

Children's Health Queensland Hospital and Health Service

Using Parent Reported Tools in Assessment for PFD

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Disclosures

Jeanne Marshall

- **Financial**
 - Salary from Children's Health Queensland Hospital & Health Service & The University of Queensland
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- **Non-financial**
 - Volunteer teaching for the Trinh Foundation in Vietnam
 - Associate Editor for Speech, Language and Hearing
 - Membership w/ ASHA (International affiliate), Speech Pathology Australia, and Dysphagia Research Society

Memorie Gosa

- **Financial**
 - Associate Professor/Chair, The University of Alabama
 - PRN, Druid City Hospital & LeBonheur Children's Hospital
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- **Non-financial**
 - Elected member of CAA
 - Editorial board member of *AJSLP*
 - Co-Founder of ADC
 - Member ASHA, DRS, & Voice Foundation

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Listening to the patient/caregiver voice


- Most diagnostic information for PFD is gathered via clinical observation and **caregiver report**
- **Caregiver report** is often underestimated in terms of value and/or captured in an informal way
- Can use **Patient Reported Outcome Measures (PROMs)** to:
 - Capture the experiences/outcomes important to patients
 - Provide validated evidence of health from the point of view of the patient/patient-proxy
 - Improve quality and impact of health services
 - Provide evidence of the outcomes of service effectiveness

(Williams et al., 2016)

- There are a **range of PROMs available**, but there is **little guidance for clinicians regarding which PROMs to use** in diagnosis for PFD (Marshall et al., 2023)

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How do we know which PROM to use?



- **Validity**
 - Does the tool measure what it is supposed to measure?
 - How was it developed/pilot-tested?
- **Reliability**
 - Does the tool give a similar result in a short timeframe under the same conditions?
- **Responsiveness**
 - Can the tool be used to measure/monitor change over time?

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ORIGINAL ARTICLE: NUTRITION

Patient-Reported Outcome Measures That Describe the Feeding Skills Domain for Pediatric Feeding Disorder: A Clinimetric Review

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- Included PROMs that elements of the feeding skills domain for children >6 months
- Excluded screening tools or tools that did not include any items relating to the feeding skills domain
- Excluded tools that only explored oral motor movement outside of eating and drinking
- Used the COnsensus-based Standards for the selection of health Measurement INSTRuments (COSMIN) checklist (Mokkink et al., 2018; Terwee et al., 2018; Prinsen et al., 2018) to support quality assessment of the various PROMs (<https://www.cosmin.nl/>)
- 22 articles describing 15 PROMs were included in final study

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Key results

- Variable methodological quality across different PROMs
- Whilst many studies described measurement of content validity, most did not consult with parents of children with PFD, which impacted on the scoring
- Many studies did not report on use of the measure over time, which impacted on the ability to rate certain items (e.g., reliability)
- Strongest performing PROMs were:
 - CHOMPS (Pados et al., 2019)
 - Feeding Impact Scales (Estrem et al., 2020)
 - PEDI-Eat (Thoyre et al., 2014)
- Only three PROMs collected information relating to social participation
 - Children's Eating Behavior Inventory (Archer et al., 1991)
 - Feeding and Swallowing Impact Scales (Lefton-Greif et al., 2014)
 - Feeding Impact Scales (Estrem et al., 2020)

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Recommendations

1. Use PROMs during your clinical assessment with families
2. Use the PROMs with stronger content validity (or use a combination of tools)
3. Use at least one PROM that captures elements of social participation in your assessment

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**Harry
'The Bread King'
& Sam, the kid
who never met a
carb he didn't
love**

**Remember that
behind every
diagnosis is a
child and family.**



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