Reliability and validity of the pediatric posterior drooling scale

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English Summary

Title Reliability and validity of the Pediatric Posterior Drooling Scale

Background Drooling is a frequent problem in children with neurological disabilities. Drooling can be distinguished in anterior and posterior. Posterior drooling is described as saliva dripping into the pharynx, creating a risk of aspiration which can lead to substantial respiratory morbidity. Valid and reliable diagnostics are needed, but not yet available. Therefore, the Pediatric Posterior Drooling Scale (PPDS) is developed, but its psychometric properties are unknown.

Research question What is the intra-rater, inter-rater, test-retest reliability and construct validity of the PPDS?

Methods This cross-sectional study included 56 children aged 1-18 years with central neurological diseases. Reliability was determined by the intraclass correlation coefficient (ICC). Validity was determined by Spearmans rho correlation, using the Functional Oral Intake Scale (FOIS) for children and, in case of cerebral palsy, complemented with the Eating and Drinking Ability Classification System (EDACS).

Results A good intra- (ICC = 0.86, p < 0.01) and inter-rater reliability (ICC = 0.81, p < 0.01) was found. The test-retest reliability was poor (ICC = 0.01, p = 0.48). Construct validity showed a low, negative correlation with the FOIS (r = -0.34, p = 0.01) and a moderate, positive correlation with the EDACS (r = 0.67, p < 0.01).

Conclusion This study was the first to apply the newly developed PPDS to a representative population-based sample. The good intra- and inter-rater reliability indicates that the PPDS can be used as pre-/post assessment for treatment of posterior drooling in clinical practice and future research.

Recommendations A proposal for an adjusted PPDS and its protocol is made. Multiple testing with the PPDS is needed when diagnosing posterior drooling taking the low test-retest reliability into account.

Keywords Pediatric Posterior Drooling Scale, posterior drooling, reliability, validity, central nervous system diseases

Dutch Summary

Titel Betrouwbaarheid en validiteit van de Pediatric Posterior Drooling Scale

Achtergrond Speekselverlies is een veelvoorkomend probleem bij kinderen met neurologische aandoeningen. Er zijn twee varianten speekselverlies: anterieur en posterieur. Bij posterieur speekselverlies druppelt het speeksel in de farynx, wat een risico op aspiratie creëert en kan leiden voor aanzienlijke ademhalingsproblemen. Valide en betrouwbare diagnostiek is nodig, maar nog niet beschikbaar. Daarom is de Pediatric Posterior Drooling Scale (PPDS) ontwikkeld, maar over de klinimetrische eigenschappen is nog niets bekend.

Onderzoeksvraag Wat is de intrabeoordelaars-, interbeoordelaars-, test-hertest betrouwbaarheid en de construct validiteit van de PPDS?

Methode Deze cross-sectionele studie heeft 56 kinderen geïncludeerd, in de leeftijd 1-18 gediagnosticeerd met centraal neurologisch aandoeningen. Betrouwbaarheid is berekend met de intraclass correlatie coëfficiënt (ICC). Validiteit (berekend met Spearmans rho correlatie) is bepaald met de Functional Oral Intake Scale (FOIS) voor kinderen en, als er sprake was van Cerebrale Parese, met de Eating and Drinking Ability Classification System (EDACS).

Resultaten Een significante, goede intra- (ICC = 0.86) en interbeoordelaarsbetrouwbaarheid (ICC = 0.81) is gevonden. De test-hertest betrouwbaarheid was niet significant en laag (ICC = 0.01). Construct validiteit toonde een significante, lage, negatieve correlatie met de FOIS (r = -0.34) en een significante, matige, positieve correlatie met de EDACS (r = 0.67).

Conclusie Dit was de eerste studie die de PPDS heeft gebruikt in een representatieve onderzoekspopulatie. De goede intra- en interbeoordelaarsbetrouwbaarheid geeft aan dat de PPDS gebruikt kan worden als voor-/nameting bij behandeling van posterieur speekselverlies in de klinische praktijk en toekomstig onderzoek.

Aanbevelingen Op basis van deze studie is de PPDS en het protocol aangepast. Het is belangrijk om een kind meervoudig te testen met de PPDS om de diagnose posterieur speekselverlies vast te stellen, vanwege de lage test-hertest betrouwbaarheid.

