

# Screening/assessment in neurodegenerative diseases: when and how?

**Moderators:**

Aude Lage

Renée Speyer

# Moderators

## **Prof. Aude Lagier**

Otorhinolaryngologist

University Hospital of Liege,  
Belgium



## **Prof. Renée Speyer**

SLP / Epidemiologist

University of Oslo, Norway



# Round table participants *(abc)*

- Hanneke Kalf (The Netherlands)
- Annette Kjaersgaard (Denmark)
- Gaëlle Soriano (France)
- Tobias Warnecke (Germany)

# Asst Prof Dr Hanneke Kalf



## Profession

Speech-language therapist

## Affiliation

Assistant professor rehabilitation

Radboud university medical center, department of rehabilitation, Nijmegen, the Netherlands

## Main clinical/research focus

Dysphagia and dysarthria in adults, including neurodegenerative diseases.

# Dr Annette Kjaersgaard



## **Profession**

Occupational therapy specialist

## **Affiliation**

Private practice

Hammel Neurorehabilitation Centre and University Research Clinic, Aarhus University, Denmark

## **Main clinical / research focus**

Oropharyngeal dysphagia and neurorehabilitation: systematic assessment and innovative interventions, aiming to elevate functional outcomes, meaningful daily activities and quality of life.

# Dr Gaëlle Soriano

## **Profession**

Dietitian

## **Affiliation**

CHU de Toulouse, Gerontopole, Geriatrics Unit, France

## **Main clinical / research focus**

Nutrition for frail older people and its association with meal-related difficulties.



# Prof Dr Tobias Warnecke



## **Profession**

Medical Doctor

## **Affiliation**

Professor of Neurology, Head of the Department of Neurology and Neurorehabilitation

Klinikum Osnabrueck – Academic Teaching Hospital of the University of Muenster, Osnabrueck, Germany

Chairman of the Parkinson Networks Germany Association

## **Main clinical / research focus**

Parkinson's disease and dysphagia.



**ROUND  
TABLE**



# Round Table Overview

- Introduction
- Screening  
  morphology
- Case
- Case
- Summary

**QUESTIONS  
&  
DISCUSSION**

# Measurements

- Screening

E.g., Trial water swallow

- “Gold standard”

FEES & VFS

- Clinical assessment

E.g., oral motor examination,  
assessment of cognition, weight.

- Patient Self-evaluation

Functional Health Status &  
Health-Related Quality of Life

- Supplementary methods

E.g., cervical auscultation, oxygen  
desaturation, scintigraphy









# ESSD White Paper

Dysphagia (2022) 37:333–349

<https://doi.org/10.1007/s00455-021-10283-7>

ORIGINAL ARTICLE

## White Paper by the European Society for Swallowing Disorders: Screening and Non-instrumental Assessment for Dysphagia in Adults

Renée Speyer<sup>1,2,3</sup>  · Reinie Cordier<sup>2,4</sup>  · Daniele Farneti<sup>5</sup>  · Weslania Nascimento<sup>6</sup>  · Walmaril Pilz<sup>7,8</sup>  ·  
Eric Verin<sup>9</sup>  · Margaret Walshe<sup>10</sup>  · Virginie Woisard<sup>11,12</sup> 



# **Purpose ESSD White Paper**

To report on the current state of screening and non-instrumental assessment for dysphagia in adults.

To discuss the measures that are available, how to select screening tools and assessments, and gaps in research that still need to be addressed in future research.

**SCREENING**

# Screening *In a Nutshell*

- **First step** in management of dysphagia by identifying patients at risk for swallowing problems
- If identified as **'at risk' of dysphagia, further assessment** is indicated.



# **Screening *In a Nutshell***

## **Great variety of types of screening**

E.g., trial swallows using water in various aliquots or a range of different viscosities, pulse oximetry, combined protocols of trial swallow and pulse oximetry, clinical features (e.g., voice alteration), cervical auscultation, elements of medical history (e.g., recurrent episodes of pneumonia)

## **Different endpoints**

E.g., penetration, aspiration or dysphagia.

## SCREENING What & Who?

1. **Construct** *E.g., at risk of dysphagia, aspiration, penetration.*
2. **Target population** *E.g., children with cerebral palsy, stroke, patients with neurological disorders, H&NC group.*

## SCREENING Quality Assessment?



1. **Study methodology** *Critical appraisal tool (E.g., QUADRAS-2)*
2. **Screening tool**
  - Diagnostic performance (Criterion validity): *Sensitivity, specificity, positive and negative predictive value, positive and negative likelihood ratio, Area Under the Curve (ROC curve).*
  - Content validity
  - Reliability: *Intra-rater, inter-rater, test-retest reliability*
  - Feasibility: *E.g., ease of administration, non-invasive method, minimal required training, availability, copyright and associated costs*



**ASSESSMENT**

# Assessment *In a Nutshell*

**‘Gold standard’ instrumental assessments:**

## ***VFSS & FEES***

- Identify (silent) aspiration
- Access?
- No international consensus which visuoperceptual or software-based measures to use for analysis of VFSS/FEES recordings
- Insufficient psychometric evidence to recommend any measure as valid/reliable (Swan et al., *Dysphagia* 2019;34:2-33); However, new studies ongoing ...

