The convergent validity of a Dutch Screening tool for Dysphagia (Signaleringslijst Verslikken) for people with severe or profound intellectual and multiple disabilities

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INTRODUCTION

Dysphagia in adults with intellectual disabilities (IDs) is potentially life-threatening with negative health consequences including asphyxia, dehydration, poor nutritional status and choking. It can result in aspiration of food or liquids into the lungs resulting in respiratory tract infection (Robertson, Chadwick, Baines, Emerson, & Hatton, 2018). Indeed, it is reported that up to 40% of adults with intellectual disability and dysphagia will experience recurrent respiratory tract infections related to aspiration (Chadwick & Jolliffe, 2009). Respiratory tract infection is one of the most common causes of death for people with intellectual disability and the principal cause of death in people with severe or profound intellectual and multiple disabilities (SPIMDs). Furthermore, such an outcome is potentially avoidable (Heslop et al., 2014; Hosking et al., 2016) and may be prevented through the enactment of dysphagia screening (Robertson et al., 2018).

Dysphagia is seen more frequently in those people who exhibit more severe levels of intellectual disability, with comorbid cerebral palsy and motor impairment (Robertson, Chadwick, Baines, Emerson, & Hatton, 2017). Such characteristics are usually associated with...
SPIIMD (Nakken & Vlaskamp, 2007). Due to the severe or profound intellectual disability combined with motor and sensory impairments, health problems in people with SPIIMD are at risk of being undiagnosed and untreated. In the Netherlands, adults with SPIIMD live principally in residential facilities, where they are dependent on others, such as direct support staff, for the identification of physical health problems; this is due to their inability to verbally express that they are feeling unwell (Petry, Maes, & Vlaskamp, 2005). This lack of conventional communication presents a significant challenge for direct support staff in identifying physical health problems, such as dysphagia.

The reported prevalence of dysphagia in people with SPIIMD varies from 15% to 50% (van Timmeren et al., 2017). This may be an underestimation as individuals with intellectual disability often aspirate silently, with neither coughing nor signs of distress when foods/fluids enter the airways (Chadwick & Jolliffe, 2009). This underestimation may also be partly due to direct support staff being unable to recognize signs of dysphagia (Chadwick & Jolliffe, 2009; Robertson et al., 2017).

In residential facilities, the assessment and management of dysphagia in people with SPIIMD usually fall within the remit of speech and language therapists and undertaken using the Dysphagia Disorders Survey (DDS; Robertson et al., 2018). The DDS is a standardized, structured evaluation for the assessment of dysphagia in people with intellectual disability (Sheppard, 2002b). Regular screening for dysphagia is important as swallowing capabilities deteriorate with age among people with SPIIMD (Chadwick & Jolliffe, 2009; Sheppard, 2002b), and those who were not previously diagnosed with dysphagia may present with advancing age. This is increasingly important as people with intellectual disability are experiencing greater longevity. It is, however, not feasible for speech and language therapists to screen all people with intellectual disability on a regular basis. Thus, direct support workers are playing a key and increasing role in such activities (Chadwick & Jolliffe, 2009).

Best practice suggests that assessment of dysphagia in people with intellectual disability begins with a suspicion of its presence. This results in a report being made by direct support workers to the speech therapist for confirmation, determination of severity and specification of treatment options (Chadwick & Jolliffe, 2009; Horiguchi & Suzuki, 2011). In view of the serious consequences of dysphagia, early recognition of the possible presence of dysphagia by direct support workers is important. However, the identification of dysphagia in people with intellectual disability is complex for reasons already iterated (Chadwick & Jolliffe, 2009) and may remain under-reported (Chadwick & Jolliffe, 2009; Robertson et al., 2017).