Trefwoorden Pediatric Posterior Drooling Scale, posterieur speekeslverlies, betrouwbaarheid, validiteit, centraal neurologische aandoeningen

Introduction

Drooling is the unintentional loss of saliva from the mouth and is a normal phenomenon in the development during childhood until the age of four (1-3). Control of saliva is associated with physical growth and the maturation of sensory and motor functions (3). In children with neurological disabilities, drooling can be a result of impaired oral motor functioning, a reduced frequency of swallowing, and the inability to maintain an upright position of the head and trunk (4). In children with cerebral palsy (CP), drooling is described in 58% of the children (5). Two types of drooling can be differentiated: anterior and posterior. Anterior drooling is described as the unintentional loss of saliva from the mouth, while posterior drooling is described as saliva dripping into the pharynx (6,7). The cause is an impaired or missing trigger to swallow due to the lack of motor control affecting swallowing coordination (6–8).

Posterior drooling is mainly caused by coordination problems and is highly correlated with dysphagia (8,9). Therefore, it is expected that posterior drooling occurs mostly in children with central neurological disabilities, whereas swallowing problems are characterized by coordination problems, and not children with peripheral neurological impairments, whereas muscle weakness is the cause. Prevalence of posterior drooling is unknown, but oropharyngeal dysphagia is present in 2 out of 3 children with CP (7,10). In case of posterior drooling, the pharyngeal phase of swallowing is affected. On that account, posterior drooling is highly correlated with aspiration, which can lead to substantial respiratory morbidity (6,7,11).

To be able to treat these children effectively, valid and reliable diagnostic tools are needed. While validated instruments are available to measure anterior drooling, no validated instruments are available to detect or to measure the severity of posterior drooling (12,13). Such an instrument is needed to measure whether intervention for posterior drooling is required, and to evaluate the effect of the intervention. Moreover, it can be used to acquire prevalence numbers of posterior drooling.

The Radboud University Medical Center (Radboudumc), the Netherlands, developed the Pediatric Posterior Drooling Scale (PPDS) (14). The PPDS is a screening tool to score the presence and severity of posterior drooling on a five-point scale by using cervical auscultation (CA). Previous research showed that CA may be used to detect swallowing, evaluate post-swallow respiration and gain information about swallowing frequency (15). A pilot study with the PPDS showed an excellent inter-rater reliability, but assessment in a larger sample is needed to confirm or disprove these findings (14). Furthermore, intra-rater and test-retest reliability were not assessed. Information about the latter two is especially important to be able

to use the PPDS in the clinical care and to follow up posterior drooling and during its treatment. Hence, a good intra-rater and test-retest reliability is needed.

The aforementioned pilot study showed sufficient construct validity as well (14). To measure construct validity the PPDS was compared to the Eating and Drinking Ability Classification System (EDACS). The EDACS is a valid and reliable classification system for children with CP. It describes five distinct levels of ability, using the key features of safety and efficiency of eating and drinking. The lowest score (I) indicates the ability to eat and drink safe and efficient, whereas the highest score (V) indicates no ability to eat and drink safe and efficient (16,17). Comparing the PPDS with another instrument for posterior drooling was not possible, because the PPDS is the first developed tool to measure posterior drooling. Because dysphagia is correlated with drooling, an instrument for dysphagia was chosen in the pilot study (9,14). However, the EDACS is developed for children with CP and is not applicable for children with other central neurological disorders. To measure construct validity in a larger and various group of children with central neurological disorders, the PPDS needs to be compared with a different instrument for dysphagia, for example the Functional Oral Intake Scale (FOIS) (18). This valid and reliable instrument for adults is adapted for pediatrics and shows signs of a high inter-rater reliability (19,20). The lowest score (1) indicates an intake of nothing per os, whereas the highest score indicates (6) a normal intake compared with children of the same age.

The aim of this study is to test the reliability and validity of the PPDS in a larger and heterogeneous group of children with central neurological disabilities (aged 0-18 years). This study is focused on the intra-rater, the inter-rater, the test-retest reliability, and the construct validity of the PPDS, in terms of the correlation between the PPDS-score and the score on the FOIS and/or the EDACS-level (the FOIS is used in all children and the EDACS complementary for children with CP diagnosis).

Methods

The design of this study is cross-sectional, examining the psychometric properties of the PPDS. This study was conducted between January 2019 and June of 2019.