# **Assessment *In a Nutshell***

## **Non-instrumental assessment: *Purposes***

- Estimate safety of swallowing risk of aspiration
- Support decisions on oral or alternative feeding routes
- Identify need for further assessment
- Establish baseline data for future comparisons  
(intervention, course of a disease)

# Assessment

## Non-instrumental

- Assessment of cognition and communication
- Evaluation of oral, laryngeal, and pharyngeal anatomy, physiology, and function (incl. cranial nerve examination)
- Oral intake, nutritional status, mealtime observations
- Intervention trials (e.g., bolus modification, postural adjustments, swallow manoeuvres)
- Patient self-report

**Few standardised CSE**  
**Few comprehensive CSE**  
**Psychometrics?**

The degree to which an instrument is free from measurement error

The degree to which an instrument measures the construct(s) it purports to measure

## RELIABILITY

### Reliability

(test-retest, inter-rater, intra-rater)

Internal consistency

The ability of an instrument to detect change over time in the construct to be measured

## VALIDITY

Content validity

Face validity

Construct validity

Criterion validity

(concurrent validity, predictive validity)

Structural validity

Hypotheses-testing

Cross-cultural validity

## RESPONSIVENESS

Interpretability

The degree to which one can assign qualitative meaning to an instrument's quantitative scores or change in scores

# Psychometric Reviews *Examples*

## Domain

1. Health-Related Quality of Life
2. Functional Health Status
3. Non-instrumental Clinical Assessments (in adults)
4. Pediatric Non-instrumental Swallowing and Feeding Assessments
5. Visuoperceptual Evaluation of FEES and VFSS

## Reference

1. Timmerman et al. (2014). *Dysphagia* 29(2):183-198
2. Speyer et al. (2014). *BioMed Res Int* Article ID 458678, 1-11
3. Cordier et al. (2023). *JCM* 12(2):721
4. Speyer et al. (2018). *Dysphagia* 33(1):1-14
5. Swan et al. (2019) *Dysphagia* 34(1):2-33

## ASSESSMENT What & Who?

1. **Construct** *E.g., at risk of dysphagia, aspiration, penetration.*
2. **Target population** *E.g., children with cerebral palsy, stroke, patients with neurological disorders, H&NC group.*
3. **Respondent** *E.g., child, parent, clinician, carer, teacher.*

## ASSESSMENT Quality Assessment?



1. **Study methodology** *COSMIN risk of bias checklist*
2. **Assessment**
  - **Measurement properties** *Criteria for psychometric quality rating*
    - Validity: *content validity, structural validity, cross-cultural validity, hypothesis testing and criterion validity*
    - Reliability: *Intra-rater, inter-rater, test-retest reliability*
    - Responsiveness
  - **Feasibility** *E.g., ease of administration, length of assessment, completion time, ease of standardisation and score calculation, required equipment, availability, copyright and associated costs.*

A glowing blue crystal ball sits on a silver stand against a background of red and purple light streaks. The word "FUTURE" is written in large, white, bold, sans-serif capital letters across the center of the crystal ball. The text is enclosed within a white, hand-drawn rectangular border with wavy edges.

**FUTURE**



# Recommendations

1. Stop non-validated dysphagia **SCREENING**.

Instead, use screening tools with good *diagnostic performance*, good *reliability/validity*, and meeting *feasibility* criteria.

*Implement* screening using tools with optimal diagnostic performance in *populations at risk* of dysphagia.

2. Stop **MEASURES** with insufficient/poor psychometric properties.

Instead, use measures with *robust psychometric properties* meeting psychometric quality and *feasibility* criteria.

3. Provide quality **TRAINING** in dysphagia screening/assessment to all clinicians involved in dysphagia care/management

# Future Research

1. Conduct research on existing measures in dysphagia with *incomplete or missing* evaluations of **PSYCHOMETRIC PROPERTIES** (i.e., validity, reliability, and responsiveness).
2. Develop new measures using **CONTEMPORARY PSYCHOMETRIC STANDARDS AND METHODS**, such as item response theory (IRT) in combination with classic test theory (CTT).
3. Ensure adequate **CONTENT VALIDITY**; conduct studies at the onset of developing a new measure to reach consensus on underlying definitions of constructs and to ensure item **relevance** and **comprehensibility**, and **comprehensiveness** of the measure.
4. **INTERNATIONAL CONSENSUS**: e.g., **definition** dysphagia, **severity** of dysphagia, Core Outcome Set (COS), **critical time points** screening/assessments.