It is, therefore, preferable that direct support staff have access to and easily applicable test to detect the presence of dysphagia, so that a timely referral can be made to speech and language therapists for further assessment (Horiguchi & Suzuki, 2011). The “Signaleringslijst Verslikken” (SV) may meet this need (Helder, 2010). The SV is a brief observational screening questionnaire that can be completed by untrained staff. Validation of the SV was performed against the DDS in a sample of adults with intellectual disability, aged 50 years and older. The results of this validation were made available in a report on a national website aiming at sharing knowledge and published in a non-peer-reviewed journal (Helder, 2010). On the basis of this, the SV was recommended for use in practice and, due to the lack of available standardized screening instruments, became widely used in the Netherlands. However, this is a weak basis for its usage and the validation of the SV against the DDS has not yet been examined in persons with SPIIMD in particular.

The aim of this study was to examine the convergent validity of the SV and the DDS for detecting dysphagia in people with SPIIMD.

2 | Method

2.1 | Design

A cross-sectional study design was employed to examine the convergent validity of the SV for detecting the presence of dysphagia in people with SPIIMD, aged 50 years and older, by comparing the scores obtained using the SV with those obtained using the DDS.

2.2 | Participants

A convenience sample of adults with SPIIMD, aged 50 years and older, was recruited from a residential facility in the Netherlands that offers support to 186 persons with severe and profound intellectual and visual disabilities. At the time of the study, 58 residents were aged 50 years and older. Representatives of 41 residents provided written informed consent for these persons to participate in the study. The participants had an intelligence quotient of less than 35, and their visual acuity at less than 6/18 was consistent with blindness or poor vision (ICD-10-CM. International Statistical Classification of Diseases & Related Health Problems Clinical Modification. 10th Revision, 2018). Participants ranged in age from 50 to 69 years (mean 58 years). Table 1 depicts the participants’ characteristics. Approval from the medical ethics

<table>
<thead>
<tr>
<th>Characteristics N = 41</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (SD)</td>
<td>58 (6.1)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>18 (43)</td>
</tr>
<tr>
<td>GMFCS level, n (%)</td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>12 (29)</td>
</tr>
<tr>
<td>II</td>
<td>13 (32)</td>
</tr>
<tr>
<td>III</td>
<td>7 (17)</td>
</tr>
<tr>
<td>IV</td>
<td>7 (17)</td>
</tr>
<tr>
<td>V</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Vision, n (%)</td>
<td></td>
</tr>
<tr>
<td>Blind</td>
<td>30 (73)</td>
</tr>
<tr>
<td>Low vision</td>
<td>11 (27)</td>
</tr>
</tbody>
</table>

Note. GMFCS: gross motor function classification system (Gorter, 2001; Palisano et al., 2000).
2.3 | Measures

2.3.1 | Signaleringslijst Verslikken

The SV (Table 2) is a questionnaire of eight items that can be administered by untrained direct support staff to screen for signs of dysphagia in people with intellectual disability aged 50 years and older (Helder, 2010). Each item of the SV is scored as either present (yes) or absent (no) with a weighting factor per item. The total score on the SV ranges from 2 to 36. A total score of 12 or more on the SV suggests the presence of dysphagia and requirement for further assessment (Helder, 2010).

Construction of the items of the SV relied largely on a review of literature and expert opinion, and was, as noted, subjected to a validation study (Helder, 2010). The weighting factor per item was determined by the correlation coefficient after a discriminant analyses and indicates the predictive value of the item so as to detect the presence of dysphagia. The sample consisted of adults with predominantly mild to severe intellectual disability. In this study, they found an interrater reliability of 90%, and a correlation of 0.7 between the SV and the DDS (Helder, 2010). The proportion of agreement on either the presence or absence of dysphagia between the SV and the DDS was 0.9.

2.3.2 | The Dysphagia Disorders Survey (DDS)

In the assessment of dysphagia, invasive instrumental explorations including video fluoroscopy are considered to be the gold standard approach (O’Horo, Rogus-Pulia, Garcia-Arguello, Robbins, & Safdar, 2015). This technique, however, is typically not available in residential facilities, and furthermore, people with SPIMD may find such an invasive instrumental exploration to be intolerable. In recognition of this, the DDS is used for people with SPIMD as an alternative to instrumental assessment. Only trained and certified professionals are permitted to perform the DDS (Sheppard, 2002b).

