

The assessment of oral symptoms in end-of-life, review of the literature

Background: Oral health issues are common and increase towards end-of-life (EoL). The connection between oral health and quality of life has been well established. The lack of knowledge and oral care training among the nursing staff is acknowledged. The concordance between the assessment by the caregivers and the patients on the patients' symptoms has shown a weak to moderate correlation. Yet, as the patients' performance status declines, a reliable symptom assessment by the caregiver(s) and the staff forms the ground for good symptom relief.

Aim: The aim of this course project was to study the prevalence of oral symptoms in EoL in correlation to the assessment performed by the patient, the caregiver or the staff. The secondary aim was to discuss on the optimal approach to assess oral health as the basis for guidelines and protocols for patients, caregivers and nursing staff.

Methods: A literature review was conducted by use of PubMed and Medline with the keywords: oral symptoms, oral health, palliative care, end-of-life, terminally ill. Inclusion criteria were age > 18 years, terminally ill patients, oral symptoms in end-of-life, original publications within 2000-2019, study focus on oral symptoms. Exclusion criteria were oral health status assessment only without symptom assessment. Five most prevalent and most commonly assessed symptoms were selected for further analysis.

Results: A total of 8 articles met the inclusion criteria, consisting of terminally ill patients with or without advanced cancer. Two studies comprised nursing staff-reported questionnaires, 5 patient-reported symptoms and 1 included a comparison between patient- and carer-reported symptoms. In five studies a clinical assessment was performed in addition to the symptom assessment. The patient population was heterogenous with regard to the stage of disease and performance status in EoL. The five selected symptoms comprised dry mouth, dysphagia, taste alterations, oral pain and fungal infections.

Dry mouth was assessed as xerostomia with or without the assessment of hyposalivation. Patient-reported prevalence ranged between 78% and 94% towards EoL. Without concomitant oral examination, the prevalence was underrated by the staff (46%) in comparison to 81% reported in relation to oral examination. There was a significant difference in the rating of Oral Problem Subcales (0-10) between patients and caregivers (mean±SD 5.8±2.5 and 5.1±2.4, respectively, $p<.01$), the caregivers underrating the symptom. Moderate to severe hyposalivation was recorded in 20% to 62% of the patients, with increasing prevalence with concomitant poor oral intake.

The prevalence of dysphagia ranged between 20% and 61% as patient-reported symptom and it increased towards EoL. In staff-reported questionnaire the prevalence was 3%. There was no difference in the rating between patients and caregivers (Oral Problem Scales, OPS (0-4), mean±SD 1.3±1.2 and 1.3±1.3, respectively).

Taste alterations were reported without significant variations. The patient-reported prevalence ranged between 67% and 71%. The rating by patients and caregivers was similar (OPS, mean±SD 1.8±1.4 and 1.7±1.4, respectively). In the staff-reported questionnaire this symptom was not assessed. Oral pain was reported in 11% when assessed by the staff, ranging between 52% and 67% by the patient, and with similar ratings between the patient and the caregiver (OPS, mean±SD 1.1±1.3 and 1.0±1.2, respectively). Fungal infections were reported between 16% and 19% when assessed by the staff, between 10% and 34% based on the oral examination presented, in comparison to the positive cultures ranging between 71.3% and 86%.

Short discussion: Several challenges were identified. The quality of the studies was considered low due to the lack of and variation in the definitions and in the methodology of the assessment of oral health. The oral health rating was less reliable when assessed by the nursing staff only. A stronger correlation was found between the assessment performed by caregivers and patients. However, older caregivers and those with health problems were reported to be less aware of the oral health problems of the patient. The prevalence of the aforementioned oral symptoms was in accordance with the literature.

Conclusion: The need for oral health professionals in the multidisciplinary team is highlighted as well as their effort and responsibility in providing commonly accepted definitions and assessment scores. Caregivers are an important resource and they should receive education on oral health assessment and treatment protocols. Thus, in addition to multidisciplinary approach, the need for interdisciplinary education and co-operation is emphasized.