A group of hands holding various blue speech bubble shapes against a white background. The word "DISCUSSION" is overlaid in a white box with a wavy border. The background is a solid red color.

# DISCUSSION

# Screening

- What is the purpose of screening?
- How to define a 'good screening'?
- How to select a screening? Which criteria?
- Which populations?
- Critical time-points for screening? Follow-up?

# Assessment

- Are VFSS and/or FEES essential in clinical decision-making for patients with dysphagia? How to evaluate recordings?
- What is the purpose of non-instrumental clinical assessment?
- How to define a 'good assessment'?
- How to select an assessment? Which criteria? Multidimensionality of dysphagia?
- When? Follow-up?

# Assessment

What is the minimum set of outcomes in dysphagia?

Do we need a Core outcome set (COS)?

an agreed minimum set of outcomes that should be measured and reported in clinical trials of a specific disease or target population

1. Define construct to be measured and target population
2. Identify existing measures (systematic reviews)
3. Determine psychometric properties & feasibility for administering within particular setting
4. Select one measure for each outcome or construct in a COS

# CLINICAL CASE I

# Clinical case 1

- 2017: 1st appointment with Mr G:
  - 56 years old
  - No relevant medical history
  - Works as informatician, low vocal use
  - Isolated vocal complaint: roughness and decrease in vocal intensity.
  - No complaint about swallowing.



# Clinical case 1

- Velum
- Phonation
- Thickened water  
(IDDSI4)
- Clear water  
(IDDSI0)
- Soft cake  
(IDDSI6)



# Clinical case 1

- Patient referred to neurologist
  - Confirmation of idiopathic Parkinson Disease
  - Levodopa started
- Patient referred to speech pathologist
  - Successful vocal rehabilitation,
  - L-SVT like, for 3 months
  - Stopped contact with his SLP

# Clinical case 1: Parkinson Disease

- What do you advise for his follow-up with the concern of dysphagia?
  - Which screening?
  - How often?

What I've done:

Annual ENT/phoniatic appointment with assessment of

- |              |   |
|--------------|---|
| • Voice      | Laryngo-stroboscopy and full voice assessment     |
| • Speech     | Assessment of phonetics, intelligibility, prosody |
| • Swallowing | FEES  |

# Clinical case 1: Parkinson Disease

- 2023:
  - Voice and speech are still correct
  - First complaint about swallowing:
    - 1 event of pharyngeal stop with lettuce



# Clinical case 1: Parkinson Disease

- 2023:
  - Voice and speech are still correct
  - First complaint about swallowing:
    - 1 event of pharyngeal stop with lettuce

Insert video 2023

- What to do now?

What I have done

- Proposed SLP for dysphagia → refused
- Sparkling/constrasted temperatures liquids
- Education about alarm signals: temperature daily follow-up
- Advices about textures evictions
- Maintained annual ENT/phoniatic follow-up

# CLINICAL CASE II

# Clinical case 2: ALS

- Mr L, 61 years old
- First appointment in 2018
- Referred to ENT-phoniatrics clinic by his neurologist
- Because ALS has been diagnosed
  
- Complaints:
  - Dysarthria
  - No clear complaint about swallowing

# Clinical case 2: ALS

- Weight: 103kg/ 1,77m
  - Weight loss: 2 kg in the past year, voluntary
- No history of pneumonia/hyperthermia/bronchorrhea





# Clinical case 2: ALS

- What do you advise for his follow-up with the concern of dysphagia?
  - Which screening?
  - How often?

## What I have done

- Proposed SLP for dysarthria and dysphagia
- Follow-up with FEES every 3 months
- After 1 year, no significant evolution ->every 6 months

# Clinical case 2: ALS

- Slow progressive deterioration of all the functions of the superior aero-digestive tract.
  - Weight loss
  - Loss of intelligibility
  - No respiratory infection but some bronchorrhea
- Gastrostomy proposed in october 2022 because of weight loss ->refused
- Alternative communication proposed,
  - tried but unsuccessful

# Clinical case 2: ALS



# Clinical case 2: ALS

- What do you advise for his follow-up with the concern of dysphagia?
  - Which screening? Which assessment?
  - How often?
  - When should we stop?

## What I have done

- Follow-up with FEES every 6 months because of poor tolerance
- Adaptation of the oral diet (textures restriction, dietetic support)



**SUMMARY**