The DDS (Table 3) consists of 15 items which are divided into two parts (Sheppard, Hochman, & Baer, 2014). Part one (seven items) consists of dysphagia-related factors such as body mass index, diet consistency and body postural control. Depending on the item, the score range varies between 0 to 1 and 0 to 4. Part two (eight items) comprises mealtime evaluation and consists of items to assess feeding/swallowing competency which include sensory motor components of the four phases of swallowing (oral-preparatory, oral-propulsive, pharyngeal and oesophageal phase). The mealtime situation covers three food textures as follows: non-chewable solid foods; chewable solid foods; and liquids. Performance for each task component and each food-type is scored as 0 for competent function and 1 for deficient function or use of compensatory support. If a person is only allowed to have thickened liquids, the items related to liquid food are scored as 1. The total score on the DDS ranges from 0 to 38.

The DDS provides a raw score that can be interpreted by applying a percentile ranking according to the DDS user manual. These scores can be assigned to the level of disorder on a five-level ordinal scale: (1) no dysphagia; (2) mild dysphagia; (3) moderate dysphagia; (4) severe dysphagia; and (5) profound dysphagia (Sheppard, 2002a; Sheppard et al., 2014).

<table>
<thead>
<tr>
<th>Items</th>
<th>Weighting factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The person experienced a choking incident in the previous month</td>
<td>6</td>
</tr>
<tr>
<td>2. The person coughs or gurgles during or following meals</td>
<td>6</td>
</tr>
<tr>
<td>3. The person needs prolonged mealtime, longer than 25 min</td>
<td>2</td>
</tr>
<tr>
<td>4. Reflux or medication for reflux</td>
<td>3</td>
</tr>
<tr>
<td>5. One or more of the following factors applies to the person:</td>
<td></td>
</tr>
<tr>
<td>Respiratory problems</td>
<td>5</td>
</tr>
<tr>
<td>Regular fever</td>
<td>5</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>5</td>
</tr>
<tr>
<td>Stroke</td>
<td>5</td>
</tr>
<tr>
<td>Dementia</td>
<td>5</td>
</tr>
<tr>
<td>Sits in a wheelchair</td>
<td>5</td>
</tr>
<tr>
<td>Swallowing problems in the past</td>
<td>5</td>
</tr>
<tr>
<td>6. The person appears drowsy or tired during meals or restless and talkative</td>
<td>3</td>
</tr>
<tr>
<td>7. Food or drinks are modified</td>
<td>6</td>
</tr>
<tr>
<td>For instance: food cut into pieces, no bread crusts, thickened fluid, several smaller portions</td>
<td></td>
</tr>
<tr>
<td>8. The person refuses to eat or drink</td>
<td>2</td>
</tr>
</tbody>
</table>

TABLE 2 “Signaleringslijst Verslikken” (translated by first author)
Standardization of the DDS was based on speech and language therapists’ clinical judgement of presence and severity of dysphagia. Correlation (r) of the total DDS score with the speech and language therapists’ expert opinions was r = 0.92. An inter-rater reliability of 97% was determined by six speech and language therapists, working in pairs, scoring DDS items for 21 participants (Sheppard, 2002b). A recent systematic review for psychometric characteristics of non-instrumental swallowing and feeding assessments reported for the DDS a moderately positive evidence for reliability (52%–58%), content validity (64%), structural validity (54%) and a strong positive evidence for hypothesis testing (44%–66%) in children with cerebral palsy and adults and children with intellectual disability (Speyer, Cordier, Parsons, Denman, & Kim, 2018).