Study population

Children aged 1-18 years with central neurological impairments receiving speech-language therapy at the Radboudumc or Rijndam Rehabilitation center were included. The population of central neurological impairments were clustered in three diagnoses groups: 1) CP, 2) acquired brain injury and, 3) other (e.g. syndromes or no diagnosis). A total of 50 children were aspired for inclusion because this is the advised number for measuring reliability and construct validity (21). The Speech-Language Therapists (SLTs) of the children approached the parents and children for consent.

Data collection

After the parents and the participant were informed and gave their consent, they were asked to fill in a questionnaire including posterior drooling related health outcomes, Appendix 1 (22). The PPDS (Figure 1) was conducted during a speech-language therapy session by one of the researchers trained in the performance of CA with the assistance of the concerned SLT. The PPDS was scored based on CA. The researcher listened to the quality of breathing and swallowing of the child using a stethoscope. The stethoscope was placed on the lateral side of the larynx and a recording was made with a voice recorder. The microphones of the voice recorder were put on earpieces of the stethoscope so the sound of the stethoscope was directly recorded. If the participant did not swallow within two minutes, the recording was stopped. The PPDS assessment was done at least one hour after a meal to prevent any influence of dysphagia on the quality of breath.

Figure 1

The PPDS was scored afterwards by the researcher who made the recording. A second researcher also scored the PPDS, based on the recording made by the first researcher, to assess the inter-rater reliability. For the intra-rater reliability, the PPDS was scored again after two weeks by the first researcher based on the recording. One of the two researchers is an expert on (posterior) drooling and the other researcher is a trained SLT.

Four weeks after the initial PPDS examination, the PPDS was conducted again on the children for the test-retest reliability. The latter was only conducted on children from Rijndam

Rehabilitation center, because children are seen on weekly basis in this center. In Radboudumc the children are visiting different outpatient clinics (drooling team, swallowing team or other multidisciplinary outpatient clinics) of the hospital, where they only have one appointment with the SLT.

Moreover, the SLT of the child rated the FOIS, to enable comparison of the scores with the PPDS for construct validity. In case of a diagnosis of CP, the EDACS was rated in addition to the FOIS.

Statistical analysis

Data were analyzed using IBM SPSS Statistics 24. Descriptive statistics were used to describe participant characteristics (age, gender and diagnosis) and the data of the questionnaire (Appendix 1). Inter-rater, intra-rater and test-retest reliability of the PPDS scores were assessed with an intraclass correlation coefficient (ICC). For the inter-rater reliability, a two-way random-effects model with single measurement and absolute agreement was used. For the intra-rater and test-retest reliability, a two-way mixed-effects model with single measurement and absolute agreement was used (23). Construct validity was determined by calculating the correlation between the scores on the PPDS and the FOIS. In case of a diagnosis of CP, a correlation with the scores of the EDACS was calculated also. The PPDS, FOIS and EDACS are ordinal scores, so the test Spearman's rho was used (24). The hypothesis is a high correlation between the FOIS/EDACS levels and the PPDS.

Ethics

This study is conducted according to the principles of the Declaration of Helsinki (25). The Medical Research Involving Human Subjects Act was not applicable in accordance with the research ethics committee of the Radboud University Nijmegen Medical Center (File number CMO: 2018-4690). This study included minors, whereby the code of conduct relating to expressions of objection by minors participating in medical research was applicable (26). No benefits and/or risks were associated with participating in this study and the burden was minimal, because the assessment is part of the usual SLT care. A compensation for injury was not available, because no risks are related to this study. Incentives are not applicable.

The recordings were irreducible to the children and got a code, which was listed in a separate code list per center. Handling and storage of collected data was in accordance with the General Date Protection Regulation (AVG) and Dutch Act on Implementation of the General Data Protection Regulation (UAVG). Data are saved for a period of 15 years, which is stated in the

Law for the protection of personal information of the Netherlands and the privacy regulations of the two centers.

Results

Participant characteristics

A total of 56 cases were included in this study; 44 at Rijndam Rehabilitation center and 12 at Radboudumc. The age of the participants ranged between 1-17 years with a mean of 8 years. The participants population compasses 43 boys and 13 girls. The participant's characteristics and information of the questionnaire filled in by the parents are presented in table 1.

