examination documented in the medical record were 6.8 hours (SD, 12.8 hours) and 1 hour (interquartile range, 0.25–9 hours), respectively. Neither age at the time of the stroke nor time difference between the prospective score and the neurological examination recorded in the medical record altered the observed $R^2$ (not shown). The $R^2$ for each of the 4 raters' retrospectively estimated total scores versus the prospectively assigned total scores ranged from 0.73 to 0.83. Figure 1 demonstrates a scatterplot of the prospective total PedNIHSS scores versus the retrospective total PedNIHSS scores by rater. Two hundred sixty-eight of 300 retrospective total scores (89%) were within 5 points of the prospectively scored totals. The sensitivity and specificity for the raters correctly scoring a total PedNIHSS that had been prospectively scored as $\leq 5$ were 87% (95% CI, 81%–92%) and 81% (95% CI, 74%–87%), respectively. In the subanalysis on the 22 subjects whose neurological examination in the chart was performed before parent study enrollment and in whom the neurological examination was performed by a general pediatric neurologist who was not the pediatric stroke neurologist who performed the prospective PedNIHSS, the $R^2$ was 0.85, slope 0.88 (95% CI, 0.77–1.00), intercept 1.44, and $P<0.001$.

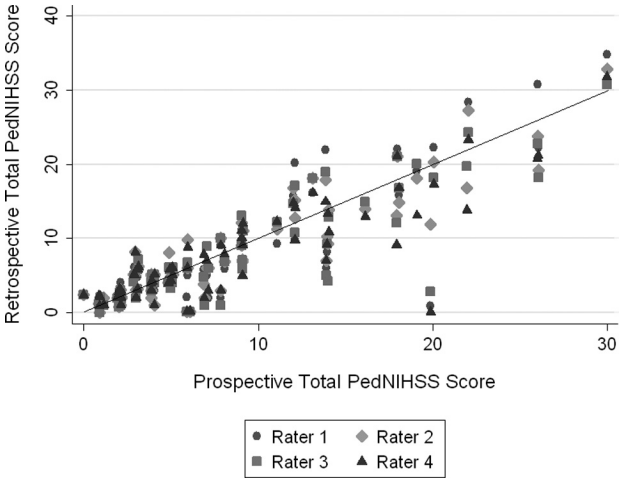


**Figure 1.** Scatterplot of prospective total Pediatric National Institutes of Health Stroke Scale (PedNIHSS) score vs retrospective total PedNIHSS score for the 4 raters. Line represents reference with slope of 1.

### Interrater Reliability of Retrospective Scores

For the total score, the ICC was 0.95 (95% exact CI, 0.94–0.99). Figure 2 demonstrates box plots of the distribution of the retrospectively estimated total PedNIHSS scores for each rater, indicating that the 4 raters' total scores were comparable. The weighted $\kappa$ for the item scores ranged from 0.47 to 0.93 (Table). The ICC was 0.95 (95% exact CI, 0.90–0.98) in the subanalysis on the 22 patients in whom the neurological examination was documented before parent

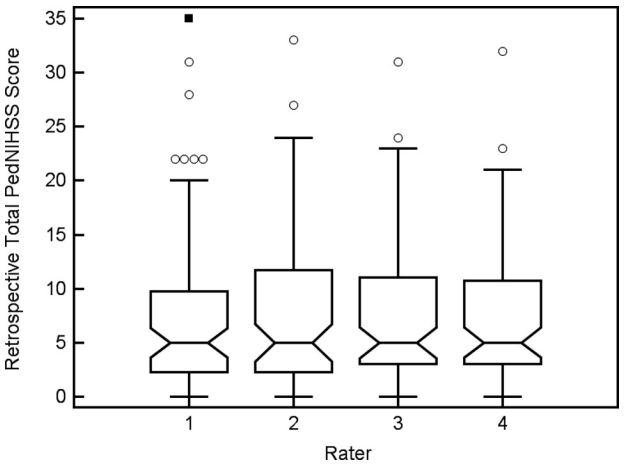


**Figure 2.** Box plots of distributions of retrospective total Pediatric National Institutes of Health Stroke Scale (PedNIHSS) scores for each rater. Lower and upper boundaries represent the 25th and 75th percentiles. The central line represents the median. The circles represent outliers, defined as those scores farther away from the box than 1.5 times the interquartile range. The square is an extreme outlier, defined as a score farther away from the box than 3 times the interquartile range. Whiskers represent the largest and smallest nonoutlying scores.

**Table. Agreement Among 4 Raters by Individual Retrospectively Scored Pediatric National Institutes of Health Stroke Scale Item**

| Item | Weighted Kappa | 95% CI for Kappa | No. (%) of Items Undocumented* |
|---|---|---|---|
| 1a. LOC | 0.82 | 0.76–0.87 | 1 (1.3%) |
| 1b. LOC questions | 0.77 | 0.69–0.83 | 3 (4%) |
| 1c. LOC commands | 0.71 | 0.62–0.79 | 6 (8%) |
| 2. Best gaze | 0.83 | 0.78–0.88 | 6 (8%) |
| 3. Visual | 0.47 | 0.35–0.59 | 18 (24%) |
| 4. Facial palsy | 0.84 | 0.79–0.89 | 2 (2.7%) |
| 5a. Motor arm left | 0.93 | 0.90–0.95 | 2 (2.7%) |
| 5b. Motor arm right | 0.93 | 0.91–0.95 | 0 (0%) |
| 6a. Motor leg left | 0.89 | 0.85–0.92 | 3 (4%) |
| 6b. Motor leg right | 0.91 | 0.87–0.94 | 0 (0%) |
| 7. Limb ataxia | 0.87 | 0.83–0.91 | 11 (14.7%) |
| 8. Sensory | 0.72 | 0.63–0.79 | 8 (10.7%) |
| 9. Best language | 0.83 | 0.77–0.88 | 9 (12%) |
| 10. Dysarthria | 0.86 | 0.80–0.90 | 14 (18.7%) |
| 11. Extinction/ inattention | 0.77 | 0.69–0.83 | 31 (41.3%) |