### Table 3: Definitions of items of the Dysphagia Disorder Survey (Sheppard et al., 2014)

<table>
<thead>
<tr>
<th>Items</th>
<th>Definition</th>
<th>Score</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Part 1. Related factors</strong></td>
<td></td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>1. Body mass index</td>
<td>A weight for height ratio scored for low levels.</td>
<td>0–2</td>
<td></td>
</tr>
<tr>
<td>2. Diet consistency</td>
<td>Texture and viscosity restrictions in diet.</td>
<td>0–4</td>
<td></td>
</tr>
<tr>
<td>3. Independence</td>
<td>Ability to feed oneself.</td>
<td>0–3</td>
<td></td>
</tr>
<tr>
<td>4. Adaptive utensils</td>
<td>Use of utensils to facilitate better oral management during eating.</td>
<td>0–3</td>
<td></td>
</tr>
<tr>
<td>5. Body postural control</td>
<td>Ability to stabilize head-neck and thorax for sitting during eating.</td>
<td>0–2</td>
<td></td>
</tr>
<tr>
<td>6. Seating supports/alignments</td>
<td>Use of supports to maintain upright sitting or eating in reclining.</td>
<td>0–1</td>
<td></td>
</tr>
<tr>
<td>7. Special feeding techniques</td>
<td>Use of compensatory techniques during eating.</td>
<td>0–1</td>
<td></td>
</tr>
<tr>
<td><strong>Part 2. Feeding and swallowing competency.</strong></td>
<td></td>
<td></td>
<td>22</td>
</tr>
<tr>
<td>8. Orienting</td>
<td>Alert to, and postural adjustment for, the approaching bolus.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>9. Reception</td>
<td>Removing liquid or solid food from utensil or biting off bolus.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>10. Containment</td>
<td>Maintaining food in mouth during oral transport and processing.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>11. Oral transport</td>
<td>Moving food in mouth and clearing oral residuals on swallowing.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>12. Chewing</td>
<td>Adequate strength and duration of chewing to reduce bolus to swallow-ready consistency.</td>
<td>0–1</td>
<td></td>
</tr>
<tr>
<td>13. Oral-pharyngeal swallow</td>
<td>Prompt swallow initiation and pharyngeal clearance sequential sip-swallow. Absent clinical signs of disorder.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>14. Post swallow</td>
<td>Clearance of residuals from upper airway. Absent clinical signs of disorder.</td>
<td>0–1a</td>
<td></td>
</tr>
<tr>
<td>15. Oesophageal swallow</td>
<td>Effective transport of bolus to, and retention in, stomach. Absent clinical signs of disorder.</td>
<td>0–1a</td>
<td></td>
</tr>
</tbody>
</table>

*aThree food textures were scored 0 for competent, 1 for deficient.*

#### 2.4 Data procedure

Each participant was filmed from frontal and side perspectives during one routine mealtime. During the week prior to filming, the participant’s direct support staff completed the SV. These direct support staff had worked with the participant for at least two months and were present during at least one mealtime in the preceding two weeks. Two speech and language therapists viewed the video and performed the DDS evaluation. Both were blinded to the results of the SV. The two speech-language therapists had attended a DDS workshop and were certified in the administration and scoring of the DDS. The first author (EAvT) collected the results of the SV and the DDS to prevent any expectation bias.
2.5 | Data analyses

Data analyses were performed using IBM SPSS Statistics 24. The results are presented in a two-way contingency table of frequencies, with the rows and columns indicating the presence versus absence of dysphagia according to SV and DDS, respectively. Because the DDS is not the gold standard, sensitivity and specificity could not be calculated. The research team determined the proportion of agreement between the SV and the DDS on either the presence or absence of dysphagia (Watson & Petrie, 2010). The McNemar’s test for contingency tables was used to test homogeneity of the marginals (Watson & Petrie, 2010). The null hypothesis of marginal homogeneity states that the two marginal probabilities for each outcome (SV, DDS) are the same: that the proportion of participants with “dysphagia present” according to the SV will be equal to the proportion of participants with “dysphagia present” according to the DDS. A p-value below 0.05 was considered statistically significant.