In two cases it was not possible to make the recording. One of the two participants refused to undergo the PPDS assessment. This case was excluded from the analyses. In the other case, it was possible for the researcher to listen with the stethoscope and score the PPDS, but it was not possible to make the recording needed for intra-rater and inter-rater agreement. This case was excluded from the reliability analyses, but included in the validity analyses. A second assessment of all children from Rijndam Rehabilitation center for test-retest reliability was not possible due to the limited timeframe of this study.

Table 1

Reliability

The intra-rater and inter-rater reliability was calculated over 54 cases. The intra-rater reliability was significant (p < 0.01) with an ICC of 0.86 (95% CI 0.76 – 0.91). Hence, the intra-rater reliability can be described as good. The ICC calculation for inter-rater reliability was also significant (p < 0.01). An ICC of 0.81 (95% CI 0.69 – 0.88) showed a good inter-rater reliability between the trained SLT and the expert. Test-retest reliability was calculated over 21 cases. The test-retest reliability analysis was not significant (p = 0.48) and found a poor test-retest reliability of 0.01 (95% CI -0.40 – 0.43). All assessments are displayed in table 2. The blue shading indicates perfect agreement between the two raters or ratings. Noteworthy is the distribution of the assessments. Most of the children scored the lowest PPDS score (0).

Table 2

Validity

Construct validity calculations were conducted with the FOIS scores and the EDACS scores separately. Due to one missing PPDS assessment, the validity analysis with the FOIS was calculated over 55 cases. The validity analysis with the EDACS was calculated over the 24 cases with a CP diagnosis. Calculations for construct validity with the FOIS showed a significant correlation between the PPDS scores and the FOIS scores (p = 0.01). It was a low,

negative correlation of -0.34. Calculations for construct validity with the EDACS showed a moderate correlation of 0.67, which was significant (p < 0.01). All scores are displayed in table 3. The blue shading indicates a perfect accordance between the scales.

Table 3

Discussion

The aim of this study was to investigate the intra-rater, inter-rater, and test-retest reliability and the construct validity of the PPDS. The intra-rater and the inter-rater reliability of the PPDS was significant and good. A poor, not significant test-retest reliability was found. Two significant correlations were found for construct validity: A low, negative correlation with the FOIS and a moderate, positive correlation with the EDACS. This is the first study to apply the newly developed PPDS to a representative population-based sample.

The PPDS was applied before in a pilot study with a small sample. In this pilot study, similar results were found; a good inter-rater reliability (14). These findings are in contrast with the inter-rater reliability for CA, which is remarkable because the PPDS is scored with CA. The systematic review of Lagarde et al. showed that the inter-rater reliability of CA is described as poor to fair in various studies (15). The inter-rater reliability differs for detecting 'normality', 'aspiration' or 'dysphagia' as outcome. A possible explanation is the clear definitions of each PPDS level. Unclear definitions and consensus about the definitions is a problem in CA (15). Noteworthy is the distribution of the PPDS scores. Most of the children scored the lowest PPDS score; i.e. 0. This score indicates a clear breath before and after the swallow, which is no indication of posterior drooling. Some studies in the systematic review of Lagarde et al. describe a higher specificity than sensitivity for CA, which would make it easier to identify a score of 0 in the PPDS than any other score (15,27,28). Due to the high number of 0-scores, this could result in high reliability scores. However, other studies claim that sensitivity is higher than the specificity in CA, which contradicts the former statement (15,29,30).

The pilot study, where the PPDS was first applied, also studied the construct validity. They found a moderate correlation between the PPDS and the EDACS, which is similar to the results found in this study (14). This study, however, made an addition to the construct validity analysis by calculating the correlation between the PPDS and the FOIS, which was found to be low. These moderate and low correlations with the PPDS can be explained by the fact that these different scales do not investigate the same problems. Posterior drooling is a pharyngeal problem. The FOIS is a scale that measures functional oral intake as indicator for dysphagia. Many problems can cause change in the consistency of a patient's intake consistency, which does not have to include pharyngeal problems. The same applies to the EDACS, which measures the safety and efficiency of eating and drinking. Eating and drinking can be safe but non-efficient. A patient scores a higher EDACS level, when no pharyngeal problems, and thus no posterior drooling, are present. This influenced the correlation. To measure construct validity for the PPDS, a comparison with an instrument focused on pharyngeal problems is

needed, for example videofluoroscopic swallow study or fiberoptic endoscopic evaluation of swallowing.

