Patient contribution to the development of a novel educational tool for adults presenting with temporomandibular disorder-related oral stage dysphagia.

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**Background:**
Temporomandibular disorders (TMDs) cause pain/dysfunction/fatigue of the temporomandibular joint. Eating, drinking, and swallowing skills are impaired in 99% of adult TMD patients, resulting in oral stage dysphagia (OD). Management is uncertain, with contradictory research findings and no specific clinical guidelines, which impacts on patient’s understanding of difficulties and clinical outcomes.

**Research Aim:**
The aim of this research was to determine patient information-needs regarding TMD-related OD management, and to develop a novel educational tool to facilitate patient empowerment.

**Methods:**
A cross-sectional design was used to survey the information needs of treatment-seeking patients presenting with TMD-related OD. Consecutive adults with TMDs who presented to 2 national specialist oral and maxillofacial surgery centres over a 6 month period in 2017 were included. Individuals were excluded if they had co-morbid conditions affecting the orofacial, mandibular, or head and neck area (e.g.: cancer/trauma).
Assessment was conducted using a newly developed subjective questionnaire, which collected data regarding information patients received regarding TMD-related OD, information priorities, and outstanding queries regarding management. Descriptive methods were used to analyse data.

**Results:**
80 participants (female=66; male=14; mean age: 40.8 years) presenting with joint (82.5%) and pain disorders (17.5%) participated. Most reported that they had not received sufficient information regarding TMD-related OD management (82.5%), with 98.75% reporting that an educational booklet would improve understanding and management. Patient’s most significant information-needs related to: treatments (97.5%), self-care strategies (97.5%), and how best to prevent/manage flare-ups (98.75%). Researchers utilised this information to develop a comprehensive educational booklet that will be clinically disseminated.

**Discussion and Conclusions:**
OD is prevalent in adults with TMDs, yet management is uncertain, with knock-on effects on information sharing, patient understanding, and empowerment. Further research should address both the development of evidence-based interventions, and the efficacy of this educational tool in addressing patient information-needs.