A scatterplot was created to visualize the distribution of the score on the SV and the classification of the severity of dysphagia according to the DDS. Confidence intervals (95% CI) were calculated with the confidence interval calculator for proportions (VassarStats, n.d.).

3 | RESULTS

The presence of dysphagia detected by the DDS was 95% and by the SV, 54% across all participants. Table 4 shows the contingency table on the presence or absence of dysphagia according to the SV and the DDS.

The proportion of agreement between the SV and the DDS was 0.59 (95% CI 0.43 to 0.72). The SV did not detect the presence of dysphagia in 17 participants (44%) who were assessed as having mild to moderate dysphagia according to the DDS. Marginal homogeneity is rejected by the McNemar’s test ($\chi^2 = 17, df = 1, p = 0.000037$) suggesting that there is a significant difference between the proportion of participants identified as “dysphagia present” by the two methods.

On the DDS, 20 participants were classified as having mild dysphagia (49%), 12 with moderate dysphagia (29%), six with severe dysphagia (15%) and one with profound dysphagia (2%). Figure 1 displays a scatterplot of the SV scores (y-axis) against the severity of dysphagia categories from the DDS (x-axis). The scatterplot shows the degree of possible underestimation in respect of the SV. The horizontal reference line represents the cut-off point of 12 for the SV. The SV did not detect the presence of dysphagia in 17 participants (44%) who were assessed as having mild to moderate dysphagia according to the DDS.

4 | DISCUSSION

The results of the study indicate that the convergent validity of the SV for detecting the presence of dysphagia in people with SPIMD is insufficient. There is a significant difference between the proportion of participants detected as having dysphagia between the SV (0.54) and the DDS (0.95). Comparison of both assessment results indicates a proportion of agreement of 0.59.

Recognition of all levels of dysphagia acuity is important so as to identify those at risk of secondary health problems (Chadwick & Jolliffe, 2009). With the use of the SV, 44% of the participants assessed by the DDS to have dysphagia would not have been referred for further screening and assessment. These participants all had mild to moderate dysphagia. Thus, the SV demonstrated inaccuracy in the range of mild to moderate dysphagia. Signs of milder dysphagia are often missed (Calis et al., 2008); as already noted, this may be due to people with SPIMD silently aspirating (Chadwick & Jolliffe, 2009) and being unable to verbally report physical health problems. This is compounded by the reality that health problems with less visible signs and symptoms will be easily overlooked in people with SPIMD (Zijlstra & Vlaskamp, 2005).

In Helder’s (2010) study, of 83 adults, aged 50 years and older, and with predominantly mild to severe intellectual disability, the overall proportion of agreement between the SV and the DDS was 0.9. The current study, with a comparable age profile, demonstrated a much lower proportion of agreement, at 0.59. The difference between this and Helder’s study may be explained by the fact that people with SPIMD have an increased risk for dysphagia to concomitant problems (Benfer et al., 2014; Robertson et al., 2017). The SV does not consider level of intellectual impairment which may be a factor for being able to self-report dysphagia, and in respect of motor impairment, the SV only refers to sitting in a wheelchair, whereas items such as the degree of spasticity, trunk control and presence of scoliosis might be valuable additions when screening for dysphagia in people with SPIMD (Chadwick & Jolliffe, 2009). Thus, the differences in results may relate to the fact that the level of intellectual disability and motor impairment is not adequately represented in the SV. On the other hand, its reference to dementia may be less relevant for this population because it is difficult to diagnose dementia in people with SPIMD.