Next to the correlation between the PPDS and the FOIS, this study also adds the results of the test-retest reliability to current knowledge. The meaning of these results are uncertain. The poor test-retest reliability is likely caused by the low sample size. The used analysis, ICC, does not work well with low sample sizes, which could be the cause of the poor test-retest reliability. When analyzing the data in qualitative way, a high agreement between the first and the second ratings is observed (16 of the 21 cases). Based on these findings, a good test-retest reliability is hypothesized when tested in a lager sample. However, the variability of the PPDS scores was low. Most of the measurements got the lowest PPDS score (0). In the other PPDS scores no agreement was observed. It is possible that a good test-retest reliability would be found in the lowest PPDS score, but not in the other scores of the PPDS. The latter would mean that the grade of posterior drooling differs over time. Future research should explore this.

Apart from of the lower sample in the test-retest reliability analyses, the minimum of 50 participants was reached in the other analysis. This minimum is appropriate for analysis of reliability and validity to lead to sufficient power of the results (21). Another strength of this study is the addition of trained SLTs to the group of raters. In the pilot study the raters were all experts of the same center. The addition of the trained SLTs make the results from this study generalizable to a larger group. The group of expert raters is small, but the group of experts complemented with trained SLTs is a larger group of raters. The results cannot be generalized to the whole population of SLTs. The training in CA is needed to use the PPDS correctly. A high sensitivity and specificity in CA is only reached when the raters reach consensus, which is done when the SLTs followed the same training in CA (15,27).

One of the limitations of the study is a missing item in the PPDS. A score 'clear breath, no swallow' is not included in the PPDS, although it is a state that occurs in clinical practice and it is an important finding. Not swallowing in the timeframe of two minutes is deviant, even for children with CP who have a lower swallow frequency. Senner et al. found that typically developing children in the age of 7-18 have a mean swallow frequency of every 48 seconds and children with CP between the 57-80 seconds (9). Thus, a finding of a clear breath but no swallow in the timeframe of two minutes is an important finding which needs to be included in the PPDS scale. Literature is insufficient about swallow frequencies below the age of seven. Another limitation of this study is the used measure protocol of the PPDS. Some items were not included in the protocol, which led to differences between raters. For example; a participant swallowed multiple times in one recording and each swallow had a different PPDS-score. The

protocol did not state clearly which score a rater should choose, which led to different choices: the mean of the scores, the worst of the scores or the PPDS-score of the first swallow, because the protocol indicated that only one swallow was required. These differences had influence on the reliability.

The authors of this study made a proposal for a new PPDS protocol, which can be found in Appendix 2, based on the results of this study. This new PPDS protocol can be used in future research and clinical practice regarding the PPDS. The found good intra-rater reliability indicates that the PPDS can be used as pre-/post assessment for treatment of posterior drooling. This instrument can be used in clinical practice and future research to measure the outcome of different treatment plans. However, it is important to take the test-retest reliability into account. The consistency of the PPDS is uncertain yet so multiple testing of posterior drooling at different moments is important to ensure the diagnosis. If different scores of the PPDS occur in multiple testing, choosing the highest PPDS score is advisable.

In conclusion, the intra-rater and inter-rater reliability of the PPDS is good between trained SLTs and experts. The test-retest reliability is poor, due to multiple factors. It is important to take the latter into account when diagnosing posterior drooling. Multiple testing with the PPDS is needed. The construct validity of the PPDS is low, compared with the FOIS, and moderate, compared with the EDACS. This is mostly caused because the FOIS and the EDACS are not limited to measuring pharyngeal problems only, but focusses on eating and drinking more broadly. The PPDS measures posterior drooling, a pharyngeal problem. To measure the construct validity of the PPDS accurately, the PPDS needs to be compared with a measurement tool aimed at pharyngeal problems only. This study was the first to apply the newly developed PPDS to a representative population-based sample, which led to recommendations for adjustment of the PPDS and its protocol. These adaptations need to be taken into account when using the PPDS in clinical practice and future research.