LOC indicates level of consciousness.
*No. of charts in which item not documented (total charts=75).

study enrollment by a nonstroke neurologist different from the pediatric stroke neurologist who performed the prospective PedNIHSS.

## Discussion

Retrospective studies have been critical in the field of pediatric stroke, but a limitation has been the inability to measure and then adjust for initial clinical stroke severity. The results of this study demonstrate that the PedNIHSS score can be assessed retrospectively from neurological examinations found in the medical record with excellent concurrent validity and interrater reliability. Our ICC for the total PedNIHSS score among the 4 raters was 0.95, which compares favorably to the ICC of 0.82 previously reported for retrospective assessment of the NIHSS in adults[4] and to the ICC of 0.99 obtained in the prospective pediatric study.[11] Compared with the weighted $\kappa$ for the item scores from the prospective pediatric study, our weighted $\kappa$ for all items were similar except for the visual item (3).[11] There was 100% agreement on the visual performance item in the prospective study, whereas in the retrospective study, this item had poorest agreement ($\kappa$=0.47). On inspection of the 4 raters' scores for this item, there were 6 instances in which 1 rater recorded a 3 (bilateral hemianopia), whereas the other raters recorded 0 (normal). These were subjects who had severe strokes with poor mental status. This scenario was perhaps more difficult to score because the directions for the prospective PedNIHSS score indicate that a comatose subject should be scored as a 3 for visual fields, whereas our algorithm indicated that items not clearly documented should be scored as 0.[11] Although the reliability for the visual item was only moderate, the ICC for the overall score was excellent. We therefore would not alter the retrospective scoring method to improve the interrater reliability of this single item.

The current study has several potential limitations. Although not all subjects in the parent study were enrolled in this ancillary study, subjects who were enrolled did not differ from those not enrolled with respect to age, sex, and prospective PedNIHSS total score. All study subjects presented to tertiary care hospitals and were enrolled in a single clinical trial in which the PedNIHSS was tested as a research tool. It is not possible to determine if documentation practices in the medical record were altered based on enrollment. Some neurologists may have documented examinations either more or less carefully due to subject participation in the parent study. Notably, the PedNIHSS score form for the study was not a part of the medical record and was not documented in the medical record in most cases. Nonetheless, if participation in the study increased the degree of documentation in the medical chart compared with documentation practices in patients not enrolled in the study, our reliability estimates or the concurrent validity estimate may have been increased. However, our excellent reliability estimate (ICC, 0.95) and concurrent validity estimate ($R^2$=0.85) from the subanalysis on 22 subjects whose neurological examination was documented before enrollment in the parent study and by a general pediatric neurologist who was not the pediatric stroke neurologist who performed the prospective PedNIHSS score suggests that documentation practices in the chart may largely have been unchanged. Furthermore, the fact that the neurological examination corresponding to 3 different PedNIHSS score items was not documented in the medical records of >15% of the subjects suggests that documentation practices in the medical record may not have been altered by subject participation in the parent study. Most pediatric strokes are mild to moderate (median prospective total score 6), and only 7 subjects had prospective total PedNIHSS scores ≥20. Therefore, extrapolation of the concurrent validity and reliability of the retrospective scoring method to scores in the upper range for the total PedNIHSS score may need additional study. Additionally, the study findings cannot be extrapolated to raters who are nonneurologist physicians, nurses, and research coordinators or to neurological examinations documented by nonneurologists. Replication of the study involving such raters who have other training, in patients whose neurological examinations were documented by practitioners other than neurologists, and in patients who are not enrolled in the prospective PedNIHSS validation study would be useful to expand the use of the retrospective estimation of the PedNIHSS score. Nevertheless, our study results are strengthened by including raters at various stages in their neurology training and by our inclusion of subjects from 9 geographically diverse centers. Both of these factors increase the generalizability of our results. Despite possible limitations, our results demonstrate that the PedNIHSS score can be scored retrospectively from medical records.

## Conclusions

Stroke in children is uncommon[14,15] with diverse and often multiple etiologies,[16] and the predictors of outcome are poorly understood. Although we hope that the PedNIHSS

score will become part of the routine examination for childhood stroke patients, scoring the PedNIHSS from medical records retrospectively is valid and reliable. The ability to assess and control for initial stroke severity will facilitate potential retrospective studies and even prospective studies with missing data on the PedNIHSS score that could provide essential information about pathophysiology, clinical course, and outcomes of pediatric stroke.

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## Disclosures

R.N.I. is a consultant/advisory board member, Berlin Heart Clinical Event Committee. L.C.J. is a consultant/advisory board member, Berlin Heart Clinical Event Committee.

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