The prevalence of dysphagia based on the DDS in the current study is 95%. This is higher than the 15%–50% reported in previous studies on adults with SPIMD (van Timmeren et al., 2016, 2017). Reliance on reported problems in participants’ medical records and care plans in those studies may have led to an underestimation of the prevalence of dysphagia (van Timmeren et al., 2016). The results of the present study are in accordance with research undertaken among children with severe generalized cerebral palsy and
intellectual disability, where a prevalence of 99% of dysphagia was ascertained by performing formal assessments with the DDS (Calis et al., 2008). The results of the current study suggest that people with SPIMD aged at least 50 years can be considered a high-risk group for having dysphagia and it is recommended, therefore, that people with SPIMD of this age should be regularly assessed for dysphagia at regular intervals by specialized professionals, such as a speech and language therapist or by a multidisciplinary dysphagia team, perhaps once per year. This suggestion is in accordance with recommendations of Chadwick and Jolliffe (2009).

4.1 | Limitations and further research

Invasive instrumental explorations such as video fluoroscopy are considered the gold standard in the assessment of dysphagia (O’Horo et al., 2015). In the present study, the SV was compared to the DDS because people with SPIMD cannot easily undergo invasive instrumental explorations. The DDS is not, however, the gold standard and therefore estimates of sensitivity, specificity, positive predictive value and negative predictive value could not be computed. Moreover, the DDS may be inadequate in the evaluation of pharyngeal aspects of dysphagia due to silent aspiration (Robertson et al., 2018). Using a stethoscope to evaluate cervical swallowing sounds intermittently during the meal would increase the sensitivity of assessment of the pharyngeal-phase signs of dysphagia specified in the DDS (Calis et al., 2008). The use of DDS as the reference standard may thus have led to an underestimation of dysphagia overall.

This study is limited by its somewhat small sample size, and that the participants were recruited from a single residential facility for people with severe and profound intellectual and visual disabilities. All of the participants had visual impairments, albeit at various degrees. Due to this, the sample may not fully represent the complete population of people with SPIMD. On the other hand, this population is very likely to experience visual impairments (van Splunder, Stilma, Bernsen, & Evenhuis, 2006; van Timmeren et al., 2016). Furthermore, the study sample led to a somewhat unbalanced group of participants with and without dysphagia. There were only two participants diagnosed as not having dysphagia according to the DDS. Further research with a representative sample of people with intellectual disability and SPIMD is required in order to provide more evidence of the SV and to determine which important factors influencing the prevalence of dysphagia must be added to the SV.

Further study is needed on how to best manage dysphagia in people with SPIMD; are people with SPIMD better off with tailored staff training on dysphagia or with an improved screening tool?

4.2 | Implications for practice

The SV was developed to be an easily applicable tool for direct support staff to screen for dysphagia in people with intellectual disability aged 50 years and older. However, it has been shown to be unsuitable for detecting the presence of dysphagia in people with SPIMD who are aged 50 years and older with less severe forms of dysphagia not being detected. Considering the high prevalence rate of dysphagia and its negative consequences, all people with SPIMD who are in this age group should be considered as having dysphagia until proven otherwise. Relying upon direct support staff to screen for the presence of dysphagia with the SV in this particular group is an unnecessary step and a risk factor for
under recognition of dysphagia. Pro-active regular assessments by speech and language therapists or a multidisciplinary dysphagia team in this specific group is justified in order to early diagnose dysphagia and specify interventions to reduce complications such as respiratory tract infections.

In view of the serious consequences of physical health problems in persons with SPIMD, early accurate identification is important in order to improve or maintain health and quality of life (Kerr et al., 2003; Robertson, Hatton, Emerson, & Baines, 2014). However, to a large extent, the identification of physical health problems is practice-based and relies on the experience and insight of professionals (Suman, 2013). The use of measurements without a strong scientific evidence-base may result in misguided decision making and may induce inadequate treatment (Stoker, 2008). Considerable care must be taken to ensure that the best possible measurement methods are used.

5 | CONCLUSION

The results of the present study indicate that the convergent validity of the SV is insufficient, and therefore, the SV is not suitable for screening for the presence of dysphagia in people with SPIMD who are aged 50 years and older. Instead of screening for the presence of dysphagia in this specific population, the present authors advise that all people with SPIMD that are in this age range to be assessed for dysphagia by speech and language therapists or by a multidisciplinary dysphagia team.

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