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Figures and tables

Methods

Pediatric Posterior Drooling Scale

- 0; clear breath, swallow, clear breath
- 1; wet breath, swallow, clear breath
- 2; clear breath, swallow, wet breath
- 3; wet breath, swallow, wet breath
- 4; wet breath, no swallow, wet breath

Results

| Table 1: Characteristics of the participar | its |
|--|-----|
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| Variables | N = 56 |
|-------------------------------|-----------|
| Age in years, mean (SD) | 8 (4.3) |
| Sex, n (%) | |
| Male | 43 (76.8) |
| Female | 13 (23.2) |
| Diagnosis | |
| Cerebral Palsy, n (%) | 24 (42.9) |
| Acquired Brain injury, n (%) | 11 (19.6) |
| Other, n (%) | 21 (37.5) |
| Pneumonia, n (%) | 10 (17.9) |
| Antibiotics, n (%) | 10 (17.9) |
| Hospitalized, n (%) | 6 (10.7) |
| VAS-scale gurgling, mean (SD) | 2.8 (2.8) |

Table 2: Reliability

| Intra-rater reliability | of the PPDS | 6 | | | | | |
|-------------------------|---------------|-----------|---------|-------|---------|---------|-----------|
| | Second rating | | | | | | |
| First rating | 0 | 1 | 2 | 3 | 4 | CBNS | Total (%) |
| 0 | 43 | 0 | 0 | 0 | 0 | 0 | 43 (80) |
| 1 | 0 | 2 | 0 | 0 | 0 | 0 | 2 (4) |
| 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 (N/A) |
| 3 | 0 | 1 | 2 | 1 | 0 | 0 | 4 (7) |
| 4 | 0 | 0 | 0 | 1 | 0 | 0 | 1 (2) |
| CBNS | 1 | 0 | 0 | 0 | 0 | 3 | 4 (7) |
| Total | 44 (81) | 3 (5.5) | 2 (4) | 2 (4) | 0 (N/A) | 3 (5.5) | 54 (100) |
| Inter-rater reliability | of the PPDS | 6 | | | | | |
| | Expert | | | | | | |
| Trained | 0 | 1 | 2 | 3 | 4 | CBNS | Total (%) |
| 0 | 39 | 1 | 3 | 0 | 0 | 0 | 43 (80) |
| 1 | 1 | 0 | 0 | 1 | 0 | 0 | 2 (4) |
| 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 (N/A) |
| 3 | 0 | 1 | 0 | 3 | 0 | 0 | 4 (7) |
| 4 | 0 | 0 | 0 | 0 | 1 | 0 | 1 (2) |
| CBNS | 1 | 0 | 0 | 0 | 0 | 3 | 4 (7) |
| Total | 41 (76) | 2 (4) | 3 (5.5) | 4 (7) | 1 (2) | 3 (5.5) | 54 (100) |
| Test-retest reliability | of the PPD | S | | | | | |
| | Second n | neasureme | ent | | | | |
| First measurement | 0 | 1 | 2 | 3 | 4 | CBNS | Total (%) |
| 0 | 16 | 0 | 0 | 1 | 0 | 0 | 17 (81) |
| 1 | 1 | 0 | 0 | 0 | 0 | 0 | 1 (5) |
| 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 (N/A) |
| 3 | 0 | 1 | 0 | 0 | 0 | 0 | 1 (5) |
| 4 | 0 | 0 | 0 | 0 | 0 | 0 | 0 (N/A) |
| CBNS | 2 | 0 | 0 | 0 | 0 | 0 | 2 (9) |
| Total | 19 (90) | 1 (5) | 0 (N/A) | 1 (5) | 0 (N/A) | 0 (N/A) | 21 (100) |

CBNS, clear breath no swallow. N/A, not applicable. Blue shading indicates cases in perfect agreement.

Table 3: Validity

| Relationship between PPDS level and FOIS level | | | | | | | | |
|---|---------|--------|-------|--------|---------|--------|---------|-----------|
| | FOIS le | vel | | | | | | |
| PPDS level | 1 | 2 | 3 | 4 | 4.5 | 5 | 6 | Total (%) |
| 0 | 1 | 2 | 2 | 5 | 8 | 6 | 20 | 44 (80) |
| 1 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 2 (4) |
| 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 (N/A) |
| 3 | 1 | 2 | 0 | 1 | 0 | 0 | 0 | 4 (7) |
| 4 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 (2) |
| CBNS | 1 | 1 | 0 | 0 | 1 | 0 | 1 | 4 (7) |
| Total | 3 (5) | 6 (11) | 2 (4) | 7 (13) | 10 (18) | 6 (11) | 21 (38) | 55 (100) |
| Relationship between PPDS level and EDACS level | | | | | | | | |
| | EDACS | level | | | | | | |
| PPDS level | 1 | 2 | 3 | 4 | | 5 | | Total (%) |
| 0 | 5 | 4 | 5 | 4 | | 0 | | 18 (75) |
| 1 | 0 | 0 | 1 | 0 | | 0 | | 1 (4) |
| 2 | 0 | 0 | 0 | 0 | | 0 | | 0 (N/A) |
| 3 | 0 | 0 | 0 | 1 | | 2 | | 3 (13) |
| 4 | 0 | 0 | 0 | 1 | | 0 | | 1 (4) |
| CBNS | 0 | 0 | 0 | 0 | | 1 | I | 1 (4) |
| 02110 | | | | | | | | () |

