

Screening instrument Dysphagia in people with Intellectual Disabilities (SD-ID)

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Background

- Increased prevalence of dysphagia in intellectual disabilities (ID)
 - 8,1 - 11,5% (overall ID), 52% (≥ 50 years), 48% (profound intellectual and multiple disabilities), 58% (Down syndrome), 99% (severe cerebral palsy)
- Timely establishing increased risk on dysphagia essential to prevent (often serious) consequences, e.g. pneumonia or airway obstruction
- Periodic screening by speech therapists not feasible in daily practice
- Quick and simple screening by caregivers is crucial
- No valid screening instrument available for dysphagia in ID**

Method

- Development SD-ID
 - Literature, existing screening instruments, experiences in daily practice
- First validation (n=42), incl. concurrent validity: SD-ID vs. Dysphagia Disorder Survey (DDS)
- Further validation (n=1064)
 - Small refinement SD-ID, similar set-up to first validation study except no DDS for SD-ID=0
- Optimization



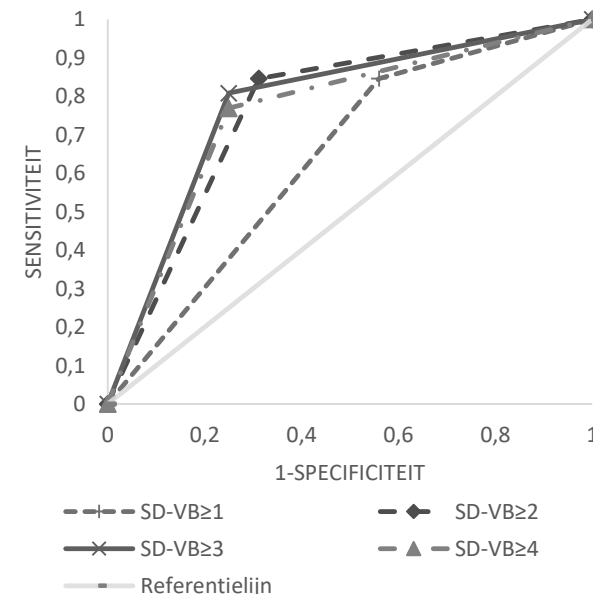
Results

1. Development SD-ID

- Part A: Risk factors (8 items) + B: Eating/drinking behaviour (20/21 items)
- Yes/no answers
- Completion by caregiver in $\pm 5-10$ min.
 - Caregiver acquainted ≥ 2 months with person
 - Caregiver observed meal during past week

2. First validation (n=42)

- Strong positive correlation SD-ID and DDS
- Sensitivity, specificity, predictive values above 70% with SD-ID=3
- Internal consistency: $\alpha = 0,907$



Results



3. Further validation (n=1064)

- Item 18 split up in 2 separate items
- Again: strong positive association SD-ID and DDS
- SD-ID $\geq$ 1 vs. SD-ID=0
 - ↑ mean age
 - ↑ people with severe/profound ID
 - ↓ people with mild ID
- Mean SD-ID score higher for DS (M=5.1 $\pm$ 5.4) vs. without DS (M=3.9 $\pm$ 4.6)
- Mean SD-ID score lower for ASD (M=3.1 $\pm$ 3.5) vs. without ASD (M=4.4 $\pm$ 5.1)
- Sensitivity, specificity, predictive values above 70% with SD-ID=4
- Internal consistency: $\alpha = 0,879$

SD-ID score	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)	Sensitivity (%)	Specificity (%)	PPV (%)	NPV (%)
	<i>Mild ID</i>				<i>Moderate ID</i>			
2	83,9	45,2	31,3	90,4	83,0	39,8	45,2	80,2
3	77,4	63,5	38,7	90,4	72,0	56,7	50,0	77,8
4	74,2	78,8	51,1	91,1	67,0	72,5	59,5	79,1
5	67,7	87,5	61,8	90,1	57,0	79,5	62,8	76,1
	<i>Severe/profound ID</i>				<i>Total group</i>			
2	97,6	33,0	80,2	83,3	92,7	39,8	61,8	83,9
3	92,9	53,8	84,8	73,1	86,3	58,0	68,4	80,1
4	88,1	67,0	88,1	67,0	81,6	73,0	76,1	79,1
5	79,0	76,9	90,5	56,9	72,5	81,1	80,2	73,8

4. Optimization

- Include DS and severe/profound ID as risk factor
- Exclude 'regularly fever' as risk factor
- Strong association item 9 and 10 ($\phi = 0,69$; $p < 0,001$) → merge

Conclusion

- SD-ID seems a promising instrument for caregivers to screen for dysphagia risk in people with ID
- Optimised and further studied version fits in a periodic work process: 1) SD-ID, 2) diagnostic observations by speech therapists (depending on SD-ID cut-off score), 3) eating/drinking advices and 4) evaluation

Discussion

Strengths

- Study focused on frequent issue in daily practice
- Large study group in 'further validation'

Limitations

- Literature review not completely systematic
- Small study population first validation, e.g. no people with DS
- No diagnostic observation (DDS) by speech therapist with SD-ID=0 in further validation

Follow up study

- Further optimization SD-ID
- Interrater and test-retest reliability
- Effect of additional risk factors

References

Robertson et al., 2017
Hermans & Evenhuis, 2014
Chadwick & Jolliffe, 2009
van der Woude et al., 2021

Disclaimer

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Funding



Abbreviations: ASD, autism spectrum disorder; DS, Down syndrome; ID, intellectual disabilities



SD-ID

V1	V2	A: risk factors	Score
1	1	Stroke	
2	2	Dementia	
3	3	Epilepsy	
4	4	Pulmonary/respiratory conditions	
5	5	Constipation or use of laxatives	
6	6	Reflux	
7	7	Regularly fever	
8	8	Presence of dysphagia in the past	
		B: Eating/drinking behavior	
9	9	Person sometimes chokes (once a month or more often)	
10	10	Person coughs during or after eating/drinking	
11	11	Person gags during or after eating/drinking	
12	12	Person takes more than 25 minutes to eat	
13	13	Person has a tendency to cram	
14	14	Person seems to be short of breath during eating/drinking	
15	15	Person has difficulty bringing food or drinks to the mouth	

16	16	Person has wet hoarseness during or after eating/drinking	
17	17	Person breaths audibly during or after eating/drinking	
18	18 19	Person is drowsy/tired during eating/drinking Person is restless and loud during eating/drinking	
19	20	Person has recently lost weight without clear cause	
20	21	Person chews insufficiently or not at all	
21	22	Person has residu of food or drinks after swallowing	
22	23	Food or drinks come out of the mouth during eating/drinking	
23	24	Person moves food poorly inside the mouth	
24	25	Person has difficulties taking a bite	
25	26	Person swallows more than twice in one bite	
26	27	Person swallows audibly during eating/drinking	
27	28	Food/fluid consistency is modified	
28	29	Person refuses to eat/drink	

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