CBNS, clear breath no swallow. N/A, not applicable. Blue shading indicates cases in perfect agreement.

Appendix

Appendix 1: Parents questionnaire

Vragenlijst – Betrouwbaarheid en Validiteit van de 'Pediatric Posterior Drooling Scale'.

| Naam | : |
|-----------------|---|
| Geboortedatum | : |
| Geslacht | : |
| Datum onderzoek | : |

- 1. Heeft uw kind het afgelopen jaar een longontsteking of onderste luchtweginfectie doorgemaakt?
 - □ ja
 - □ Nee
 - 1a. Zo ja, heeft uw kind hiervoor antibiotica gekregen?
 - □ ja
 - □ Nee
 - 1b. Indien 'ja' op vraag 1, is uw kind hiervoor opgenomen geweest in het ziekenhuis?
 - □ ja
 - □ Nee
- 2. Kunt u een cijfer geven voor de ernst van rochelen, hoesten of kokhalzen op speeksel voor uw kind?

0 -----10

Appendix 2: Proposal adjusted PPDS measuring protocol (Dutch)

Pediatric Posterior Drooling Scale

Radboudumc

Aanleiding

Tot nu toe werd posterior drooling alleen aangegeven in termen van ja of nee. Bij kinderen met een neurologisch aangedane slik kan posterior drooling voorkomen met ernstige gevolgen zoals benauwdheid, slijmvorming in het faryngeale gebied of terugkerende longontstekingen. Het bepalen van de Ernst van posterior drooling is van belang voor de te kiezen behandeling en evaluatie daarvan.

<u>Schaal</u>

Om een beter beeld te krijgen van de Ernst is een schaal ontworpen, die ingevuld kan worden met behulp van cervicale auscultatie (CA).

| Observatie via CA | Score |
|---|-------|
| Heldere ademhaling – Slik – Heldere ademhaling | 0 |
| Heldere ademhaling – Geen slik – Heldere ademhaling | 1 |
| Rochelende ademhaling – Slik – Heldere ademhaling | 2 |
| Heldere ademhaling – Slik – Rochelende ademhaling | 3 |
| Rochelende ademhaling – Slik – Rochelende ademhaling | 4 |
| Rochelende ademhaling – Geen slik – Rochelende ademhaling | 5 |

Voor wie

De schaal is bedoeld voor kinderen vanaf 1 jaar en wordt alleen gebruikt om de ernst van posterior drooling te kunnen scoren.

<u>Werkwijze</u>

- A. De observatie vindt plaats ongeveer 1 uur na de laatste orale voeding (drinken of eten).
- B. Voor de observatie wordt eerst bepaald of er slikacties geobserveerd worden om te weten of er spontaan geslikt wordt. Dit kan gedaan worden met behulp van de Drooling Quotiënt.
- C. Cervicale auscultatie start na een slik en duurt tot een volledig patroon ademhaling slik ademhaling is waargenomen. De informatie na de slik is ook belangrijk (heldere of rochelige ademhaling).

- D. Geef eerst het kind zelf de kans om tot spontaan slikken te komen. Na een periode van 1 minuut, mag er verbaal aangestuurd worden tot slikken. Hulp middels mondcontrole mag **niet**.
- E. Er kan voor gekozen worden om de cervicale auscultatie op te nemen middels iPhone of audio-recorder om de mate van posterior drooling op een later moment opnieuw te kunnen beoordelen en deze te vergelijken.

Meervoudige testen op verschillende momenten van de dag/week is belangrijk. Drie keer testen wordt geadviseerd. Posterieur speekselverlies kan wisselen in ernstgraad. Het is belangrijk om de hoogst gemeten ernstscore mee te nemen bij (overweging van) behandeling.